



PHYSICAL ACTIVITY IN THE LIVES OF  
ADULTS WITH CEREBRAL PALSY

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STUDENT DECLARATION

“I, Cadeyrn James Gaskin, declare that the PhD thesis entitled *Physical Activity in the Lives of Adults with Cerebral Palsy* is 111,160 words in length, exclusive of tables, appendices, and references. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.”

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## ABSTRACT

The aim of this thesis was to investigate physical activity and psychosocial functioning in adults with cerebral palsy. Four studies were conducted that incorporated a description of the relationship between these variables (Study 1) and an in-depth exploration of physical activity and psychosocial functioning in the lives of six adults with the condition (Studies 2, 3, 4). In Study 1, adults with cerebral palsy ( $N = 51$ ) completed questionnaires that included measures of physical activity, health-related quality of life (HRQL), mood states, physical self-efficacy, and social support. Although most participants (70.6%) reported that they were involved in exercise, many of the activities they performed seemed to be of low intensity, even for adults with severe cerebral palsy (e.g., hand exercises for weak hands, massage, stretching). Most of the data were substantially skewed, with many participants performing minimal physical activity, and experiencing low levels of physical function, minimal role limitations, high social functioning, low levels of four negative mood states (tension-anxiety, depression-dejection, anger-hostility, confusion-bewilderment), and high social support. With the exception of the correlations between physical activity and physical functioning ( $r_s = .45$ ), role limitations – physical ( $r_s = .32$ ), vigour-activity mood state ( $r_s = .36$ ), and social support from friends ( $r_s = -.43$ ), there were typically weak associations between physical activity and the subscales of the HRQL, mood states, physical self-efficacy, and social support measures. In light of previous research on physical activity and people with neurological conditions (e.g., multiple sclerosis, Sutherland, 2001), the weakness of these correlations was somewhat surprising. Difficulties in recruiting participants for physical activity



intervention studies raised the question of why adults with cerebral palsy did not want to be involved in physical activity (or, at least, physical activity research). I designed three studies that focused on the lives of adults with cerebral palsy who had engaged in different levels of physical activity. In Study 2, I examined the lives of two adults (Judy, aged 60; Alana, aged 29) who had minimal involvement in physical activity. The women had similar childhood experiences, which included having to perform difficult, and sometimes painful, physiotherapy; needing to wear callipers to assist their walking; lacking competence at physical activity; and being socially isolated from their classmates. These aspects of their life histories seemed to contribute to their subsequent avoidance of physical activity, which, in turn, may have adversely influenced the timing of the onset of functional decline. In Study 3, I investigated the lives of two adults (Amy, aged 25; Ben, aged, 30) who were involved in physical activity. Despite both participants having punishing experiences with physical activity as children, they both were involved in, and valued, physical activity as adults. Physical activity was a means of displaying competence, delaying further functional loss, and becoming more, or remaining, socially connected. In Study 4, I explored the lives of two adults (David, aged 27; Tim, aged, 24) who had minimal involvement in physical activity and who then participated in weight-training and warm-water aerobic programmes. Both participants learnt to walk, but lost this ability in early adolescence when they had to have tight hamstring muscles surgically lengthened, because they were experiencing back pains. The minimal physical activity in which they engaged during their adult lives was directed towards trying to walk again. Walking seemed to be intimately connected with psychosocial growth. The

weight-training programme seemed to benefit David through providing him with another avenue for self-improvement towards his goal of attracting a life partner, a new source of narcissistic supplies, an opportunity to demonstrate competence physically, and an experience of being treated with positive regard by the trainers and me. Tim's warm-water aerobic programme provided him with an opportunity to develop competence at swimming and at walking, and to enhance his self-esteem for these activities. The six life histories also provided evidence of how adverse social experiences negatively influence psychosocial development. The main conclusion of this thesis is that involvement in physical activity may be important for people with cerebral palsy in their endeavours to successfully face the various psychosocial challenges throughout life. Implications of this research include that parents and teachers of children with cerebral palsy should provide support for their involvement in physical activity, physiotherapists should try to reduce the pain and increase the perceived relevancy of the treatments they deliver to young people with cerebral palsy, and psychologists should be aware of some of the difficulties people with cerebral palsy face and how they may manifest in adults with the condition.

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## CHAPTER 1

### INTRODUCTION

Physical activity has significant physical health benefits (US Department of Health and Human Services [USDHHS], 1996), and is positively associated with health-related quality of life (HRQL; Berger & Motl, 2001) and psychosocial functioning (Landers & Arent, 2001). People with cerebral palsy may not obtain these health benefits, however, because many of them engage in minimal physical activity (Heller, Ying, Rimmer, & Marks, 2002; Longmuir & Bar-Or, 2000). Rimmer (2001) argued that people with cerebral palsy may need to do greater amounts of physical activity than people in the general population to offset functional loss during ageing, which is typically more rapid for people with this condition than for able-bodied people. Reasons for the low levels of involvement in physical activity may be understood through examining the relationships between physical activity and both HRQL and psychosocial functioning, and through investigating the meanings and experiences of physical activity in the lives of people with cerebral palsy.

Cerebral palsy is a life-long, non-progressive, neurological condition that adversely affects movement and posture (The Australian and New Zealand Perinatal Societies, 1995). Approximately 2 to 2.5 of every 1000 live born children in the Western world are diagnosed with cerebral palsy (Missiuna, Smits, Rosenbaum, Woodside, & Law, 2001). Comorbidities are common in people with cerebral palsy, with mental retardation and seizures being the most prevalent (Stanley, Blair, & Alberman, 2000).

In comparison to the research efforts that have been applied to investigating children and adolescents with cerebral palsy, comparatively little research has been conducted on adults with the condition. This situation is perhaps the result of researchers and practitioners viewing cerebral palsy as primarily a paediatric condition (Bottos, Feliciangeli, Sciuto, Gericke, & Vianello, 2001). The available evidence, however, suggests that cerebral palsy adversely interacts with the ageing process (Turk, Overeynder, & Janicki, 1995). Therefore, more research into cerebral palsy across the lifespan would seem warranted.

The general health of people with cerebral palsy may be improved through increasing their physical fitness levels (Rimmer, 2001). People with cerebral palsy have traditionally been advised to avoid some types of exercise (e.g., weight training), however, on the basis that such exercises may exacerbate certain aspects of their condition (e.g., spasticity; Bobath & Bobath, 1984). Research has shown, however, that people with cerebral palsy are able to train their aerobic systems (e.g., Bar-Or, 1995; Emons & Van Baak, 1993) and improve their strength (e.g., Dodd, Taylor, & Damiano, 2002). There has been no support for the concern that increased spasticity may result from performing exercises with maximal effort (Fowler, Ho, Nwigwe, & Dorey, 2001).

Although there is ample evidence demonstrating that exercise can enhance the physical and psychological health of individuals in the general population, including their HRQL (Berger & Motl, 2001), little research has been conducted on populations with chronic neurological conditions, such as cerebral palsy. In their research on exercise and people with another neurological condition, Sutherland, Andersen, and Stoové (2001) showed that exercise can improve the

HRQL and psychosocial functioning of people with multiple sclerosis, a population that health care professionals had told not to exercise, because it would leave them fatigued and, therefore, decrease their abilities to perform activities of daily living. People with cerebral palsy constitute another population in whom sedentary living dominates and the usefulness of some exercises (e.g., weight training) has been controversial.

Research on physical activity in the lives of people with cerebral palsy is warranted. The purpose of this thesis was to examine the relationship between physical activity and both HRQL and psychosocial functioning in adults with cerebral palsy, and to investigate the meaning and experiences of physical activity in their lives.

## CHAPTER 2

### REVIEW OF LITERATURE ON THE EFFECTS OF PHYSICAL ACTIVITY ON THE HEALTH-RELATED QUALITY OF LIFE AND PSYCHOSOCIAL FUNCTIONING OF PEOPLE WITH CEREBRAL PALSY

The literature underpinning this thesis is reviewed in two chapters. The original research plan for this thesis was to conduct a correlational study, followed by two experimental studies on the effects of physical activity on the HRQL and psychosocial functioning of adults with cerebral palsy. In the present chapter, I review the literature on the effects of physical activity on HRQL and psychosocial functioning that led to that original research proposal.

In this chapter, I introduce the relationship between physical activity and health. In the following section, I explore the literature pertaining to the association between physical activity and both HRQL and aspects of psychosocial functioning, including anxiety, cognitive functioning, depression, mood, and self-concept (e.g., self-efficacy, self-esteem). I provide a background to cerebral palsy before reporting on the physical, functional, and psychosocial health of adults with the condition. I consider the role of exercise in the management of cerebral palsy, focusing on the physical activity levels, energy expenditure, physiological exercise potential, and trainability of people with this condition. The chapter concludes with a statement of the purpose of this thesis.

#### Physical Activity and Health

The effect of physical activity on health has received a great deal of research attention. Extensive reviews (e.g., Bouchard, Shephard, & Stephens, 1994; USDHHS, 1996) have concluded that engaging in physical activity can

have substantial society-wide health benefits, including reduced mortality rates. The USDHHS concluded that regular physical activity reduces the risk of premature mortality, coronary heart disease and coronary heart disease mortality, colon cancer, and non-insulin-dependent diabetes mellitus. Physical activity may be beneficial for individuals who have developed osteoarthritis, and weight-bearing physical activity in childhood and adolescence reduces the risk of osteoporosis in later life. Strength training may also be of benefit to older adults in maintaining independent living and reducing the risk of falls. Physical activity may also reduce obesity by increasing energy expenditure.

The USDHHS (1996) was more reserved in stating the effects of physical activity on HRQL and mental health. The USDHHS stated that there was an apparent improvement in HRQL and mental health from physical activity in those individuals who were compromised by poor health. The USDHSS concluded that physical activity appeared to be associated with a reduction in the symptoms of depression and anxiety, a lowering of the risk of developing depression, and an improvement of mood. Recent reviews (Landers & Arent, 2001; Mutrie, 2000) have adopted a stronger position on the relationship between physical activity, HRQL, and psychosocial functioning. For example, Mutrie concluded that there was evidence for a causal link between exercise and a reduction in depression. The recommendations of the USDHHS, however, were designed for, and employed evidence from, a primarily unimpaired population (Cooper et al., 1999). Two areas of research need, identified in the Cooper et al. consensus statement pertaining to research on physical activity and health among people with disabilities, were to “characterize the physical activity patterns of people with



disabilities” and to “determine the relationship between type and intensity of activity with regard to longevity and quality of life” (p. 144).

In summary, there is sound evidence to support the association between physical activity and physical health for people in the general population. The relationship between physical activity, HRQL, and psychosocial functioning has not been as strongly established for people with disabilities. Further, research is sparse on the physical activity patterns of people with disabilities, and the potential benefits of physical activity for these people are unclear.

#### Physical Activity, Health-Related Quality of Life, and Psychosocial Functioning

HRQL is a component of the broader quality of life concept (Rejeski, Brawley, & Shumaker, 1996), whereas psychosocial functioning refers to various constructs, such as anxiety, cognitive functioning, depression, mood, and self-concept (e.g., self-efficacy, self-esteem). Wherever possible, meta-analyses were reviewed to ascertain the existence and strength of the relationships between physical activity and both HRQL and psychosocial functioning.

#### *Physical Activity and Health-Related Quality of Life*

HRQL represents “those attributes valued by patients, . . . [including] their resultant comfort or sense of well-being; the extent to which they were able to maintain reasonable physical, emotional, and intellectual function; and the degree to which they retained their ability to participate in valued activities within the family, in the workplace, and in the community” (Wenger & Furberg, 1990, p. 344). No meta-analyses have been conducted that examine the relationship between physical activity and HRQL. A vast number of studies, however, have been conducted that have evaluated the effectiveness of physical activity

programmes and have used measures of HRQL. This past research has shown that exercise can improve HRQL in healthy, but previously sedentary people (King et al., 2000; Stewart, King, & Haskell, 1993), older adults (Damush & Damush, 1999), and people with chronic health conditions, such as a history of stroke (Greenlund, Giles, Keenan, Croft, & Mensah, 2002), chronic obstructive pulmonary disease (COPD; Boueri, Bucher-Bartelson, Glenn, & Make, 2001; Finnerty, Keeping, Bullough, & Jones, 2001; Garcia-Aymerich et al., 2004; Rossi et al., 2005), chronic peripheral neuropathies (Ruhland & Shields, 1997), kidney failure (van Vilsteren, de Greef, & Huisman, 2005), and knee osteoarthritis (Rejeski et al., 2002). I sourced only two studies, however, that investigated physical activity, HRQL, and people with chronic neurological conditions, both of which involved people with multiple sclerosis (Oken et al., 2004; Sutherland et al., 2001). Sutherland et al. (2001), for example, found substantial differences in HRQL for people with multiple sclerosis, who participated in a warm-water aerobic exercise program, compared to participants in a no-intervention control group. Large effect sizes were found for the 8 of 11 HRQL subscales. The greatest effect was found for the energy subscale ( $\eta^2 = .51$ ), where just over half the variance in scores was accounted for by group membership. People in the exercise group reported higher levels of energy.

In summary, there is strong support for a positive association between physical activity and HRQL. Even so, most of the research has been conducted with people who have acquired chronic health conditions (e.g., COPD) during their adult lives and may have experienced diminished HRQL as a consequence of these conditions. The timing of the onset of congenital conditions (e.g., cerebral

palsy, spina bifida) is obviously different than that of late-onset, acquired conditions (e.g., COPD, multiple sclerosis). People with congenital conditions do not experience events that cause marked loss of HRQL, where they can recall their level of function before the events. Research is needed to ascertain whether the relationship between physical activity and HRQL for people with congenital conditions is similar to that found in those with acquired chronic health conditions.

### *Physical Activity and Psychosocial Functioning*

#### *Physical Activity and Anxiety*

In the 1997 Australian *National Survey of Mental Health and Wellbeing of Adults* (Henderson, Andrews, & Hall, 2000; McLennan, 1998), 9.7% of adults surveyed reported symptoms from the prior 12-month period that allowed diagnosis of one or more anxiety disorders. Anxiety is commonly examined as a state or a trait. State anxiety refers to “subjective consciously perceived feelings of tension and apprehension, associated with . . . arousal of the autonomic nervous system” (Spielberger, 1966, p. 17), whereas trait anxiety refers to a “general disposition to respond to a variety of situations with high levels of state anxiety” (Woodman & Hardy, 2001, p. 291). Six meta-analyses have been conducted on the relationship between physical activity and anxiety (Calfas & Taylor, 1994; Kugler, Seelbach, & Kruskemper, 1994; Long & Van Stavel, 1995; McDonald & Hodgdon, 1991; Petruzzello, Landers, Hatfield, Kubitz, & Salazar, 1991). All meta-analyses have associated physical activity with a reduction of anxiety, with effect sizes (derivatives of Cohen’s *d*) ranging from .15 to .45. Not all meta-analyses, however, reported results for the overall change in anxiety because most

effect sizes pertained to state anxiety or trait anxiety. The effect sizes for the overall change in state anxiety and trait anxiety with physical activity ranged from .28 to .38, and from .25 to .49, respectively. These findings indicate that physical activity is related to reductions in both transient and dispositional anxiety, albeit in some cases only moderately so.

Petruzzello et al. (1991) found that the largest reductions in state anxiety have been found for aerobic exercise ( $ES = 0.26$ ) of 21 to 30 minutes duration ( $ES = 0.41$ ). Similar results were found for trait anxiety, in that the greatest effect sizes were found for aerobic exercise ( $ES = 0.36$ ) of 21 to 30 minutes ( $ES = 0.41$ ) or greater than 40 minutes duration ( $ES = 0.42$ ). The largest reductions in trait anxiety were also found for exercise programmes that lasted for 10 to 12 weeks ( $ES = 0.50$ ) or greater than 15 weeks ( $ES = 0.90$ ). In comparison to the number of studies in which aerobic exercise has been investigated, few studies have used non-aerobic types of exercise in the study of anxiety. Although continuous forms of exercise (i.e., aerobic exercise) may be more effective at reducing anxiety, more research needs to be conducted on non-aerobic types of exercise to ensure that they do not have anxiety-reducing potential. Larger effect sizes have also been found in studies in which having high stress levels was a criterion for participants to be included in the research (Long & Van Stavel, 1995).

### *Physical Activity and Cognitive Functioning*

Cognitive functioning is a term that encompasses a broad range of mental activities. One meta-analysis has been published on the physical activity-cognition association (Etnier et al., 1997). An overall effect size (a derivative of Cohen's  $d$ ) of 0.25 was found, indicating that physical activity has a small (Cohen, 1988), but

positive, relationship with cognitive functioning. Because cognitive functioning incorporates many diverse constructs, there are numerous associated measures. Etnier et al. reported that 106 different cognitive tests were used in the 134 studies included in their meta-analysis. Because of the difficulty in comparing the results from such a broad range of studies, it seems premature to make a judgement on the efficacy of using physical activity to improve cognitive functioning. The sizable effects found in some studies, however, should encourage researchers to continue investigating this topic.

### *Physical Activity and Depression*

From the data collected in the 1997 *National Survey of Mental Health and Wellbeing of Adults*, the prevalence of depression and dysthymia within the Australian population was calculated at 5.1% and 1.1%, respectively (McLennan, 1998). Five meta-analyses have been conducted that have examined the physical activity-depression relationship (Calfas & Taylor, 1994; Craft & Landers, 1998; Kugler et al., 1994; McDonald & Hodgdon, 1991; North, McCullagh, & Tran, 1990). In all meta-analyses, physical activity was associated with a reduction in depression, with the overall effect sizes (derivatives of Cohen's *d*) ranging from 0.38 to 0.97. The strength of the research literature led Mutrie (2000) to conclude that there was evidence for a causal link between physical activity and reduction in depression.

A major issue within these meta-analyses is the inclusion of effect sizes from studies in which different forms of depression were investigated. The *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revision, American Psychiatric Association, 2000) defines many forms of depression and

broadly classifies the forms into two parts: mood episodes and mood disorders. Although the authors of at least two of these meta-analyses were aware of the issue of definition (Craft & Landers, 1998; North et al., 1990), they combined effect sizes from studies that had investigated people with different forms of depression. A lack of conceptual clarity in the studies themselves may have influenced the meta-analytic results.

North et al. (1990) identified a number of potential mediators of the exercise-depression relationship. The moderator variable that had the largest effect ( $\Omega^2 = .24$ ;  $\Omega^2$  is analogous to  $R^2$  and  $\eta^2$ ) on the exercise-depression relationship was the length of the exercise programme (North et al., 1990). The effect sizes increased, monotonically, in magnitude with the length of exercise programme. Most studies reported small to medium effects (Cohen, 1988) and used protocols that lasted 5 to 8 weeks ( $ES = .30$ ) or 9 to 12 weeks ( $ES = .31$ ). The largest effects were found for programs of 21 to 24 weeks ( $ES = 2.93$ ) and greater than 24 weeks ( $ES = 2.00$ ), however, there was only one study in the 21 to 24 week group. Craft and Landers (1998) also found larger effect sizes for programmes that lasted between 9 and 12 weeks ( $ES = 1.18$ ), than for programmes lasting 8 weeks or less ( $ES = 0.54$ ).

North et al. (1990) found the group of comparison (i.e., the group of participants to which the experimental group was statistically compared) to be a moderating variable ( $\Omega^2 = .23$ ). Aerobic exercise was more effective in the treatment of depression than no treatment ( $ES = 0.71$ ), participants waiting to receive an antidepressant treatment ( $ES = 0.54$ ), relaxation ( $ES = 0.50$ ), doing an enjoyable activity ( $ES = 0.39$ ), doing less running/exercise ( $ES = 0.29$ ), and

psychotherapy ( $ES = 0.19$ ). Although anaerobic exercise was more effective than aerobic exercise ( $ES = -0.20$ ), this difference was not statistically significant. With only two studies performing this comparison, more work is necessary. Aerobic exercise in combination with psychotherapy was more effective than aerobic exercise alone ( $ES = -0.81$ ). This result suggests that a combination of treatments may be more effective than single treatments.

Craft and Landers (1998) concluded differently after finding no significant difference between the effect sizes of comparison group interventions. This result was probably due to lack of power in the Craft and Lander's meta-analysis. Compared to the North et al. (1990) meta-analysis, the Craft and Landers meta-analysis contained fewer studies ( $ns = 66$  and  $22$ , respectively) and fewer categories of comparison groups. Inspection of the effect sizes for the difference between aerobic exercise and each comparison group revealed substantially larger effect sizes for the contrast between aerobic exercise and wait-list control ( $ES = 0.77$ ) than between aerobic exercise and both group/individual therapy ( $ES = 0.06$ ) and behavioural interventions ( $ES = -0.03$ ).

North et al. (1990) found that participants' health status ( $\Omega^2 = .17$ ), where participants were sourced from ( $\Omega^2 = .13$ ), their level of health ( $\Omega^2 = .11$ ), and purpose of exercising ( $\Omega^2 = .11$ ) moderated the exercise-depression relationship. With regard to health status, there was a significant difference in the strength of effects between people who were receiving haemodialysis ( $ES = 2.31$ ) and those who had schizophrenia ( $ES = 1.43$ ), had experienced myocardial infarctions ( $ES = 0.95$ ), were depressed ( $ES = 0.55$ ), were athletes ( $ES = 0.42$ ), were feeling down ( $ES = 0.36$ ), or were apparently healthy ( $ES = 0.29$ ). There was a significantly

greater exercise-depression association in participants with post-myocardial infarctions than in those who were depressed, athletes, feeling down, or apparently healthy. There was a significant difference between participants who were medical or psychological patients ( $ES = 0.94$ ) and those who were high school students ( $ES = 0.60$ ), health club members ( $ES = 0.49$ ), community citizens ( $ES = 0.49$ ), or college students/faculty ( $ES = 0.16$ ). Concerning level of health, there were larger effects for participants who were undergoing medical treatment ( $ES = 0.97$ ) than for those who were requiring psychological treatment ( $ES = 0.60$ ) or were apparently healthy ( $ES = 0.31$ ). A confounding variable in these last two results, however, is the medication taken by individuals receiving medical treatment. Regarding the purpose of exercising, significantly greater effects were found for people being medically rehabilitated ( $ES = 0.97$ ) than for those who participated in exercise for academic experiments ( $ES = 0.67$ ), psychological rehabilitation ( $ES = 0.55$ ), or general health ( $ES = 0.29$ ). Collectively, these results suggest that the relationship between exercise and depression is present irrespective of individuals' health. The magnitudes of the effects range from small (Cohen, 1988) to extremely large. It seems the largest effects have been found for individuals who could most benefit from antidepressant treatment. That is, larger effect sizes were found for individuals who were experiencing chronic health issues (e.g., those receiving haemodialysis, those who had schizophrenia, those who had experienced myocardial infarctions).

In their meta-analysis of studies involving participants who were clinically depressed or had depression resulting from mental illness, Craft and Landers (1998) found significantly greater exercise-depression effect sizes for individuals



who initially had moderate to severe depression ( $ES = 0.88$ ) than for those who had mild to moderate depression ( $ES = 0.34$ ). North et al. (1990) reported contradictory findings, however, in that the effect sizes of individuals who were initially depressed ( $ES = 0.53$ ) and those who were not depressed ( $ES = 0.59$ ) were similar. This result was not significant and the effect size was extremely small ( $\Omega^2 = .005$ ), leading North et al. to conclude that exercise may not only be useful for those individuals who were depressed, but also for those who were non-depressed. The appropriateness of dichotomising continuous variables in both meta-analyses (Craft & Landers, 1998; North et al., 1990) is questionable, however. A more meaningful comparison may have been between clinically depressed individuals and healthy individuals.

In summary, exercise helps to reduce depression. This reduction is greatest for exercise programmes of long duration (i.e., over 20 weeks). From the few studies available, it seems that aerobic exercise in combination with psychotherapy may have the greatest antidepressant effect. Because few studies have used anaerobic exercise as their training protocol, the relative merits of aerobic versus anaerobic exercise remain unclear. There seems to be a monotonic pattern in the relationship between exercise and depression, with people most in need of antidepressant treatment likely to obtain the greatest reduction in depression through exercise.

### *Physical Activity and Mood*

A consistent definition of mood has not been applied within the physical activity-mood literature (Arent, Landers, & Etner, 2000). Concepts, such as anger, confusion, depression, fatigue, tension, and vigour, have all been included

within the general category of mood (McNair, Lorr, & Droppleman, 1971). The term *mood* has also been used interchangeably with other terms, such as affect, psychological benefit, and well-being within the literature on exercise and mood in older adults (Arent et al., 2000). The concepts examined under each of these rubrics have also differed between studies. Although Lazarus (1991) has provided conceptual clarity by distinguishing mood from other constructs, the two meta-analyses performed in the physical activity-mood research (Arent et al., 2000; McDonald & Hodgdon, 1991) have taken a broad interpretation of the mood construct.

Arent et al. (2000) specifically focused on the physical activity-mood relationship in 32 studies involving older adults (*ESs* are derivatives of Cohen's *d*). In studies that used intervention and control groups, the intervention groups had enhanced mood ( $ES = 0.34$ ), with an increase in positive affect ( $ES = 0.33$ ) and a decrease in negative affect ( $ES = 0.35$ ). Studies that used a pre-test/post-test design demonstrated that mood could be significantly improved by physical activity ( $ES = 0.38$ ), enhancing positive affect ( $ES = 0.35$ ) and decreasing negative affect ( $ES = 0.39$ ). A positive relationship was also reported in studies that had correlational designs ( $ES = 0.48$ ). These results show that physical activity is beneficial to mood among this age group.

McDonald and Hodgdon (1991) separately compiled effect sizes for 26 studies involving the subscales of the Profile of Mood States (POMS; McNair et al., 1971) and the Multiple Affect Adjective Check List (MAACL; Zuckerman & Lubin, 1965) as measures of mood. Effect sizes (derivatives of Cohen's *d*) ranged in magnitude from .18 for anger on the POMS to 1.12 for depression on the

MAACL. Results from the MAACL should be viewed with caution, however, because some authors have expressed reservations about the validity and reliability of the instrument (Kelly, 1972; Megargee, 1972). Most effects were small to medium (Cohen, 1988) in magnitude and all were in the hypothesised direction. That is, physical activity was associated with a reduction in tension, anger, depression, fatigue, and confusion, and an increase in vigour.

In summary, meta-analytic findings show a positive relationship between exercise and concepts classified under the rubric of mood. Effect sizes have tended to be small to medium in magnitude. Greater conceptual clarity in future studies could allow firmer conclusions to be drawn on the degree to which different aspects of mood are affected by exercise.

#### *Physical Activity and Self-Concept*

Self-concept refers to “an organized configuration of perceptions of the self which are admissible to awareness” (Rogers, 1950, p. 78). A distinction is made between self-concept, which is comprised of the images people have of themselves, and self-esteem, which is their feelings toward those images. Such clarity does not always appear in the literature, however, because researchers have sometimes interchanged self-concept with other constructs, such as self-awareness, self-esteem, self-ideal, self-image, and self-knowledge (McDonald & Hodgdon, 1991). Therefore, a broad conceptualisation of self-concept was necessary when conducting meta-analyses on studies of physical activity and self-concept.

Four meta-analyses have been conducted on the physical activity-self-concept literature (Calfas & Taylor, 1994; Gruber, 1986; McDonald & Hodgdon,

1991; Spence, Poon, & Dyck, 1997). The magnitudes of overall effects (derivatives of Cohen's  $d$ ) ranged between 0.12 and 0.56. The most recent meta-analysis (Spence et al., 1997) included 51 studies and focused on research that used adults as participants. The Spence et al. analysis revealed small effects for the association between physical activity and global self-concept ( $ES = 0.23$ ), physical self-concept ( $ES = 0.23$ ), and social self-concept ( $ES = 0.20$ ).

Unfortunately, none of the meta-analyses reported statistical evidence of possible moderator variables. Insights into what variables may moderate the exercise-self-concept relationship may be gained from the Gruber (1986) study, through visual inspection of the effect sizes for different groups of comparison (i.e., the group of participants to which the experimental group was statistically compared). These observations should be viewed with caution, however, because Gruber did not provide adequate information to permit the determination of the degree to which these variables moderate the relationship.

Gruber's (1986) meta-analysis focused on studies that used experimental designs and used predominantly preadolescent children as participants. Larger improvements in self-concept were found for children who were handicapped ( $ES = 0.57$ ) than those considered normal ( $ES = 0.34$ ). In this context, the term "handicapped" was broadly defined, and included "the emotionally disturbed, trainable mentally retarded, economically disadvantaged, educable mentally retarded, and perceptually handicapped" (p. 32). It could be that the handicapped children perceived themselves poorly, in comparison to normal children, and had the most to benefit from a programme involving physical activity.

Large improvements in self-concept were found for teaching by clinical method ( $ES = 0.82$ ) and when physical fitness and aerobic activities were prescribed in the curriculum ( $ES = 0.89$ ; Gruber, 1986). Children benefited more from clinical programmes than alternative methods (pupil enhancement,  $ES = 0.39$ ; teacher dominated,  $ES = 0.15$ ; undefined methods,  $ES = 0.55$ ), because of the careful planning and tailoring of programmes by specialty staff to meet individual needs. The children also derived greater benefit from physical fitness and aerobic activities in comparison to other curricula (perceptual-motor or motor development programmes,  $ES = 0.29$ ; learning sports skills,  $ES = 0.40$ ; dance, mime, and creative dance programmes,  $ES = 0.32$ ). The advantage of using physical fitness and aerobic activities may be that they are relatively simple to perform and children may experience positive feedback on a frequent basis through meeting fitness goals.

In summary, although conceptual ambiguity has made it difficult to perform meta-analyses on the relationship between exercise and self-concept, such analyses have been conducted and show a positive relationship between the two variables. From the results, a tentative hypothesis would be that exercise might be most beneficial to people with poor self-concept.

### *Summary*

The studies and meta-analyses that have examined the relationship between physical activity and HRQL or aspects of psychosocial functioning, have found physical activity to be associated with a reduction in anxiety, depression (or more accurately, depressed mood), and other negative mood states, and an increase in HRQL, positive mood states, self-concept, and cognitive functioning.

The overall effect sizes ranged in magnitude from small to extremely large. In the studies, and all meta-analyses, the overall results were in the hypothesised directions. That is, physical activity was consistently associated with improvements in HRQL and psychosocial functioning.

The investigation of potential moderators of the relationship between exercise and psychosocial functioning has examined many possible variables, but few have been consistently found across studies. Hampering this effort has been the lack of effect sizes in some categories of moderator variables, which can result in effect sizes from only one study distorting the results. A case in point is the comparisons between aerobic and anaerobic exercise, where results seem equivocal across meta-analyses, largely due to the small number of studies using an anaerobic exercise protocol, in contrast to the vast majority of studies, which have used an aerobic exercise intervention.

The length of training was a strong moderator of the relationship between exercise and both anxiety and depression. In both cases, longer exercise programmes (> 9 weeks) yielded the largest effects. It appears that treatment of a long duration is necessary to assist people with anxiety or depression. These results should be interpreted cautiously, however, because few studies have been conducted over an extended period of time.

Larger effect sizes have been found for those populations, which could most benefit from improved psychosocial functioning. Evidence of this contention can be found in the literature on exercise and anxiety, depression, and self-concept. People with higher levels of anxiety, people with higher levels of

depression, and people with poor self-concept have been shown to benefit greatly from exercise, as evidenced by improvement on these variables.

Although the evidence for a positive association between exercise and both HRQL and psychosocial functioning is compelling, there is an absence of research examining this relationship with people who have congenital, chronic health conditions. Cerebral palsy is one such condition. As will be reviewed shortly, evidence of positive physical benefits from exercise for people with cerebral palsy is available in the literature. It is uncertain, however, what the possible benefits for this population may be, in terms of HRQL and psychosocial functioning.

### Cerebral Palsy

Cerebral palsy has been defined as “not a single entity but covers neurological impairments characterised by abnormal control of movement or posture resulting from abnormalities in brain development or an acquired non-progressive cerebral lesion” (The Australian and New Zealand Perinatal Societies, 1995, p. 85). This section provides an overview of the condition. Please refer to Appendix A for a full review of the condition, including its incidence and prevalence, aetiology, classification systems, pathophysiology, diagnosis, and management.

#### *Overview of Cerebral Palsy*

Cerebral palsy is prevalent in approximately 2 to 2.5 of every 1,000 live born children in the Western world (Missiuna et al., 2001). The prevalence rate was stable between the 14 studies included in the Missiuna et al. review, with the highest rate, of 3.87, reported in the United Kingdom (Sinha, Corry, Subesinghe,

Wild, & Levene, 1997), and the lowest rate, of 1.19, reported in Germany and Sweden (Krägeloh-Mann et al., 1994).

The aetiology of cerebral palsy is complex, due to the number of exposures that have been associated with the condition. Exposures that lead to cerebral palsy may occur prenatally, perinatally, or postnatally. Stanley et al. (2000) have proposed that greater understanding may be developed by using a causal pathways model to explain the aetiology of cerebral palsy, than by continuing to investigate the effects of single exposures.

Stanley et al. (2000) illustrated one known causal pathway to cerebral palsy involving a mother and father who are Rhesus (Rh) incompatible. Understanding this causal pathway has allowed the development of strategies to prevent cerebral palsy for each couple's children. Stanley et al. suggested other causal pathways are initiated periconceptually or in early pregnancy, and because of premature birth, intrauterine growth restriction, birth asphyxia, and multiple pregnancy. Although research has been conducted that has associated the risk of cerebral palsy with these pathways, as exposures themselves or exposures within these pathways, much research still needs to be undertaken to understand fully the causal pathways to the condition and points for potential intervention.

Comorbidity is common in people with cerebral palsy, especially those with more severe forms of motor disorder (Stanley et al., 2000). Mental retardation and seizure disorders are the most common types of comorbidities (Surveillance of Cerebral Palsy in Europe [SCPE], 2002). The cerebral palsy of people with a single diagnosis (i.e., motor disorder) may have stemmed from different aetiological pathways than the cerebral palsy of people with dual (e.g.,



motor disorder and seizures) or triple (e.g., motor disorder, mental retardation, and seizures) diagnoses (Arpino, Curatolo, Stazi, Pellegri, & Vlahov, 1999).

Although the impairments that manifest with cerebral palsy may predispose people who have the condition to shorter lives, most people with cerebral palsy survive into adulthood (Blair, Watson, Badawi, & Stanley, 2001; Hutton, Colver, & Mackie, 2000; Hutton & Pharoah, 2002). Blair et al. found intellectual impairment to be the strongest predictor of mortality among people with cerebral palsy, with the risk of mortality doubling between each of six categories of intellectual impairment (i.e., IQ > 85, 70-85, 50-69, 35-49, 20-34, <20).

Cerebral palsy can be classified based on the type of motor disorder, topography, and function. Spasticity, dyskinesia, and ataxia are three types of motor disorder (Stanley et al., 2000). On the Western Australian Cerebral Palsy Register, Stanley et al. found that the pure form of spasticity accounted for 76.2% of cases. Topography refers to the limbs affected by cerebral palsy. The most commonly occurring patterns of impairment are quadriplegia, diplegia, left hemiplegia, and right hemiplegia. Functional classification systems have been developed for sport (Cerebral Palsy International Sports and Recreation Association, 2001) and clinical practice (Palisano et al., 2000; Palisano et al., 1997). For international sport, an 8-grade system is used, in which athletes are classified according to functional ability. Athletes compete with other athletes in their grades. In clinical practice, Palisano et al. (1997) developed a 5-level system, analogous to medical grading systems, to measure motor function in children with

cerebral palsy. Sandström, Alinder, and Öberg (2004) have provided support for the validity of the system with adults who have cerebral palsy.

### *The Adult with Cerebral Palsy*

A relatively small proportion of the literature on cerebral palsy has focused on adults with the condition (Zaffuto-Sforza, 2005). Cerebral palsy has typically been viewed as a paediatric condition, especially in the development of therapeutic interventions (Bottos et al., 2001). In this subsection, I briefly review the literature on the physical and functional health of adults with cerebral palsy, before examining the psychosocial research.

#### *Physical Health*

Adults with cerebral palsy frequently develop physical health issues that are secondary to their condition (Bottos et al., 2001; Turk, Geremski, Rosenbaum, & Weber, 1997). Bottos et al. found that the most common physical health issues of participants were feeding (31.9%), epilepsy (25.0%), bladder (18.1%), bowel (18.1%), speech (12.5%), and visual (12.5%) impairments. Half of the participants in this study did not report any health issues. For women with cerebral palsy, the most common physical health issues were pain (84%), hip and back deformities (59%), bowel problems (56%), bladder problems (49%), poor dental health (43%), increased spasticity during menstruation (35%), gastroesophageal reflux (28%), and increased incontinence during menstruation (24%).

Possibly contributing to the health issues of adults with cerebral palsy, was the limited preventive medical care they received as adults (Bottos et al., 2001; Murphy, Molnar, & Lankasky, 1995). Murphy et al. found that over 90% of the participants in their research did not have regular health examinations. Reasons

for the infrequency of examinations may have been because the examination rooms could not be easily accessed or the equipment was poorly set-up to be used by people with severe motor impairments.

The participants at the National Invitational Colloquium on Aging and Cerebral Palsy (Turk et al., 1995) suggested that health care professionals need to address many physical health issues of adults with cerebral palsy. Specifically, physical health issues that need to be addressed included musculoskeletal (e.g., deformities, decrements in mobility and functioning, increases in pain and fatigue, osteoporosis and fractures, the impact of previous treatment, soft tissue injuries), oral (e.g., feeding, dental health), gastrointestinal (e.g., gastroesophageal reflux, constipation, inadequate nutrition), urologic (e.g., urinary incontinence and retention issues), and reproductive problems (e.g., for men: impotence, lack of physical ability to meet their own sexual needs; for women: concerns regarded menopause, fertility, the ability to maintain a pregnancy and give birth; in general: birth control, sexually transmitted diseases, acquired immune deficiency syndrome, reproductive health, the issue of using a third person to facilitate sex). One question emanating from this identification of physical health issues is why men raised sexual concerns relating to reproduction, whereas women raised concerns relating pregnancy and childbirth. A possible explanation is that women also had sexual concerns, but perceived pregnancy and childbirth issues to be more important for them.

### *Functional Health*

Functional deterioration in people with cerebral palsy is typically faster than would be expected in the general population due to the natural ageing

process (Ando & Ueda, 2000; Bottos et al., 2001; Jahnsen, Villien, Egeland, Stanghelle, & Holm, 2004; Strauss, Ojdana, Shavelle, & Rosenbloom, 2004). Bottos et al. (2001) found a marked decline in locomotion with age for people with cerebral palsy. Although 41.4% of participants walked independently before 18 years of age, only 22.2% walked independently at follow-up when they were, on average, 33 years old. There were also declines in the number of participants who walked with aids, or had limited mobility using a walker, between under 18 years of age (17.1% and 17.1%, respectively) and follow-up (13.9% and 6.9%, respectively). There were corresponding increases in the number of participants who used locomotion just to bear weight for transfers or did not bear weight at all. At follow-up, 25.0% of participants used locomotion to bear weight for transfers and 32.0% did not bear weight. Of the 13 participants who lost independent walking, nine lost this function between the ages of 20 and 40 years, and seven reported marked insecurity when walking as the reason why independent walking was lost. Wheelchairs were used by 71% of participants, with higher use of wheelchairs by those with greater severity of both motor impairment and type of cerebral palsy (e.g., tetraplegia).

Ando and Ueda (2000) found functional deterioration in 35% of adults with cerebral palsy who worked in community workshops in Japan. Most working Japanese adults with cerebral palsy are employed in community workshops, rather than in general industry. Although the occurrence of functional deterioration increased with age, as would be expected in the general population, deterioration was reported by 21% of adults aged below 25 years old. Accounting for differences in functional ability, factors that were associated with functional

deterioration included the type of facility at which the participants worked and the severity of involuntary movements of the head and neck. The magnitudes of these effects, however, are small. Nevertheless, this finding suggests that care should be taken not to place people with cerebral palsy in environments that, over a period of time, could exacerbate their condition.

### *Psychosocial Health*

Few studies have been conducted on the psychosocial health of adults with cerebral palsy. In an Australia-wide survey of 279 adults with cerebral palsy, Morgan and Balandin (1997) found that respondents regularly experienced frustration (36%), anxiety (22%), anger (17%), and depression (16%). Although some of these conditions may be associated with negative physical states or changes, the study did not explore the reasons behind these psychological manifestations. Because these variables were measured as single items, rather than being measured using instruments with sound psychometrics, it is not possible to compare the occurrence of these conditions with normative data from the general population.

Of the 72 adults in the Bottos et al. (2001) study, the majority lived at home with their parents (75%), were not married (88.7%), had a minimum of a secondary school education (65.7%), and were unemployed or worked in sheltered employment (82.3%). The intellectual level of each participant was classified as profound learning disability (LD), moderate/severe LD, mild LD, or normal/borderline intelligence. Participants with greater intellectual impairment were more likely to be unemployment. Participants who were married tended to be those with higher intelligence and those who were older age (>40 years). Of

the seven participants who were married, six had normal/borderline intelligence, and one had mild intellectual impairment. There may be several reasons for the low marriage rate, including: the social stigma of having a romantically intimate relationship with people who have physical disabilities; the exclusion of people with disabilities from full participation in social activities because they are erroneously perceived as incapable of fulfilling some valued social roles; the myths that people with disabilities are asexual, incapable of sexual functioning, and unable to pursue their sexual desires in a socially acceptable manner; and lack of support from parents (DeLoach, 1994; Shuttleworth, 2000).

Cho, Park, Park, and Na (2004) further examined marriage and psychosexual functioning in adults with cerebral palsy. In comparison to unmarried able-bodied men, unmarried men with cerebral palsy had lower levels of sexual information, experience, drive, attitude, affect, and satisfaction, and a higher degree of psychological symptoms. Unmarried women had greater body image issues than married women. Married men and women with cerebral palsy reported more psychological symptoms than did married able-bodied men and women, respectively. Adults with cerebral palsy who could ambulate in the community reported receiving more sexual information and having more sexual experience than those adults with cerebral palsy who could not ambulate in the community. The results of the Cho et al. study suggest that psychosexual functioning may be dependent upon gender, level of physical function, and marital status. Adults with cerebral palsy who are male, unmarried, and have low levels of physical ability may have less psychosexual functioning than other adults with cerebral palsy and adults from the general population.

Difficulties in communication have been highlighted as a concern of adults with cerebral palsy (Turk et al., 1995). Bottos et al. (2001) identified poor speech as a major issue of adults with cerebral palsy. Hearing and vision impairments also contribute to communication problems. Turk et al. stated that language and central processing difficulties hampered communication, especially for those individuals with intellectual impairment. Communication may become more difficult with age, due to pulmonary changes having an adverse effect on breath control during speech.

*Self-concept and self-esteem.* There is little research comparing the self-concept and self-esteem of adults with cerebral palsy with that of adults in the general population. It may be possible, however, to gain an insight into the self-concept and self-esteem of adults with cerebral palsy through the literature on children and adolescents with the condition. The majority of the empirical evidence (e.g., King, Shultz, Steel, Gilpin, & Cathers, 1993; Manuel, Balkrishnan, Camacho, Paterson, & Koman, 2003a; Östring & Nieminen, 1982) has refuted the propositions that children and adolescents with disabilities may have poor self-concepts (e.g., Abramson, Ash, & Nash, 1979) and low self-esteem (e.g., Bryan & Herjanic, 1980; Minde, 1978; Strax, 1988), in comparison to their peers without disabilities. In her review of 10 studies that examined the self-esteem of children with physical disabilities, Llewellyn (2001) concluded that the presence of a physical disability did not mean that a child would have low self-esteem.

King et al. (1993) investigated the self-concept, social self-efficacy, personal values, and interpersonal styles of 53 adolescents with disabilities (cerebral palsy,  $n = 27$ ; cleft lip or palate or both,  $n = 17$ ; spina bifida,  $n = 9$ ).

Because there was only one significant difference between adolescents with different disabilities (i.e., adolescents with cleft lip or palate or both scored higher than adolescents with cerebral palsy on the measure of athletic competence), data from the 53 adolescents were combined in the later analyses, which compared the male and female adolescents' scores with male and female scores from a normative sample. Although King et al. adjusted the Type I error rate for multiple tests of significance and commented on the power of these tests in the discussion, they did not report the effect sizes for the differences between the study sample and the normative sample on the variables of interest. Estimates of Cohen's  $d$ , however, could be calculated from the statistics the authors provided. In regard to self-concept, the largest differences between the two samples (i.e., adolescents with disabilities and adolescents from a normative sample, for both males and females) occurred for the following subscales: athletic competence (females,  $d = 0.87$ ; males,  $d = 0.62$ ), social acceptance (females,  $d = 0.82$ ), romantic appeal (females,  $d = 0.72$ ; males,  $d = 0.66$ ), and physical appearance (females,  $d = 0.50$ ). In all of these medium to large effects, the scores of the adolescents in the normative sample were higher than the adolescents with disabilities.

No significant differences were found in the social self-efficacy and self-acceptance of adolescents from the two samples (King et al., 1993). Two effect sizes of small to medium magnitude, however, were calculated. Females with disabilities had lower social self-efficacy ( $d = 0.29$ ), but higher self-acceptance ( $d = 0.32$ ) than females without disabilities. No significant differences were found for personal values. Three effect sizes of small to medium magnitude, however, were calculated. Females with disabilities placed greater importance ( $d = 0.42$ ),



and males lesser importance ( $d = 0.31$ ), on achievement than adolescents without disabilities. Females with disabilities also placed lesser importance on variety than those without disabilities ( $d = 0.24$ ). In terms of their interpersonal style, adolescents with disabilities were less independent (males,  $d = 0.51$ ; females,  $d = 0.46$ ) and less persistent (females,  $d = 0.87$ ; males,  $d = 0.48$ ) than adolescents without disabilities.

Magill and Hurlbut (1986) found no difference in overall self-esteem of adolescents with or without cerebral palsy. Female adolescents with cerebral palsy, however, were found to have poorer self-esteem than male adolescents with cerebral palsy and adolescents without disability. Caution is required when interpreting these results, because Magill and Hurlbut followed their multivariate analysis of variance with univariate analysis, a procedure that does not control for inflation of Type I error (Schutz & Gessaroli, 1993). Magill and Hurlbut did not calculate effect sizes for these differences. Cohen's  $d$  values, however, could be estimated from the statistics provided. Specifically, female adolescents with cerebral palsy had lower physical self-esteem than males with cerebral palsy ( $d = 1.49$ ), males without disability ( $d = 1.46$ ), and females without disability ( $d = 1.26$ ). Females with cerebral palsy also scored lower on social self-esteem than males ( $d = 0.59$ ) and females ( $d = 1.35$ ) without disability. The magnitudes of these effects, however, are particularly striking. Magill and Hurlbut explained these differences between males and females, and adolescents with and without disability, within an interactionist framework, where self-esteem stems from interactions with others. Females may place more importance on social interaction than males, may have greater awareness of how others perceive them, and may

judge physical appearance to be important for successfully engaging with others in a social context. It would follow that the physical self-esteem of females with cerebral palsy would be lower than that of other adolescents.

Blake and Rust (2002) produced contrary evidence, however, finding a positive association between physical impairment and social self-efficacy. Included in their sample of 48 university students with disabilities were eight students with cerebral palsy. Social self-efficacy was positively associated with the visibility and severity of the disabilities, as rated by the first author ( $r_s = .30$  and  $.33$ , respectively). There was a negative association between social self-efficacy and age of onset of disability ( $r = -.35$ ), suggesting that students with congenital disabilities may have had higher social self-esteem than students with acquired disabilities.

There may be a number of reasons why the association between physical impairment and social self-efficacy in the Blake and Rust (2002) study was in the opposite direction to those of other studies. First, the sample comprised college students, who, compared with other people with disabilities, may have had to overcome barriers to achieve in education at the tertiary level. Successfully overcoming obstacles may have lead to higher self-efficacy. Second, people with visually obvious disabilities may have had to accept their disabilities quicker than those who were able to hide their disabilities from other people. Third, being college students, they may be way ahead of the general population in terms of academic, intellectual, and social ability.

In the Manuel et al. (2003a) study of 50 children and adolescents with cerebral palsy, four variables were associated with self-esteem: gender, physician-

assessed functional status, perceived parental over-protectiveness, and perceived impact of disability. These variables explained a substantial proportion of variance in self-esteem scores ( $R^2 = .45$ ); but only gender and perceived impact of the disability were significantly associated with self-esteem. Females and those who had more adverse perceptions of the impact of their disability reported lower self-esteem compared to males and those who perceived the impact of their disabilities to be low, respectively.

*Social support.* Few studies have investigated the effects of social support, or lack thereof, and adults with cerebral palsy. This lack of research attention may be somewhat surprising because social support has been shown to have a key influence on psychological health (Penninx, Kriegsman, van Eijk, Boeke, & Deeg, 1996; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). Researchers have typically focused on the social support received by the parents and families of people with cerebral palsy (e.g., Brehaut et al., 2004; Kim & Kumar, 2004; Manuel, Naughton, Balkrishnan, Paterson Smith, & Koman, 2003b), rather than that received by those with the condition. Two studies (King et al., 1997; Martin & Mushett, 1996), however, have provided some insights into social support and people with cerebral palsy.

In their study of 78 elite swimmers with disabilities (45 of whom had cerebral palsy), Martin and Mushett (1996) found that friends, parents (mothers more so than fathers), and coaches were primary providers of social support for the athletes. Friends and parents were prominent in providing non-sport-related social support, whereas coaches gave the swimmers greatest support in the sports setting. Social support was positively associated with self-esteem. Moderately

large relationships were found between self-esteem and three aspects of social support: emotional challenge ( $r = .40$ ), listening ( $r = .37$ ), and technical challenge ( $r = .37$ ). Although these findings may suggest that higher levels of social support may benefit self-esteem, a weakness of the study was that self-esteem was measured by a single item, “How confident are you in your ability to train to achieve your athletic potential?” This item seems to tap the self-efficacy construct, more than it does self-esteem. More research is necessary to establish the possible effect of social support on self-esteem.

King et al. (1997) investigated the efficacy of a 10-week social skills training programme for 11 withdrawn unpopular children (i.e., those not well liked by their peers;  $M = 12.0$  years old), eight of whom had cerebral palsy. The 20-session training programme focused on five key areas: conversational skills, coping with difficult others, initiating interactions with peers, interpersonal problem solving, and verbal and nonverbal communication. Although these children were considered to be withdrawn and unpopular (as determined by their teachers’ ratings of their popularity with classmates), their scores on measures of global self-worth, social acceptance, classmate support, close friend support, and loneliness were not too dissimilar from those of a normative sample of children without disabilities. From the statistics provided, I calculated Cohen’s  $d$  values. The children in the training programme had higher global self-worth ( $d = 0.28$ ), lower social acceptance ( $d = 0.55$ ), lower classmate support ( $d = 0.23$ ), higher close friend support ( $d = 0.71$ ), and greater loneliness ( $d = 0.62$ ) than the children in the normative sample. These results provide an unclear picture of what these children were experiencing. It seems that they were not accepted by many

classmates, but were successful in having a few close friendships. Between the pretest and posttest of the programme there was an increase in the childrens' perceptions of their social acceptance ( $d = 0.55$ ). There were no other changes at posttest, but the children's feelings of loneliness had reduced between the posttest and the six-month follow up ( $d = 0.70$ ). Although this study highlighted that some children with cerebral palsy may experience adverse social circumstances, the extent of the unpopularity of the children with disabilities may not have been that substantial and the measures used may not have been sensitive to large differences in classmate popularity.

### *Summary*

In summary, there has been minimal study of the health of adults with cerebral palsy. Studies have shown that adults with the condition typically experience a variety of physical health issues and a decline in function, which is faster than for people from the general population, as they grow older. Researchers who have investigated the psychosocial health of adults with cerebral palsy have suggested that these people may commonly experience negative mood states, low self-esteem, and low social support. There have been few studies in this area, however, and some of this research has been equivocal. For example, cerebral palsy may influence certain domains of self-esteem (e.g., physical) more so than global self-esteem. In future investigations of the health and psychosocial functioning of adults with cerebral palsy, the findings of previous research offer strong rationale for the inclusion of physical health, functional health, mood, self-efficacy (possibly physical self-efficacy, in particular), and social support as potential variables of interest.

## The Management of Cerebral Palsy Through Exercise

Exercise may be a core factor in a multidisciplinary approach to the management of cerebral palsy (Brunstrom, 2001). Through gaining and maintaining physical fitness, many people with cerebral palsy may be able to retain mobility and independence for longer periods of time. In this section, I briefly review the research on the physical activity levels, energy expenditure, physiologic exercise potential, and trainability of people with cerebral palsy.

### *Physical Activity Levels*

To compensate for loss of function due to the natural ageing process and changes relating to their condition (e.g., contractures, pain, reduced mobility, spasticity), people with cerebral palsy may need to do a greater amount of exercise than people in the general population (Rimmer, 2001). Research has shown, however, that adults with cerebral palsy typically are not doing sufficient exercise to meet USDHHS (1996) recommendations for the general population (Heller et al., 2002; Turk et al., 1997). In the Heller et al. study, for example, approximately half of the adults with cerebral palsy exercised, with the frequency of exercise being, on average, 1.6 times per week.

The sedentary living of people with cerebral palsy may begin in childhood and adolescence. Longmuir and Bar-Or (2000), in their study of 987 young people with health conditions (i.e., physical disabilities, chronic medical conditions, visual impairments, hearing impairments), found that a greater proportion of young people with cerebral palsy led sedentary lives than people with other conditions.

### *Energy Expenditure*

People with cerebral palsy typically have greater energy requirements than people who do not have this condition (Hemingway, McGrogan, & Freeman, 2001; Johnson, Ferrara, & Poehlman, 1993; Johnson, Goran, Ferrara, & Poehlman, 1996; Johnson, Hildreth, Contompasis, & Goran, 1997; Rose, Gamble, Burgos, Medeiros, & Haskell, 1990; Rose, Gamble, Medeiros, Burgos, & Haskell, 1989). Johnson and colleagues (Johnson et al., 1996; Johnson et al., 1997) have found athetosis and ambulation to be important contributors to higher energy expenditure. Athetosis may cause hypermetabolism in people with cerebral palsy.

### *Physiological Exercise Potential*

People with cerebral palsy are able to perform aerobic and anaerobic exercise. The physical work capacity (PWC), measuring aerobic fitness, for people with cerebral palsy is approximately half that of people without the condition (Lundberg, 1978, 1984; Tobimatsu, Nakamura, Kusano, & Iwasaki, 1998; van den Berg-Emons, van Baak, de Barbanson, Speth, & Saris, 1996). Similar results have been found for mean power, a measure of anaerobic capacity (Bar-Or, 1986; van den Berg-Emons et al., 1996). Factors that limit aerobic and anaerobic performance include involuntary movements (Lundberg, 1976), impaired coordination, spasticity (Bar-Or, Inbar, & Spira, 1976), and cocontraction of muscles (Unnithan, Dowling, Frost, & Bar-Or, 1996).

The prescription of strength training for people with cerebral palsy has traditionally been rare (Fowler et al., 2001), because of assumptions made about the likely responses of spastic muscles to maximal lifting. Bobath and Bobath (1984), for example, contended that strength training would increase spasticity

and promote associated reactions in people with cerebral palsy. Although little research has been conducted on the validity of these assumptions, the few studies that have been performed have found no basis for these warnings (Fowler et al., 2001; Ross & Engsberg, 2002). Guidelines for the prescription of strength training for people with cerebral palsy have recently become available (Laskin, 2003).

### *Trainability*

Several studies have shown that the cardiovascular fitness of people with cerebral palsy can be improved through aerobic training (Bar-Or et al., 1976; Berg, 1970; Emons & Van Baak, 1993; Fernandez & Pitetti, 1993; Lundberg, Ovenfors, & Saltin, 1967; van den Berg-Emons, van Baak, Speth, & Saris, 1998). Changes in fitness have occurred despite many of the studies using low-intensity training programmes. Fernandez and Pitetti (1993), for example, had seven ambulatory adults with cerebral palsy participate in submaximal exercise (i.e., eliciting heart rates between 40% and 70% of their PWC) for 30 minutes, twice per week, for eight weeks. For males and females, the PWC/body weight (mL/kg.min) improved 10.6% and 16.3%, respectively, between pretest and posttest. Depending on initial aerobic endurance and the intensity and type of training, improvements in cardiovascular fitness of between 5% and 25% are possible (Rushall & Pyke, 1990). The results from the participants in the Fernandez and Pitetti (1993) study compare favourably with Rushall and Pyke's guidelines. The pretest and posttest PWC/body weight values for both men and women, however, were in the bottom 10% of values for the general population (American College of Sports Medicine, 2005).



Strength training can benefit people with cerebral palsy (Allen, Dodd, Taylor, McBurney, & Larkin, 2004; Blundell, Shepherd, Dean, & Adams, 2003; Dodd et al., 2002; Taylor, Dodd, & Larkin, 2004). In their review, Dodd et al. found that the magnitudes of the effect sizes (Cohen's  $d$ ), for the participants' strength gains in the 10 reviewed studies, ranged from .24 (Lockwood, 1993) to 5.27 (Damiano, Vaughan, & Abel, 1995). Several studies have also found functional (Damiano & Abel, 1998; Darrah, Wessel, Nearingburg, & O'Connor, 1999; MacPhail & Kramer, 1995; O'Connell & Barnhart, 1995) and psychological (Darrah et al., 1999) benefits of participation in strength training interventions. In Damiano and Abel's study of children, for example, the largest functional benefits of a 6-week, individualised strength-training programme were found when the children were asked to walk as fast as they could, without running. Velocity at the fastest walking speed increased from pretest to posttest ( $d = 0.44$ ), which was mainly due to an increase in cadence ( $d = 0.64$ ), rather than an increase in stride length ( $d = 0.13$ ). At the fastest speed, children also achieved greater stability.

In a recent study, Blundell, Shepherd, Dean, and Adams (2003) found that a 4-week functional strength training programme produced similar changes in walking speed ( $d = 0.51$ ) in eight children with cerebral palsy. Contrary to the findings of Damiano and Abel (1998), however, the increase in speed was due to increases in stride length ( $d = 0.81$ ), rather than cadence ( $d = 0.16$ ). This contrast in findings may be due to differences in the strength-training programmes. The programme used in the Blundell et al. study had functional exercises using the children's own body weight as resistance. Exercises included standing balance exercises and sit-to-stands. The Damiano and Abel programme, however,

involved exercises for targeted leg muscles, using velcro-attached free weights. Both approaches were effective at increasing walking speed, and the most beneficial form of strength training may be dependent on the needs of the individual with cerebral palsy.

Darrah et al. (1999) measured the effect of a 10-week exercise programme on the perceived competence of 23 adolescents with cerebral palsy. The programme took place three times per week and incorporated both aerobic and strength training. A substantial increase in the physical appearance subscale of the Self Perception Profile for Adolescents (Harter, 1988) occurred from pretest to posttest ( $z = -2.75$ ), for those participants aged over 12 years. Although a control group was not included in this research, the findings provide strong encouragement for more research on the effects of exercise on the psychological well-being of people with cerebral palsy.

### *Summary*

Involvement in physical activity may have an important role in the management of cerebral palsy. People with this condition, however, do not seem to be doing sufficient exercise to offset possible functional loss due to cerebral palsy. Although cerebral palsy limits the physiological exercise potential of people with this condition, their aerobic capacities and strength are trainable. Exercise prescription guidelines, for people with cerebral palsy, are available to fitness professionals.

## Summary of Literature on Physical Activity, Health-Related Quality of Life, and Psychosocial Functioning

Research has established a positive association between physical activity and HRQL and psychosocial functioning in the general population. Little is known, however, about the potential of physical activity to affect the HRQL and psychosocial functioning of people with congenital, chronic health conditions, such as cerebral palsy. From the few studies that have been conducted on the health of adults with cerebral palsy, several issues may need to be addressed by health professionals and further examined by researchers, including poor physical health, functional decline, negative mood states, low self-esteem in particular domains (e.g., physical), and lack of social support. These variables may be assessed psychometrically, using instruments designed around HRQL (that, among other constructs, incorporates physical and functional health), mood, physical self-efficacy, and social support. Many of these health and psychosocial functioning issues may be improved through participation in physical activity. Until recently, however, practitioners have been cautious in prescribing certain types of exercise (e.g., strength training) for people with cerebral palsy, because it was assumed that such training would negatively affect their condition. Research has shown, however, that people with cerebral palsy can obtain positive physical benefits from aerobic exercise and strength training, and that their condition is not exacerbated through involvement in such physical activity.

### Purpose of the Thesis

The original aim of this thesis was to examine the effect of physical activity on the HRQL and psychosocial functioning of adults with cerebral palsy.

In the first study, the amount of physical activity engaged in by a sample of adults with cerebral palsy was quantified using several self-report measures. The concurrent measurement of HRQL, mood, physical self-efficacy, and social support allowed for their association with physical activity to be determined. I hypothesised that greater involvement in physical activity would be related to higher levels of HRQL and psychosocial functioning. I then planned to conduct two intervention studies. These two studies were designed to investigate the effect of warm-water aerobic exercise and strength training, respectively, on the HRQL and psychosocial functioning of adults with cerebral palsy.

Following the correlational study (Study 1), I was unable to recruit sufficient participants for the two exercise intervention studies. Apart from making intervention studies using an experimental design impossible, this difficulty in recruiting participants raised the question of why these people with cerebral palsy did not want to be involved in physical activity (or, at least, physical activity research). One possibility was that negative experiences with physical activity in the lives of people with cerebral palsy might have adversely influenced their decisions to be active. The remaining three studies of this thesis were designed to investigate the meaning and experiences of physical activity in the lives of adults with cerebral palsy. In Studies 2, 3, and 4, I examined the lives of adults with cerebral palsy who did minimal physical activity, who were engaged in physical activity, and who had done minimal physical activity before participating in exercise programmes, respectively. As a background to these studies, I review the literature on people's meanings and experiences of physical activity (Chapter 4). I also consider many other life experiences of adults with

cerebral palsy. A life history approach (Denzin, 1989a; 1989b) was the method of choice for these three studies. Such a design does not call for complete biographies of people, however, but may focus on specific topics of interest. Although I focused on the participants' involvement, or lack thereof, in physical activity, I also discussed other aspects of their lives that influenced the development of their personalities and their choices regarding physical activity.

## CHAPTER 3

### STUDY 1 – THE RELATIONSHIP BETWEEN PHYSICAL ACTIVITY, HEALTH-RELATED QUALITY OF LIFE, AND PSYCHOSOCIAL FUNCTIONING OF ADULTS WITH CEREBRAL PALSY

#### Introduction

Little is known about the levels of physical activity in which adults with cerebral palsy engage. Although studies of people with cerebral palsy have shown that most participated in some physical activity (Heller et al., 2002; Turk et al., 1997), it seems the frequency, duration, and intensity of activity did not meet USDHHS (1996) recommendations, or Rimmer's (2001) suggestion that people with cerebral palsy should do a greater amount of physical activity than people from the general population.

In the descriptive study of her doctoral dissertation on people with another neurological condition, multiple sclerosis, Sutherland (2001) found that physical activity was associated with HRQL and psychosocial functioning. Sutherland reported medium to large correlations between physical activity and almost all subscales of the HRQL, daily hassles, and mood instruments. Medium to large positive and negative associations were also found for the measures of social support and depression, respectively. The aim of Study 1 was to establish physical activity levels in adults with cerebral palsy and to explore associations between physical activity, HRQL, and psychosocial functioning.

Method

Participants

The participants were 51 (32 male, 19 female) adults with cerebral palsy from Australia and New Zealand. They ranged in age from 19 to 66 ( $M = 38.20$ ,  $SD = 11.69$ ). The distribution of the severity of cerebral palsy by type of motor disorder, topography, and motor function is shown in Table 3.1. Half of the participants (51%) required assistance to complete the questionnaire.

Table 3.1

Classification of Cerebral Palsy

Classification system	Present study % <sup>a</sup>	Stanley et al. (2000) % <sup>b</sup>
Motor disorder		
Spastic	51.0	76.2
Dyskinetic	7.8	5.8
Ataxic	3.9	5.0
Mixed		12.4
Spastic/dyskinetic	7.8	
Spastic/ataxic	5.9	
Dyskinetic/ataxic	7.8	
Spastic/dyskinetic/ataxic	13.7	
Topography <sup>c</sup>		
Quadriplegia	37.5	11.9
Triplegia	2.5	
Diplegia	25.0	23.6
Hemiplegia	30.0	43.4
Monoplegia	2.5	
GMFCS level <sup>d</sup>		
1	5.9	
2	23.5	
3	15.7	
4	25.5	
5	29.4	

*Note.* <sup>a</sup>The percentages for motor disorder and topography do not total to 100% due to a small number of participants ( $ns = 1$  and  $1$ , respectively) not responding to these items. <sup>b</sup>These comparison percentages are from the Western Australian Cerebral Palsy Register 1975-90 ( $N = 756$ ). <sup>c</sup>To allow comparison with Stanley et al. (2000), topography percentages are for the spastic type of cerebral palsy, and mixed types that include spasticity. <sup>d</sup>Higher GMFCS levels indicate greater functional impairment.

## *Measures*

A questionnaire was used to collect background information about the participants and to measure their HRQL, mood states, physical self-efficacy, and social support. The questionnaire can be found in Appendix B.

### *Background Information*

Participants were asked to record their age and gender, to classify the type of disability they had, and to state whether they had any other long-term medical conditions. They were asked to classify the type of cerebral palsy they had by the parts of their bodies that are affected by the condition (i.e., quadriplegia, triplegia, diplegia, hemiplegia, or monoplegia), by the type of movement disorders they had (i.e., spastic, dyskinetic, ataxic, and/or rigid cerebral palsy), and by their gross motor function. An adaptation of the Gross Motor Function Classification System (GMFCS; Palisano et al., 2000) was used as a measure of gross motor function. The GMFCS has five levels that are differentiated based on the severity of cerebral palsy. The descriptions of the five levels of function from Palisano et al. were used in the survey and participants were asked to indicate the level that matched the severity of their cerebral palsy. To improve participant comprehension, the terms “gross motor skills,” “an assistive mobility device,” and “assistive technology” were changed to “large physical movements,” “a physical aid, such as a cane or walking frame,” and “physical aids,” respectively.

### *Level of Physical Activity*

A modified version of the Physical Activity and Disability Survey (PADS; Rimmer, Riley, & Rubin, 2001) was used to measure the type and amount of physical activity in which the participants engaged. Rimmer et al. reported



adequate reliability for the instrument's four subscales: exercise, household activity, leisure-time physical activity (LTPA), and time indoors. Internal consistencies ranged from .67 (exercise) to .77 (time indoors), and the 1-week, test-retest reliability ranged from .78 (time indoors) to .95 (LPTA). Rimmer et al. tested the concurrent and predictive validity of the PADS by correlating subscale scores with measures of fitness (absolute peak  $\text{VO}_2$ , relative peak  $\text{VO}_2$ , maximum workload, and time to exhaustion). Judging the concurrent and predictive validity of the PADS against these measures of physical fitness is, however, questionable, because many people are quite active without having high levels of fitness. Therefore, the PADS may have greater validity than is indicated by the associations found in the Rimmer et al. study. In addition, the measures of physical fitness focused solely on aerobic fitness. The largest association in this study was between time indoors and maximum workload, before a health promotion intervention ( $r = -.33$ ). The instrument was able to detect differences in experimental and control groups, before and after a 12-week health promotion intervention.

The PADS was modified for the present study, because the original instrument was designed for use during semi-structured interviews. It contained screening items, which assessed what parts of the participants' bodies were affected by their disabilities and what mobility aids they used, four sections of questions on physical activity levels, and a demographic information section. The screening items and demographic information section were not used in the present study, because the items were either in the background information section of the questionnaire or were irrelevant to the study. The exercise section asked

participants, “Do you currently exercise?” If they answered “yes,” then they were directed to record the activities they performed and how much time (minutes per day and days per week) they spent on each activity. To assist comprehension, the following text was added: “Some examples would be running for 30 minutes a day on 3 days of the week, and swimming for 45 minutes on 1 day of the week.”

The LTPA section was formatted the same as the exercise section. The primary question was, “Do you currently participate in any sports, recreational, or physical leisure activities?” The word “physical” was inserted into this question so that activities that involved physical activity were elicited, rather than activities where the participant was sedentary. To assist comprehension, the following text was added: “Some examples would be playing basketball for 30 minutes on 1 day a week, and going ten-pin bowling for 60 minutes on 1 day a week.” The household activity section focused separately on indoor activities and outdoor activities.

These two parts were formatted the same as the previous two sections. The primary questions were, “Are most of your indoor household activities done by you or someone else?” and, “Do you do any outdoor household activities such as gardening?” To assist comprehension of the first primary question, the following text was added: “Some examples would be washing dishes for 15 minutes per day on 7 days of the week, and vacuuming for 90 minutes on 1 day of the week.” To assist comprehension of the second primary question, the following text was added: “Some examples would be mowing the lawns for 30 minutes once a week, and gardening for 60 minutes per day on 2 days of the week.” In the Rimmer et al. instrument, the time indoors section had two forced-choice questions and one open-ended question. The two forced-choice questions pertained to how much

time participants spent inside their homes during the week (Monday to Friday) and weekend (Saturday and Sunday). The response options were 1 (*less than 6 hours a day*), 2 (*6 to 10 hours a day*), and 3 (*more than 10 hours a day*). To avoid trichotomising continuous scales, however, these two questions were modified in the present study to allow for open-ended responses. The modified questions were, “From Monday through Friday, how many waking hours a day do you usually spend inside your home?” and “On Saturday and Sunday, how many waking hours a day do you usually spend inside your home?” The third question asked participants to record the average number of hours per day that they spend sitting or lying down, excluding sleeping at night.

#### *Health-Related Quality of Life*

The RAND 36-Item Health Survey 1.0 (Hays, Sherbourne, & Mazel, 1993) was used to measure HRQL. The questionnaire is identical to the Medical Outcomes Study Short-Form Health Survey (SF-36; Ware & Sherbourne, 1992); the scoring methods on two of the eight subscales, however, differ. The RAND survey was chosen because the distance between adjacent scores within each item is consistent throughout the instrument, whereas the coding of two items in the SF-36 (the severity item of the bodily pain subscale and the overall health item of the general health perceptions subscale) is different from the coding of the other items (i.e., the points on the scales are not equidistant). Although Hays et al. support Ware and Sherbourne’s rationale for the method of coding these items, they suggest that the method should be applied to all items, or not at all, rather than to selected items. The eight subscales included in the measure are: physical functioning, role limitations due to physical health problems, role limitations due

to personal or emotional problems, energy/fatigue, emotional well-being, social functioning, bodily pain, and general health perceptions. There is also an additional item that measures perceived change in health. The internal consistencies of the subscales are adequate, with alpha values ranging from .78 (bodily pain and general health perceptions) to .93 (physical functioning). The instructions for items 3 to 12 were changed to “The following items are about activities you might do during a typical day. Does your health, including your cerebral palsy, currently limit you in these activities? If so, how much?” The words “including your cerebral palsy” were added, because people with congenital disabilities may perceive their disabilities to be separate from their health. Also, the word “currently” was changed from the word “now” to improve the clarity of the question. The subscales each have between two and 10 items. The item, “Did you feel full of pep?” was changed to, “Did you feel full of energy?” to suit the Australian sample. The response choices were either dichotomous (*yes* or *no*) or on Likert scales ranging from 1-3 to 1-7 depending on the subscale.

### *Mood States*

The Profile of Mood States-Short Form (POMS-SF; Shacham, 1983) was used to measure mood states. The instrument is a shortened version of the original 65-item POMS (McNair et al., 1971). The shortened version consists of 37 adjectives designed to assess six transient distinct moods or affective states: tension-anxiety, depression-dejection, anger-hostility, vigour-activity, fatigue-inertia, and confusion-bewilderment. Each subscale has between five and eight items. Two adjectives were adjusted to suit the Australian sample (i.e., “bushed”

was changed to “tired,” and “full of pep” was changed to “full of energy”). These word changes were consistent with prior research conducted with an Australian sample (Sutherland et al., 2001). The instructions were, “Below is a list of words that describe feelings people have. Please read each one carefully. Then circle one number on each line that best describes how you have been feeling during the past week, including today.” The words “on each line” were changed from “to the right” to retain consistency in wording throughout the survey. Responses on a 5-point Likert scale indicate the participant’s level of agreement with each item ranging from 0 (*not at all*) to 4 (*extremely*). Shacham reported that the POMS-SF has good face validity and internal consistency, with the alpha values ranging from .80 to .91. The POMS-SF was demonstrated to be a suitable substitute for the original instrument with the correlations (*rs*) between the scores of the original and shortened subscales ranging from .95 to .98.

### *Physical Self-Efficacy*

The Physical Self-Efficacy Scale (PSES; Ryckman, Robbins, Thornton, & Cantrell, 1982) was used to measure physical self-efficacy. The 22-items represent two subscales: perceived physical ability (PPA) and physical self-presentation confidence (PSPC). These subscales can be summed to produce an overall physical self-efficacy score (PSE). Examples of items would be, “My physique is rather strong,” (PPA item) and “Sometimes my laugh embarrasses me” (PSPC item). Participants respond to the items on a 6-point Likert scale, ranging from 1 (*strongly disagree*) to 6 (*strongly agree*). The instructions on the instrument were, “Below is a list of statements that describe different physical qualities. Please read each one carefully. Then circle one number on each line to

indicate the extent to which you agree or disagree with the statement.” The words “on each line” were changed from “to the right” to retain consistency in wording throughout the survey. Rykman et al. (1982, Study 1) found adequate internal consistency values for the PPA (.84) and PSPC (.74) subscales, and for the PSE scale (.81). Rykman et al. also found support for the scale’s construct validity, convergent validity, discriminant validity, and predictive validity.

### *Social Support*

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) was used to measure social support. The 12-item instrument has three subscales that measure potential sources of support: family, friends, and significant others. The scores on the subscales can be summed to provide an overall measure of perceived social support. An example of an item would be “My family really tries to help me.” The instructions were, “Below is a list of statements that describe different types of social support. Please read each one carefully. Then circle one number on each line to indicate the extent to which you agree or disagree with the statement.” The words “on each line” were changed from “to the right” to retain consistency in wording throughout the survey. Participants respond to each item on a 7-point Likert scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*), with higher scores indicating greater perception of social support. Zimet et al. reported adequate internal consistency scores, with alpha values of .87 (family), .85 (friends), and .91 (significant others). Test-retest scores after a 2-3 month period were .85 (family), .75 (friends), and .72 (significant others). Research supports the concurrent validity

and construct validity of the MSPSS (Kazarian & McCabe, 1991; Zimet et al., 1988).

### *Procedure*

Approval for this study was gained from the Victoria University Human Research Ethics Committee. We approached major disability organisations and university disability officers and asked them to promote our research to clients of those organisations who were eligible to participate in the research. To promote the research to adults with cerebral palsy who may not have been known to these organisations, the Media and Marketing Branch of Victoria University coordinated a media release. Participants received questionnaires either from some of the major disability organisations or from the researchers, at their request.

Participants received an envelope that contained a covering letter, information sheet, the questionnaire, and a reply-paid envelope addressed to the researchers (see Appendix B). On the last page of the questionnaire the participants were invited to give personal details (name, address, daytime and evening phone numbers, email address), if they wished to receive information about participating in further studies.

Consistent with previous work on the health and well-being of people with cerebral palsy (Longmuir & Bar-Or, 2000; Morgan & Balandin, 1997), only those people with the cognitive ability to respond to the questionnaire items were asked to participate in the research. Sufficient cognitive ability was determined by staff from disability organisations, who promoted the research to their clients, or was self-determined by the people with cerebral palsy who responded to requests for participants made through the media. Those people who did not have the motor

skills needed to complete the questionnaire were encouraged to participate with the assistance of a person or computer. The covering letter to participants, which accompanied the questionnaire, stressed that their responses to questionnaire items must be their own and not those of the person providing assistance. A further reason why people with intellectual impairment were excluded from the study is that they may have found it difficult to participate in the exercise intervention studies, in which they would have been invited to take part. In their research on the effect of co-contraction on the oxygen uptake of children with cerebral palsy, Unnithan, Dowling, Frost, and Bar-Or (1996) noted that children with intellectual impairment were unable to cope with the physical testing regimen used in their research. Although research with people who have cerebral palsy and intellectual impairments is clearly warranted, psychological and physical testing procedures may have to be different than those used with people with cerebral palsy who have no intellectual impairments.

Informed consent was implied from the return of the questionnaire. The questionnaires were given non-identifying codes when they were received from participants. When the data were entered into a computer, the responses to questionnaire items were kept in a separate file from any identifying personal details provided. On completion of the present study, and of Studies 2, 3, and 4 in this thesis, a summary of findings for all four studies was sent to participants.

### *Analysis*

Descriptive statistics (frequencies, means, standard deviations) were used to report the physical activity levels of people with cerebral palsy. Correlational analyses were performed to explore the relationships between the physical



activity, HRQL, and psychosocial functioning variables. Because the physical activity data were not normally distributed, Spearman's rho ( $r_s$ ) was used to measure the strength of the associations. Using Cohen's (1988) conventions,  $r_s$  values of .10, .30, and .50, are considered small, medium, and large in magnitude, respectively. Because 76 tests were performed, statistical significance was judged at the .0007 level (i.e.,  $\alpha = .05/76$ ).

## Results

### *Physical Activity*

Most participants (70.6%) reported involvement in exercise. The activities that the participants were involved in ranged from those of low intensity (e.g., hand exercises for weak hands, massage, stretching) to those of high intensity (e.g., training for competitive swimming). Under half of the participants (39.2%) undertook leisure-time physical activity. Participants were involved in a diverse range of leisure time physical activities, with the more common activities being swimming ( $n = 5$ ), ten-pin bowling ( $n = 4$ ), bocce ( $n = 3$ ), and wheelchair sports ( $n = 3$ ). Approximately a quarter of participants were involved with indoor (28.0%) and outdoor (25.5%) physical activities.

Participants were involved in almost one hour of physical activity per day ( $M = 51.76$  mins,  $SD = 51.61$ ). There was, however, a wide variation in time spent performing physical activity, ranging from no physical activity to almost 3 hours (177.86 mins). The descriptive findings for each type of physical activity are presented in Table 3.2. The statistics for the total sample are deceptive, because they are heavily skewed. Due to many participants not engaging in each type of physical activity, the means are lower than for those participants who performed

physical activity. To provide information on the participants who were involved in physical activity, descriptive statistics for the sub-samples of participants who undertook each type of physical activity are also provided in Table 3.2.

Table 3.2  
*Time Spent (Minutes Per Day) Performing Each Form of Physical Activity*

Type of physical activity	Total sample			Sub-samples <sup>a</sup>		
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N<sup>b</sup></i>	<i>M</i>	<i>SD</i>
Exercise	51	22.33	29.09	33	34.51	29.81
Leisure-time physical activity	51	7.00	14.84	17	21.00	19.37
Household activity	51	22.42	41.43	17	67.27	46.46

*Note.* <sup>a</sup>The sub-samples are of the participants who did each type of physical activity, respectively. <sup>b</sup>These *Ns* are lower than the *Ns* reported for participation in each of these physical activity types because some participants indicated that they were involved in these activities, but did not record how much time they spent performing them.

*Health-Related Quality of Life and Psychosocial Functioning*

The descriptive statistics for the HRQL, mood, physical self-efficacy, and social support subscales are shown in Table 3.3. For most of these subscales, there were large variations in the participants' scores. Many of the distributions of data on the subscales were skewed. The physical functioning subscale was positively skewed, indicating that many participants experienced impaired levels of physical function. Both role limitations subscales and the social functioning subscale were negatively skewed. Participants typically reported low levels of role limitations. They also recorded high levels of social functioning. Four of the POMS subscales (tension-anxiety, depression-dejection, anger-hostility, confusion-bewilderment) were positively skewed, meaning that participants generally experienced low levels of these mood states. The social support subscales (family, friends, significant others) were all negatively skewed, indicating that participants typically experienced higher levels of social support from these sources.

Table 3.3

*Means and Standard Deviations of Health-Related Quality of Life and Psychosocial Functioning Subscales*

Measure of HRQL or psychosocial functioning	<i>M</i>	<i>SD</i>
HRQL		
Physical functioning	21.91	26.19
Role limitations – physical	68.50	40.66
Role limitations – emotional	74.00	40.01
Energy/fatigue	59.09	18.69
Emotional well-being	70.84	14.70
Social functioning	77.94	22.02
Pain	72.06	22.86
General health	70.47	20.56
Mood		
Tension-anxiety	0.91	0.84
Depression-dejection	0.65	0.58
Anger-hostility	0.69	0.64
Vigour-activity	1.90	0.85
Fatigue-inertia	1.44	0.96
Confusion-bewilderment	0.86	0.73
Physical self-efficacy		
Perceived physical ability	29.57	7.15
Physical self-presentation confidence	45.75	9.73
Social support		
Family	4.87	1.74
Friends	5.55	1.34
Significant others	5.97	1.43

*Note.* The possible ranges of subscale scores were: HRQL (0 to 100), mood (0 to 4), physical self-efficacy (PPA, 0 to 60; PSPC, 0 to 72), and social support (1 to 7).

*Relationships Between Physical Activity, Health-Related Quality of Life, and Psychosocial Functioning*

Only two subscales had an association with exercise of at least a medium magnitude (see Table 3.4). Exercise was positively correlated with vigour-activity and negatively associated with social support from friends. Four HRQL subscales (role limitations – physical, social functioning, pain, general health) and the vigour-activity subscale of the mood scale were moderately correlated with

LTPA. There was a large correlation between household activity and the physical functioning subscale of the HRQL measure, and a medium, negative association between household activity and social support from friends. Total physical activity was associated, to at least a medium magnitude, with two HRQL subscales (physical functioning, role limitations – physical), vigour-activity, and social support from friends.

Table 3.4

*Relationships Between Physical Activity, Health-Related Quality of Life, and Psychosocial Functioning*

Measure of HRQL or psychosocial functioning	Exercise	Leisure-time physical activity	Household activity	Total physical activity
<b>HRQL</b>				
Physical functioning	.14	-.07	.63*	.45
Role limitations – physical	.18	.42	.08	.32
Role limitations – emotional	.18	.09	-.22	.02
Energy/fatigue	.19	.18	-.07	.17
Emotional well-being	.12	.17	-.02	.15
Social functioning	.11	.37	.09	.27
Pain	-.08	.34	.04	.13
General health	.12	.34	.01	.22
<b>Mood</b>				
Tension-anxiety	.07	-.21	.15	.08
Depression-dejection	-.01	-.25	-.18	-.25
Anger-hostility	.04	-.07	-.12	-.11
Vigour-activity	.31	.30	.07	.36
Fatigue-inertia	.06	-.10	.04	-.01
Confusion-bewilderment	.14	-.19	-.12	-.10
<b>Physical self-efficacy</b>				
Perceived physical ability	.06	.15	.24	.27
Physical self-presentation confidence	.08	.18	.03	.11
<b>Social support</b>				
Family	-.02	.04	-.22	-.16
Friends	-.28	-.19	-.32	-.43
Significant others	-.03	.09	-.23	.00

Note. \* $p < .0007$ .

## Discussion

The profiles of participants with motor disorders recruited for the present study closely approximated those of larger samples of people with cerebral palsy (Stanley et al., 2000). Although there was a comparatively lower percentage of participants who identified themselves as having a pure spastic type of cerebral palsy, than was reported from the Western Australian Cerebral Palsy Register (Stanley et al., 2000), and a higher number of participants with mixed-type cerebral palsy, this result may have been due to participant errors in self-classification. Many adults with cerebral palsy may be unaware of their exact medical diagnoses, and, therefore, may have used the descriptors of each type of cerebral palsy to guide them. In contrast with someone who has been trained to differentiate between the types of cerebral palsy, it may have been difficult for many participants to omit some types of cerebral palsy in their self-diagnoses.

The distribution of participants in terms of the degree of gross motor function, as measured using an adapted version of the GMFCS (Palisano et al., 2000), was relatively even among the five levels of severity. No research has been published, however, that provides evidence of the distribution of gross motor function among people with cerebral palsy. The distribution may not be reflective of the population of people with cerebral palsy. The lower percentage of people with level 1 severity may be due to the recruitment strategies used in the present research. Major disability organisations were the principal sources of participants. These organisations, however, typically are in contact with people with more severe forms of cerebral palsy. Promotion of the present research through university disability officers and the media may have been ineffective in obtaining

an adequate number of participants with the milder forms of the condition. It is also plausible that some of the people with the milder forms of cerebral palsy received promotional material, but did not wish to identify themselves as people with this condition.

It seems doubtful that the adults with cerebral palsy in this sample were involved in enough physical activity (and of the necessary intensity) to meet the recommendations for exercise in the general population (USDHHS, 1996), or Rimmer's (2001) more stringent suggestions for adults with cerebral palsy. Similar to previous research on adults with cerebral palsy (Heller et al., 2002; Turk et al., 1997), most people were involved in exercise. It is uncertain, however, whether the activities were engaged with sufficient intensity to produce improvements in physical fitness. Judging the intensity of exercise from the type of activity should be done with caution, because an activity that may not be of moderate intensity for people in the general population may be of sufficient intensity to lead to changes in fitness for people who are physically impaired. Research has demonstrated that people with cerebral palsy do more work when exercising at a similar intensity than people from the general population (Lundberg, 1978, 1984; Tobimatsu et al., 1998; van den Berg-Emons et al., 1996). Even in exercising due caution when interpreting these results, however, it seems that the adults with cerebral palsy were not engaging in enough physical activity of sufficient intensity to gain associated health benefits

Although many of the participants reported involvement in exercise, few indicated that they took part in LPTA or were active in or outside of the homes. In part because of the severity of their conditions, many adults with cerebral palsy

were not involved with household physical activities, which restricted their opportunities to gain and maintain physical fitness. This lack of involvement in household physical activities contrasts with that of the general population, and would require compensation in other areas (e.g., a greater amount of exercise).

The variation in each type of physical activity was substantial. The extent of engagement in physical activity ranged from no involvement to elite sport participation. Comparing those people involved with at least one type of physical activity with those people in the total sample, the participants involved in exercise, LTPA, and household activity spent, on average, 12, 14, and 45 minutes longer per day, respectively, performing these activities than did the total sample. The participants who engaged in exercise did so to a sufficient extent to meet USDHHS (1996) recommendations.

With the exception of the physical functioning subscale, the means on the HRQL subscales compare favourably with the results from the MOS (Hays et al., 1993). The mean of the physical functioning subscale was substantially lower than the mean for males and females of the general population. With most of the items of the physical functioning subscale explicitly or implicitly requiring ambulation, it is not surprising that the mean on this subscale was low in the present study. Over half of the participants classified themselves at a GMFCS level that precluded ambulation without substantial assistance. Whereas the items on the physical functioning subscale required participants to compare their physical ability against specific standards (e.g., lifting or carrying groceries), most of the items on the other subscales asked them to self-reference their responses (e.g., how they have been in the prior four weeks). Through responding to items with

respect to themselves, rather than specific standards, many participants reported positively about their HRQL.

Participants tended to experience low levels of tension-anxiety, depression-dejection, anger-hostility, and confusion-bewilderment. The participants, however, reported feeling fatigue-inertia and vigour-activity to a moderate degree. The low levels of physical activity that many participants performed may have contributed to the feelings of low energy and high fatigue. The mean scores were similar to those of the cancer patients in Shacham's (1983) study.

The participants' cerebral palsy seemed to affect their perceptions of their physical abilities more than their confidence with their bodies. In comparison to a sample of undergraduate psychology students (Ryckman et al., 1982, Study 2), the participants of the present study had substantially lower PPA and lower PSPC. Although researchers (e.g., King et al., 1993; Manuel et al., 2003a; Östring & Nieminen, 1982) have claimed that children and adolescents with cerebral palsy do not have lower self-esteem than their able-bodied peers, these researchers did not consider their physical self-efficacy. The findings of the present study suggest that the presence of cerebral palsy may affect self-esteem in the physical domain.

The participants received social support from a range of sources. The data for all three forms of social support (i.e., family, friends, significant others) were substantially negatively skewed. Some participants received high levels of social support. There was wide variation, however, in the degree of support participants received. The mean scores on each form of social support were within one



standard deviation of the mean scores of undergraduate students in the Zimet et al. (1988) study.

There appeared to be a pattern in the comparison between the participants' scores on the HRQL and psychosocial function subscales and scores from normative data. The participants with cerebral palsy, from the present research, scored lower on subscales that related to their physical functioning. The higher scores on the other subscales seem to suggest that they may have found other ways to lead enjoyable lives and did not dwell on the consequences of their impairments.

In general, the types of physical activity were weakly associated with the measures of HRQL, mood, physical self-efficacy, and social support. The strongest correlation was between household activity and physical functioning. The physical functioning subscale may have served as a proxy for the degree of physical impairment. Those adults who were less physically impaired undertook more household activity.

Several moderate to large associations were found between LPTA and HRQL subscales. The presence of these correlations, and the absence of similarly sized associations between exercise and these HRQL subscales, suggested that the activity type was pertinent. Generally the activities that the participants recorded as exercises were directed towards maintaining and improving fitness and physical function (e.g., gym exercises, physiotherapy, stretching), and may not have been enjoyable for participants, whereas LPTAs are performed for fun (e.g., pool/snooker, ten-pin bowling, wheelchair sports). A further distinction was that the exercise activities are those that people typically perform on their own or with

professional assistance (e.g., physiotherapy), whereas the LTPAs are those that people generally participate in with others.

A potential reason for the lack of a greater number of sizable relationships between physical activity and the HRQL subscales is the use of the RAND instrument (Hays et al., 1993) as the measure of HRQL. This questionnaire was designed for the general population, and may not have been sensitive enough to detect differences in HRQL for people with cerebral palsy. The high degree to which the data were skewed tends to support this conclusion. Although instruments have been developed to measure HRQL in people with a variety of health conditions, a questionnaire has yet to be developed for adults with cerebral palsy.

The medium-sized correlations found for the vigour-activity subscale on the mood measure and exercise, LPTA, and total physical activity, may have been influenced by the physical fitness of the participants. Although physical fitness was not measured in the present study, involvement in physical activity often causes increased fitness, which, in turn, may contribute to the feeling of vigour.

The apparent contradiction in findings between the positive or negligible associations between the physical activity types and social functioning, and the negative associations between the types of physical activity and social support from friends, may be resolved by reviewing the content of the questions. The items in the social functioning subscale pertained to the extent to which physical health or emotional problems interfered with normal social activities, whereas the social support from friends subscale has items relating to the closeness of relationships with others. The effect of physical health and emotional problems on

normal social activities may be independent of whether or not social support is received from friends. Further, whereas items in the social support subscale focused specifically on friends, the HRQL subscale more broadly included family, neighbours, and groups.

A possible explanation for the negative associations between social support from friends and physical activity could be that many participants had friendships with people who did not value involvement in physical activity or did not participate in physical activity with the participants. Because their impairments may restrict the types of activities they are able to perform, some adults with cerebral palsy may seek out friendships with people who are not highly physically active (e.g., other people with disabilities) or with people who may not participate in physical activity with them (e.g., some carers). A number of the participants in the present study had extensive contact with other people with cerebral palsy and other disabilities, and with carers, through the disability organisations with which they were affiliated. Being in these types of environments may promote social interactions, but may, possibly, negatively affect involvement in physical activity.

The associations between physical activity, HRQL, and psychosocial functioning are small in comparison to Sutherland's (2001) research on people with multiple sclerosis. In Sutherland's descriptive study, medium to large correlations were found for these variables. Although Sutherland's use of a disease-specific instrument to measure HRQL (i.e., the MSQOL; Vickrey, Hays, Harooni, Myers, & Ellison, 1995) may partially explain some of the findings, it is unlikely that the contrasting results could be attributable to differences in the

measures used. The differences in results were also apparent for mood and social support, and may have been due to the dissimilarity between the two neurological conditions: cerebral palsy and multiple sclerosis. Whereas cerebral palsy is an early onset condition, people develop multiple sclerosis much later in life. People with multiple sclerosis lose function, with associated psychological consequences, as part of the disease progression. In contrast, people with cerebral palsy do not know what it is like to be able-bodied, but grow and adapt to bodies that have impaired function from birth.

The associations may have been attenuated, however, because of the patterns of responding. For example, many people reported that they had no involvement in at least one of the types of physical activity. Such restriction in the range of responses can reduce the magnitudes of correlations (Shavelson, 1988).

A potential issue that could have skewed the HRQL and psychosocial functioning was that half of the participants required the assistance of another person to complete the questionnaires. The presence of another person (potentially a significant other) could have resulted in socially desirable reporting. Although not possible in the present research due to the wide geographical spread of participants, researchers conducting studies in the future could consider alternative questionnaire administration strategies. If the participants are local, for example, the researchers could administer the questionnaires themselves.

A weakness of the present study is that the sample was not representative of the population of people with cerebral palsy in terms of cognitive function. Many people with cerebral palsy have associated intellectual impairments (Stanley et al., 2000; SCPE, 2002). Because some people with cerebral palsy and

intellectual impairment would not have had the cognitive ability to understand and to respond to the questionnaire items, they were excluded from participating in the present study. Given the number of people with cerebral palsy who also have intellectual impairment, it seems worthwhile to understand how physical activity may affect HRQL and psychosocial functioning for these people. Research with people in this population would require the creation or use of instruments appropriate for the study of people with intellectual impairments, such as observational tools, pictorially based questionnaires, and third-party reports.

In summary, the present research provides evidence that adults with cerebral palsy may not be engaging in sufficient physical activity to produce the improvements in fitness needed to obtain associated health benefits (USDHHS, 1996), and to reduce the effect of functional decline due to ageing in combination with cerebral palsy (Rimmer, 2001). Although many people with cerebral palsy exercised, it is doubtful whether some of the activities the participants engaged in were of an intensity that would bring about the desired changes in physical fitness. Physical activity was associated with only a small number of the HRQL, mood, physical self-efficacy, and social support subscales. This finding was in contrast to prior research that showed moderate to large associations between these variables in people with multiple sclerosis. An understanding of why relationships were not found between these variables may be gained through in-depth personal investigations of the role of physical activity in the lives of adults with cerebral palsy. Qualitative research is needed to achieve a deeper understanding of the meaning and experiences of physical activity for people with this condition. Through taking a life history approach, insight may be gained into how past

experiences with physical activity may influence current participation and psychosocial functioning.

## CHAPTER 4

### REVIEW OF LITERATURE ON THE MEANING AND EXPERIENCES OF PHYSICAL ACTIVITY IN THE LIVES OF PEOPLE WITH CEREBRAL PALSYP

Following Study 1, I intended to conduct two intervention studies to investigate the effect of warm-water aerobic exercise and strength training, respectively, on the HRQL and psychological well-being of people with cerebral palsy. Although most participants in Study 1 (49 of 51) indicated they would like to be involved in further research, few of those contacted wished to be involved in an exercise programme.

The focus of the thesis changed to investigate the life histories of people with cerebral palsy. I designed three studies to consider the life histories, with specific interest on experiences with, and meaning of, physical activity, of people who (a) had minimal involvement in physical activity throughout their lives (Study 2); (b) had been involved in physical activity during their lives (Study 3); (c) had minimal involvement in physical activity before participating in a 10-week exercise programme, associated with this research (Study 4). I interpreted the participants' lives using classical and neo-psychodynamic theory.

In this chapter, I review the literature on people's meanings and experiences of physical activity. Next, I consider those studies that have investigated aspects of the lives of people with cerebral palsy. Following this section, I present myself, in relation to the research topic. The chapter concludes with a statement of the purpose of Studies 2 to 4.

## Meaning and Experience of Physical Activity

Few studies have explored individuals' meaning of, and experiences with, physical activity using qualitative paradigms. Sport and exercise psychology researchers have typically preferred using quantitative frameworks (Culver, Gilbert, & Trudel, 2003) to investigate the influence of physical activity on HRQL and psychological functioning. Although this approach has yielded much useful information, Mutrie (1997) has argued that qualitative research may be useful in understanding how physical activity affects psychological health. Berger, Pargman, and Weinberg (2002) attributed the lack of qualitative research to the focus, in Western society, on utilitarian achievement and physical measures of exercise (e.g., heart rate, percentage of body fat), to the dominance of the medical model, and to many people lacking the skills for self-analysis. In those studies that have been conducted, using qualitative paradigms, researchers have typically focused on people with disabilities or older adults as participants.

Several meanings of exercise have been commonly expressed in the literature (Berger et al., 2002). These meanings include: fun and enjoyment; freedom to choose, freedom from social values, and freedom from body and mind; health and appearance; time for one's self; creating an opportunity for self-exploration, self-awareness, and self-reflection; becoming empowered and self-responsible; communing with nature; delaying the ageing process; and spirituality.

### *Meaning and Experience of Physical Activity for Older Adults*

Several studies have investigated older adults' experiences of physical activity (e.g., Crone-Grant & Smith, 2002; Dionigi, 2002; Stathi, Fox, & McKenna, 2002). In research with 28 retired older adults, Stathi et al. found that



physical activity had an important role in maintaining and enhancing many dimensions of subjective well-being (i.e., developmental, physical, mental, social). Physical activity was instrumental in assisting older adults to continue to develop. Having retired, some older adults stated that they had less at which they could be successful. Performing physical activity provided an opportunity for achievement. Physical activity staved off functional decline, meaning that independence could be continued. Physical activity also provided a chance to maintain a busy life, and influenced the participants' physical well-being. In this regard, physical activity was viewed as a way to improve fitness, thereby diminishing functional decline and enhancing health. Physical activity affected mental well-being in several ways. The older adults stated that, through physical activity, they were able to maintain their cognitive faculties, and keep a positive outlook on life. The older adults perceived they had greater control in their lives, had enhanced self-confidence, and had an improved body image. Involvement in physical activity also distracted the older adults from the negative consequences of ageing. Physical activity also had a role in the social well-being of the older adults. It allowed them to continue to interact with the world outside of their homes, and to maintain their family lives and social activities. Material well-being was also identified as a dimension of subjective well-being, but not influenced by involvement in physical activity.

Dionigi (2002) conducted brief interviews with 110 Australian Masters Games' athletes with respect to the meanings they derived from their competitive sport participation. Two dominant themes emerged: adapting to older age and expressing youthfulness. With regard to adapting to older age, competitive sport

had a role in facilitating enjoyment, friendship, fitness, and travel; in forming individuals' identities; in enabling the display of competence; and in providing competition for the athletes. Within the "expressing youthfulness" theme were the ideas that competitive sport allowed athletes to regress to a time when they were younger, or to identify with people of a younger generation. It also permitted them to stave off functional decline, which they tended to associate with becoming older more than their chronological age. Dionigi's analysis of the data into two broad themes, however, may have been overly simplistic. Many additional themes seem evident in the data from participants that Dionigi cites, such as achievement, identity, and self-esteem.

*Meaning and Experience of Physical Activity for People with Disabilities*

Other researchers have investigated the perspectives of people with disabilities (Blinde & McClung, 1997; Cousminer, 2003; Goodwin & Compton, 2004; Guthrie, 1999; Guthrie & Castelnuovo, 2001; Henderson & Bedini, 1995; Hutzler, Fliess, Chacham, & Van den Auweele, 2002; Peganoff, 1984; Vogler, Koranda, & Romance, 2000). A strength of this literature is that the studies, collectively, have been conducted with people whose ages range across the life span, which allows some insight into how the meanings and experiences of physical activity may change, or remain similar, as a people with disabilities age. Vogler et al. reported a case study of the inclusion, with the assistance of an adapted physical education (PE) teacher, of a 6-year-old boy (Sammy), with severe cerebral palsy, in a kindergarten PE class. Although Vogler et al. did not interview Sammy about his experiences, perhaps because he was mostly nonverbal, the reactions of teachers and classmates may be informative about the

inclusion of a child with physical disability in early childhood physical education. Teachers and classmates socially accepted Sammy. As Vogler et al. clarified, however, this acceptance should not be equated with social competence. The adapted PE teacher stated that Sammy's male classmates acted as though his disability was not an issue for them, but some of the girls exhibited maternal patronising behaviours. The classroom PE teacher had reservations about how the children would behave as they moved through subsequent school grades and the PE activities changed from being typically cooperative or individualistic, to being competitive. There were some activities in which children did not want to partner Sammy, because he was not as active as they were. With the assistance of an adapted PE teacher, Sammy was able to engage in physical activity with other children at a level that would not have been possible without assistance. According to the adapted PE teacher, Sammy was highly motivated to perform PE because he was involved in activities with his classmates.

Wanting to be like other children, and to be accepted as part of their social groups were themes that were much clearer in studies with older children (Hutzler et al., 2002) and a girl in her early adolescence (Peganoff, 1984) with disabilities. Hutzler et al. (2002) investigated the experiences of 10 children (aged 9 to 14), eight of whom had cerebral palsy, with respect to their inclusion and empowerment in regular school PE classes. Although the researchers used a cognitive-behavioural framework to interpret the data, two, closely-related, psychodynamic themes were present in the data from the children, which were cited throughout the findings: identification with people who did not have disabilities, and internalised ableism. Speaking about their involvement in PE –

and, more generally, in school life – many children articulated the wish to be with, and to be like, their classmates. Involvement in PE provided children with the sense that they were like other members of their classes. Two illustrative quotes are, “I feel one of the group, like everybody else,” (p. 311) and, “I want to be like everybody else” (p. 313). Exclusion from activities was distressing to some children, because it accentuated their differences from the other children. The internalised ableism of some of the children was manifested in avoidance of association with other people with disabilities. Only two of the children participated in complementary extracurricular physical activity for people with disabilities. The children in the study consistently identified with people who were able-bodied, with one child stating that she felt ashamed if she was with other children who had disabilities. Hutzler et al. suggested that maladaptive behaviours and anxiety could result from the excessive avoidance of people with disabilities as role models, in favour of normative models, because there may be a larger gap between real and ideal self-images.

Peganoff (1984) reported a case study of a 14-year-old female, who participated in an 8-week aquatic programme, which an occupational therapist facilitated. The adolescent had spastic cerebral palsy, which affected the right side of her body. The posture of her right upper extremities was characterised by shoulder adduction, internal rotation, and flexion of the elbow and wrist. The coordination and function of her right shoulder was compromised. During the initial assessment, the therapist noted that the adolescent became frustrated when executing some movements, and had poor self-image. The poor self-image manifested in a comment the adolescent made about herself, “I’m deformed, no

one wants me around. I can't do what my friends can" (p. 470). Although Peganoff mainly focussed on the physical and functional aspects of the treatment, various observations were made that gave insight into the adolescent's self-concept and self-esteem. At the start of the intervention, the adolescent refused to participate in the programme in the presence of her mother and outside observers. She needed some coaxing to participate in the programme, and continually expressed concerns about her physical appearance when wearing a swimsuit. The adolescent also frequently referred to her swimming ability in negative terms. Although body image concerns remained at the end of the programme, the adolescent participated in the presence of her mother and other guests. To try to feel more comfortable with her physical appearance, she became involved in a weight reduction programme. Other behavioural changes were that she became actively involved in the planning of the aquatic sessions and she began to pursue this activity in her free time, and with peers. Even though the description of the psychological outcomes of this case study was limited, Peganoff demonstrated that physical activity interventions might have many mental health benefits. A closer examination of the psychological outcomes of such interventions would seem warranted.

As people with disabilities move through adolescence and adulthood, negative perceptions towards their own physical abilities, and negative attitudes of some people who provide access to physical activity participation, may reduce their opportunities to engage in physical activity with others (Cousminer, 2003). In Cousminer's paper, he described the difficulties he faced in joining a fitness centre. Cousminer was an undergraduate student with cerebral palsy who took

many months to join his university's fitness centre, because of his own perceptions (i.e., he did not feel he belonged in a fitness centre) and an initial failed attempt to join (i.e., there was no staff qualified to work with him and the centre stated that he was a liability). Through his doctor's intervention, however, he joined the centre and was able to perform an exercise programme with the assistance of a trainer. Subsequently, the centre introduced a programme to allow other people, who need assistance with gym equipment due to disability or injury, to perform effective workouts. This personal account illustrates some of the issues that adults with cerebral palsy confront when attempting to engage in physical activity.

Given the personal and societal barriers that sometimes exist to people with disabilities who wish to engage in physical activity (Cousminer, 2003), programmes that facilitate the inclusion of people with disabilities in such activities may be beneficial for people in this population (Blinde & McClung, 1997). Blinde and McClung investigated the influence of individualised recreation programmes on the physical and social selves of 23 people with physical disabilities (aged 19 to 54). The recreation programmes were a range of physical activities, such as bowling, horseback riding, racquetball, and weightlifting. These programmes extended over periods of between 5 and 24 weeks. In terms of participants' perceptions of their physical selves, they experienced their bodies in new ways, they had enhanced perceptions of their physical attributes, they redefined their physical capabilities, and they had increased self-confidence to pursue new activities. With regard to their social selves, participants had more social interactions and experiences, and they initiated social activities with people

outside of the programmes. In essence, the participants seemed to have gained a greater sense of physical and social self-efficacy.

The meanings of physical activity for women with disabilities reported in the literature are quite diffuse, with a common theme being the use of physical activity to maintain physical function (Goodwin & Compton, 2004; Guthrie, 1999; Guthrie & Castelnovo, 2001; Henderson & Bedini, 1995). Goodwin and Compton (2004) interviewed six women with physical disabilities (ages 22 to 37) about their experiences with physical activity and aging. Three themes emerged from the interviews on aging, disability, and physical activity: the experience of something normal, the loss of physical freedom, and the maintenance of function through involvement in physical activity. Aside from using physical activity to improve function, however, the researchers did not clearly delineate other roles of physical activity in the lives of these women.

Henderson and Bedini (1995) interviewed 16 adult women (aged 29 to 53) about the value they placed on physical activity, the attitudes they had towards physical activity and disability, and the conditions necessary for physical activity. Three values of physical activity were identified: leisure, therapy, and mental and physical maintenance. These values were not mutually exclusive, in that women could have more than one value toward physical activity. Henderson and Bedini suggested that freedom of choice underpinned these values. Some women participated in physical activity to comply with advice from medical practitioners (i.e., those for whom physical activity was therapy), and others were involved for the enjoyment of performing the activity (i.e., those for whom physical activity was leisure). Henderson and Bedini, rather superficially, identified three types of

attitude toward participation in physical activity: conformers, resisters, and adjusters. The women could also fit more than one type. Conformers were those women who accepted that the decline in ability to perform physical activity was part of their conditions. Resisters were women who were determined to be involved in physical activity, despite their disabilities, and, sometimes, despite societal constraints. Adjusters were women who adapted to their situations by finding meaningful ways to participate in physical activity. Conditions necessary for women to be involved in physical activity were physical health (high energy, high stamina, low pain level), transportation to the place of physical activity, accessible places of physical activity, and social support from people with whom they could do physical activities.

In two studies (Guthrie, 1999; Guthrie & Castelnuovo, 2001), Guthrie explored how women with disabilities managed their disabilities, and the role that physical activity played in this process. In both studies, through inductive content analysis, three general dimensions were identified in explaining the role of physical activity and disability management: minimising bodily significance, normalising the body, and optimising mind-body functioning. Some of the women managed their disability by minimising bodily significance. Mental, social, and spiritual activities were used to cope with their disabilities. These women participated in physical activity because of advice from medical practitioners, and generally perceived their involvement as an unpleasant experience. For some of these women, involvement in physical activity was motivated by the fear of the negative consequences, in terms of their disability, of not exercising. Other women managed their disabilities through normalising their bodies. Physical



activity was important in this process, as they tried to realign their bodies with able-bodied and feminine body-beauty ideals. That is, they used physical activity to improve function and to change the shapes of their bodies' (e.g., lose weight, gain muscle). Some women managed their disabilities by optimising mind-body functioning. With respect to their minds, these women typically determined their identity using their own criteria, rather than adopting societal values. With respect to their bodies, they performed physical activity to improve the quality and quantity of their motor performances. Women who managed their disabilities through the optimisation of mind-body functioning tended to be those women with congenital disabilities, more so than those women with acquired disabilities, who typically tried to minimise bodily significance or normalise their bodies.

### *Summary*

The few studies that have investigated individuals' meanings and experiences of physical activity have provided evidence of the value of using qualitative frameworks for examining of the role of physical activity in people's lives. The interpretation of the data collected in these studies, however, has tended to be somewhat superficial, and the richness of the participants' stories has not been portrayed in depth. Researchers have typically provided journalistic reportage, often reducing their ostensibly rich data to a limited number of themes. For people with disabilities, several issues were evident through the quotations provided by the researchers, and included: identification with people who did not have disabilities, internalised ableism, compliance with advice from medical practitioners, sexuality and intimacy concerns, and poor self-image. For older adults, issues of competence, identity, independence, regression to a younger age,

identification with younger people, and social connectedness were evident *leitmotifs* in the research. Although the researchers discussed some of these issues, a deeper consideration of individuals' experiences of physical activity, and what it means to them, is a fertile area for further research.

### Issues in the Lives of People with Cerebral Palsy

Although cerebral palsy is primarily considered a physical condition, living with such a disability can have an influence on an individual's psychological development. In this section, I report on research that has highlighted issues that people with cerebral palsy have faced during their lives. Much of this research has been case reports of psychotherapy with people who have cerebral palsy (Acquarone, 1995; Blotzer, 1995; Donovan, 1995; Feuerstein, 1995; Jureidini, 1988; Lantican, Birdwell, & Harrell, 1994; Olkin, 1995; Sullivan, 1953). These cases demonstrate how the presence of a physical disability, such as cerebral palsy, can have a major effect on a person's psychological functioning. Common issues of the clients (and their parents) in these cases were: anger, coping with having a disability, depression, independence versus dependence, parental acceptance of disability, sexuality, and suicidal ideations and attempts. For clarity, I have presented these issues separately. In the cases, however, it was common for people with cerebral palsy to present with more than one of these issues.

#### *Anger*

Many of the clients in psychotherapy expressed anger at themselves, and their cerebral palsy, or at the judgemental and unaccommodating world they saw around them (Blotzer, 1995). Blotzer suggested that people with disabilities could

even be angry with themselves for being angry. In the case of Mathew (Olkin, 1995), a 14-year-old with cerebral palsy, anger stemmed from his discomfort with the affected right side of his body, and from having to work hard at school to keep up with his classmates because of his functional loss. Matthew's anger manifested sporadically, and was expressed through punching filing cabinets and walls, through attempting to discredit his psychotherapist to avoid returning to the next session, and through lying to adults about the cause of his disability. These outlets for his anger represented safer targets than those that were the underling causes (e.g., possibly his classmates and parents). In other cases, however, anger is repressed (Donovan, 1995; Jureidini, 1988), and, in the case that Jureidini reports, anger found an outlet in quiet sarcasm and the consumption of alcohol.

### *Coping with a Disability*

Issues of coping with disability were common among psychotherapy clients with cerebral palsy. One coping strategy present in two case studies was the separation of the mind and body (Jureidini, 1988; Olkin, 1995). Mathew, in a case Olkin described, attributed positive values to his "inner self," and attributed internalised, negative messages about disability to his "outer self." He had a split self-concept, because he had not incorporated his disability into his self-concept. Olkin suggested that such a mind/body split could result in cognitive dissonance, or even symptoms that are more severe. The case of David, described by Jureidini, was similar to that of Mathew in how he separated mind from body. David idealised his mind and hated his body. One example of when the split was evident was in his projections of his frustrations onto others. David felt that he would

have had fewer problems at school, if staff realised that he had a “good” mind contained within a “bad” body.

### *Depression*

Depression has been common in the case histories of the psychotherapy clients with cerebral palsy (Donovan, 1995; Feuerstein, 1995; Jureidini, 1988; Lantican et al., 1994). Although the reasons for depression were not reported in two of these cases (Feuerstein, 1995; Lantican et al., 1994), a shared theme of the other two cases was the clients’ failure to successfully achieve in the normal world. In the case of Sally (Donovan, 1995), the job she was employed in became too demanding for her. The severity of Sally’s cerebral palsy was minimal, and she perceived that people expected her to accomplish more than she was able. Coping with her cerebral palsy, however, seemed to require greater energy than Sally acknowledged and other people realised. After several years of employment, she was struggling to perform her job, and became increasingly ill and depressed. Before she resigned from this job, Sally was feeling extremely exhausted and overwhelmed. When Sally entered psychotherapy she had little empathy for herself, and blamed herself for her inability to do the work, rather than acknowledging that she had physical limitations due to her condition.

### *Independence Versus Dependence*

The issue of independence versus dependence was prominent in a number of the psychotherapy cases (Blotzer, 1995; Feuerstein, 1995; Jureidini, 1988; Olkin, 1995). Key aspects of this issue are the concepts of competence and control. Having cerebral palsy limits physical functioning, and may make a person dependent on others to perform some of the activities of daily living for them.

Such a situation means that a person with cerebral palsy does not, and often cannot, display competence at a range of tasks. Relying on another person to perform these tasks diminishes the sense of control over the environment a person with cerebral palsy feels.

For Diane, in a case Blotzer (1995) described, one of the times at which the issue of independence versus dependence arose was on her way to psychotherapy. On the day of Dianne's first session there had been a major snowfall and the snowplough operators had inadvertently covered most of the ramps around her psychotherapist's office with snow. Dianne was initially unable to enter the building driving her motorised wheelchair, and needed the assistance of two people who were walking past to lift her and her wheelchair over a curb. Diane, who prided herself on being independent, found this experience demeaning. She was frustrated and angry with the snowplough operators, who had been unthinking in their placement of the snow, and with her psychotherapist, for not informing her that the building was inaccessible by wheelchair from the car park.

### *Parental Acceptance of Disability*

The problems of parental acceptance of disability were discussed by many of the psychotherapy clients with cerebral palsy (Acquarone, 1995; Donovan, 1995; Jureidini, 1988). Having a baby with an abnormality, such as cerebral palsy, is an emotional blow to the parents, who have to grieve for the loss of their fantasised normal baby (Jureidini, 1988). How the parents then react towards the child over the subsequent years can have a profound impact on the personality of their child. Such was the case with Sally (Donovan, 1995). Sally's mother did not

accept her daughter's disability, and continuously tried to help Sally to overcome the disability, or, at least, minimise the external appearance of cerebral palsy. She mirrored her mother's lack of acceptance of cerebral palsy, which contributed to Sally discounting the influence of her condition on her difficulties she was having at work. Through psychotherapy Sally came to understand the impact of her cerebral palsy on her life and began to change of negative values towards disability.

### *Sexual Behaviour and Intimacy*

Several researchers have identified sexual behaviour and intimacy concerns as critical issues for adults with cerebral palsy (Joseph, 1991; Jureidini, 1988; Shuttleworth, 2000; Steinbock & Zeiss, 1977; Turk et al., 1995). For adults with severe cerebral palsy, gaining sexual pleasure (e.g., by masturbating) is difficult because of their limited physical function (DeWolfe & Livingston, 1982; Donnelly, 1994). Sexual satisfaction is often dependent on others (e.g., caregivers) taking seriously the sexuality of the person with severe cerebral palsy and developing plans to afford the person with this condition the enjoyment of sexual experiences.

For adults with cerebral palsy who wish to engage in sexual relationships with others, significant sociocultural barriers exist (Joseph, 1991; Jureidini, 1988; Shuttleworth, 2000; Turk et al., 1995). Although prostitution and sex surrogacy remain options for people with cerebral palsy (Joseph, 1991), many desire sexual intimacy within a loving relationship. The desexualisation of people with cerebral palsy, however, makes attracting a potential partner difficult (Shuttleworth, 2000; Turk et al., 1995). Prominent social and cultural issues for the 12 men in

Shuttleworth's study included: adolescent isolation from situations in which sexual identities are formed and learning about courting and sexuality happens; negative messages from parents about the likelihood of their children with cerebral palsy having sexually intimate relationships, which were often intended to protect their children from the heartache of possible future rejections; lack of sexual role models with disabilities; and unattainable cultural ideals of attractiveness.

### *Suicidal Ideations and Attempts*

In some of the psychotherapy case histories, suicidal ideations (Olkin, 1995) or suicidal attempts (Jureidini, 1988) were present. David, in a case Jureidini described, attempted suicide three times, following his failures to pass his matriculation examinations. Following his first suicide attempt, David's father arranged for him to attend a sheltered workshop, which David found enormously insulting because he had aspirations of gaining competitive employment alongside people from the general population. He experienced feelings of having lost control to his father, who David had ambivalent feelings towards; of having let down his mother; and of having been beaten by his body and by society. He attempted suicide by drinking kerosene. David was subsequently allowed to resit his matriculation examinations, but failed again and was transferred to the sheltered workshop. David experienced severe depression during the 18 months that followed, and attempted suicide a further two times.

### *Summary*

There are few studies that have explored issues in the lives of adults with cerebral palsy. Much of the information I have presented came from reports of

people with cerebral palsy in psychotherapy. In each case, psychological issues manifested, due, at least in part, to the client's cerebral palsy. The central theme to these issues appears to be the client's difficulties with meeting the demands of an unaccommodating society. Further research is required to explore more fully issues in the lives of adults with cerebral palsy.

### Summary of Literature on the Meaning and Experiences of Physical Activity in the Lives of People with Cerebral Palsy

The examination of the meaning and experiences of physical activity in people with disabilities has been quite superficial. From reading the quotations from participants, which have been reported in studies on the meaning and experiences of physical activity, several issues seem prevalent: identification with people who did not have disabilities, internalised ableism, compliance with advice from medical practitioners, sexuality and intimacy concerns, and poor self-image. Physical activity may also be connected with other issues faced by people with cerebral palsy, such as those explored in psychotherapy cases: anger, coping with having a disability, depression, independence versus dependence, parental acceptance of disability, sexuality, and suicidal ideations and attempts. For example, participation in physical activity may increase the independence of some people with cerebral palsy by enhancing their levels of function. Research is needed to explore the meaning and experiences of physical activity, and its connection with other issues they have faced, in the lives of adults with cerebral palsy.



### Purpose of Studies 2, 3, and 4

The aim of the three studies that follow was to investigate the meaning and experiences of physical activity of adults with cerebral palsy. The following three studies investigated the meanings and experiences of physical activity within the lives of six adults with cerebral palsy. I conducted Study 2 with two adults who had been involved in minimal physical activity throughout their lives. I used a life history method (Denzin, 1989a, 1989b) and paid special attention to the participants' experiences with physical activity and their attempts to be physically active. In Study 3, I employed an identical design to Study 2. The participants in Study 3, however, were two adults who were involved in physical activity. The design of Study 4 departed from the designs of Studies 2 and 3 through the embedding of physical activity interventions in the life histories. Study 4 involved two adults who had engaged in minimal physical activity throughout their lives (as did the Study 2 participants). One participant undertook a warm-water exercise programme, which occurred as part of his attendance at a day centre for people with disabilities, and the other participant received physical training in a 10-week weight-training programme.

## CHAPTER 5

### STUDY 2 – LIFE HISTORIES OF ADULTS WITH CEREBRAL PALSY WHO HAD MINIMAL INVOLVEMENT IN PHYSICAL ACTIVITY

#### Introduction

In Study 1, many of the participants reported minimal involvement in physical activity, and the relationships between physical activity and aspects of HRQL and psychological well-being were typically small in magnitude. Given the much larger associations between physical activity, HRQL, and psychological well-being in Sutherland's (2001) multiple sclerosis research, the findings from Study 1 are somewhat surprising. I suggested (see Study 1) that a possible reason for these differences could be the timing of the onset of these two neurological conditions. Unlike people with multiple sclerosis, people with cerebral palsy never acquire some of the functional capabilities of those who are able bodied. Further functional loss may also occur earlier in life for people with cerebral palsy than for people with multiple sclerosis. Perhaps the experiences of physical activity for people who have had disabilities throughout their lives, such as those with cerebral palsy, may be different to those who have acquired a disability in adulthood.

Insight into the significance of physical activity to people with cerebral palsy may be gained through an investigation of the lives of people with this condition. In the present study, I explored the lives of two people with cerebral palsy who had minimal involvement in physically activity throughout their lives, with the aim of understanding the meaning and experiences of physical activity.

## Method

### *Participants*

The participants were two women with cerebral palsy: Judy, aged 60, and Alana, aged 29. Both participants had spastic hemiplegia. They had engaged in little or no physical activity throughout their lives. Additional characteristics of these participants and the method by which they were recruited are detailed within each of the life histories.

### *Design*

Denzin's (1989a, 1989b) approach to conducting life history research was used to guide the present study. According to Denzin, a life history need not incorporate all aspects of a person's life, but may concentrate on a selected topic of interest. The focus of the present study was on participants' experiences of engaging in, or attempting to engage in, physical activity, as well as their perceptions of other people and events in their lives that may have contributed to these experiences.

### *The Researcher*

By conducting the interviews, I was the instrument used for data collection in the present study. These life histories are what Sparkes (2002) terms *modified realist tales*. That is, although the life histories are *realist tales*, they do contain elements of *confessional tales*. A realist tale has four main features: the almost complete invisibility of the researcher from the written description of the research to try to convey scholarly authority, the systematic focus on minute detail, the attempted portrayal of the points of view of those being studied, and the researchers' interpretations of the participants' worlds (interpretative

omnipotence; Van Maanen, 1988). A confessional tale has three main features: the written description of the researchers' presence in the research process, the articulation of the researchers' points of view, and the argument that the research data were uncontaminated, despite the researchers' confessions of difficulties conducting the research. Like a realist tale, to ensure the voices of my participants come through strongly, I have made extensive use of quotations from them. I also used interpretative omnipotence, in that I have analysed the data in accordance with the theory I have chosen and the research question I sought to answer. Like a confessional tale, my voice is a necessary component of this research. My cerebral palsy had an influence on the dynamics between the participants and me and on my interpretation of their stories. This influence has been detailed in the reporting of the life histories. Before launching into the participants' life histories, I provide some context and evolution of this research. I present some of my experiences, to provide some background as to where I am positioned on many of the issues that the participants raised during the interviews. This background primarily focuses on my experiences with physical activity. I then comment on my experiences as an interviewer.

### *Context and Evolution of the Research*

I did not want to do this research. I had been extremely successful at avoiding people with cerebral palsy, and, generally, people with disabilities my whole life. I saw myself as a *person* who happened to have cerebral palsy, rather than a *person with cerebral palsy*. The cerebral palsy was a separate, and much unwanted, part of me. I was raised by my parents as a "normal" child, who was going to succeed in the normal world, and who received the message that I should

not use my disability as an excuse for *anything*. In brief, I strongly identified with people without disabilities.

The choice of this topic for research was, in the beginning, not mine. I had originally decided on a topic in applied sport psychology. After 18 months from the start of my enrolment in a PhD, however, I was struggling to find participants, and the data I was collecting seemed messy, being confounded by several environmental variables. I spoke with Mark, my later co-supervisor, about the issues I was having, and we agreed that a change of topic was necessary. He suggested the present topic. I was ambivalent in that I greatly admired the work of another PhD student in the area of exercise, HRQL, and psychological functioning, but detested the thought of conducting research with people who had the same disability as I did. Quickly, however, I realised that time was ticking and that having supervisors who liked my topic, even if I did not, was valuable. I just wanted to get my PhD done.

### *My Life Experiences*

My Mum recently recalled to me an early experience I had with physical activity. Mum and Dad had bought me a blue pedal car, with the anticipation that I would enjoy sitting in it, when Mum was hanging washing on the line. I had other ideas, however, and was able to pump the pedals with my feet and drive up and down the driveway. I can only recall positive experiences in regard to my family and my attempts at physical activity when I was a boy. After the pedal car came a tricycle (with blocks and straps so that my feet would stay on the pedals) and, later, a bicycle with training wheels. Mum spent hours with me helping me learn to walk, and there were hours of fun playing sport (mainly cricket), either

with my Mum or my Grandad. My Grandpop and Nana also encouraged my interest in sport. I would spend hours on Saturday afternoons watching sport with either of my grandfathers. Even though I would never be competitive in sports with “normal” people, I was able to demonstrate competence through the progressive development of my skills, and would relish opportunities to practice my skills by myself, or with others. Through reflecting on these experiences, I felt satisfaction in what I was achieving, and decided to continue participating in physical activity.

One of my earliest memories was of watching the Los Angeles Olympics on television. I was captivated by seeing the athletes excel, and, in hindsight, probably identified strongly with them. It probably did not hurt, also, that New Zealand did particularly well during those games.

These experiences may have contributed to my internalised ableism, which developed in tandem with disparaging attitudes towards people with disabilities. Although my parents did not explicitly promote negative attitudes towards people with disabilities, some of the messages I received were that people with disabilities were inferior to those who were able-bodied. For example, early on in my life I did not interact with other people with disabilities on the advice of a physiotherapist. The physiotherapist and my parents perceived it to be undesirable for me to be with children who had disabilities, because I might have adopted their bad habits. A further example is when my parents excluded me from a picnic being hosted by a community organisation, of which my dad was a member, for people with intellectual impairments. My parents perceived that the wives of other club members might view me as being the same as the guests of the picnic (i.e.,

intellectually impaired), and they were concerned with what effect this type of comparison would have on me.

The drawing of negative attention from members of the general public was something I was aware of from a young age. This negative attention manifested, for example, as stares from people because I moved awkwardly or as being spoken to in a manner that suggested to me that they thought I had an intellectual disability in addition to my physical impairment. I did not want to have a disability, I wanted to be like the other, able-bodied, children. To paraphrase Pinocchio, I wanted to be a real boy (Collodi, 1883/1981).

Because of cerebral palsy, I mastered physical tasks of daily living (e.g., walking, aspects of dressing) more slowly than would normally be expected. My Mum persisted with me in developing those skills, and also repeatedly delivered the message that persistence on my part was necessary, because there was nobody in the “real world” who would help me, so I had to do these tasks for myself. Although this message may be interpreted with regard to the Oedipus complex (Freud, 1916/1991, 1917/1991c), it probably also laid the foundations for guilt and shame to be associated with dependence on others and reinforced the idea that people with disabilities were inferior to their able-bodied counterparts.

My primary school days were a happy time for me. I felt that my teachers and classmates accepted me for who I was. I was given every opportunity to succeed academically, with the principals of the school providing me with the assistance of teacher aides and an electronic typewriter (and later a computer), to help me physically keep up with the other children. I was successful academically and had many friends. In my lunchtimes, I usually joined in with sporting

activities, such as cricket. During my last year at primary school, I got an adult tricycle (I don't have the balance necessary to ride a bicycle), which allowed me to ride about with my friends after school.

My transition to high school was an anxious time for me, because I had to establish new social networks and achieve academically in this new environment. By the end of my five years at high school, I had achieved both. In my third year at high school, we had the first set of externally-graded exams. When I received my grades I thought I did alright, and was quite shocked to find that my grades had ranked me fourth in the region. Having achieved this level of excellence, however, I academically cruised through my remaining two years at high school. Socially, I had plenty of friends, and in my last year of school I was voted into the position of Student Representative on the Board of Trustees, under the sardonic, but self-flattering, banner of "The Fantastic Spastic." This success spoke volumes about the people in the school, and their acceptance of someone who was not quite "normal."

In my latter years at high school I was also involved in sport. One of my friends had made the first-eleven soccer team and he invited me to come and watch the team practice. The coach of the team was one of my teachers, and he quickly involved me with the team in a coaching/management role. This coaching relationship lasted several years, with our personal relationship enduring beyond the school years. I was also allowed to play cricket after several of my friends argued for my inclusion in a team. Although some teachers had fears for my safety, they permitted me to play. Even though my ability to play cricket competitively was virtually non-existent, it was on the cricket field where I had



two of my most cherished experiences; I caught two people out. Peak performance was something I strived for, and in those two instances I had a glimpse of what it felt like.

I was also physically active during winter, when I started refereeing men's soccer, as well as officiating for some of the teams I coached. Often on a Saturday I would officiate in two or three games. Refereeing was a way that I could become more involved with sport.

I had known for some time that I would never be competitive with able-bodied athletes. Although competing with people who had cerebral palsy was an option, I was not aware of events, such as the Paralympics. Knowledge of such events, however, would have been unlikely to result in my participation in them. My initial thoughts regarding the Paralympics, when I found out about them in 2000, were scathing. I did not want to be associated with anything disabled.

Given that I did not perceive myself as having the possibility of an athletic career, I focused greater attention on coaching. I saw coaching as a way to be successful in sport. Upon leaving school, I continued to coach soccer, and began coaching the girls' cricket and soccer teams for the school. At university, I studied sport coaching and management as a major inside a business degree.

Despite my academic success at school, I was concerned whether I would be able to keep up at university. To give myself a greater chance of succeeding academically at university, and to improve my social network, I enrolled in a one-week introductory course to my degree. Although I gained little academically from the course, I met some people, with whom I became close.

I was doing resistance exercises at home, but was becoming increasingly frustrated with the limitations of my few pieces of equipment. During my first year at university I plucked up enough courage to go to the gym. I wanted to be fitter for my soccer refereeing, and I also had a belief that if I were more muscular then I would be attractive to potential partners. Since this time, I have realised that increased muscle mass does not equate to being more attractive. Rather than stopping weight training, however, I developed different motives for training, including the intrinsic pleasure of doing the exercises, the sense of competence when I increase the weights I lift, and social reasons (e.g., talking with trainers and regular gym patrons).

By the end of my bachelor's degree, I had achieved academically, with the University awarding me a scholarship, for one-year postgraduate study, for having grades in the top five percent of graduates. During the degree, one of my lecturers for coaching was a sport psychologist. He suggested that I do my honour's research project with him. The entry into my honours year was a time when I was becoming frustrated with coaching. Even though I was gaining skills and experience, I felt the barriers to a physically-disabled person moving up the coaching levels were insurmountable. Having a sport psychologist as a supervisor, however, provided me with the model that other forms of involvement in sport were possible.

My frustration with coaching resulted in me stopping coaching the three teams I was with at that stage. I felt burnt out because of the organising and coaching I had to do for the teams, and was questioning my ability to perform because I could not execute the skills of cricket in ways that could be modelled by

my players. Although my non-physical coaching skills were improving, I felt that I could not compensate for my physical inadequacies.

I started my honour's year with the goal of gaining a first class pass. To this end, I progressively worked longer and longer hours, until I had little time for anything else. I trained at the gym five or six days per week, was involved with soccer, and spent the remainder of my time studying. By the time I had finished my honour's year, I was mentally exhausted, but I had achieved my goal of gaining first class honours.

Towards the end of the year, one of the referees in my region was appointed to an elite panel, and, therefore, required to complete a prescribed training programme. Given my background, he asked me to come and assist him. Before long, a small group of referees, who all aimed at officiating at the highest level, had formed, and I became their coach. The next winter soccer season, I gave up active refereeing, continued coaching, and started to learn how to inspect (grade) the referees. Working with these highly-motivated people was the most rewarding coaching I had done. I was able to use my coaching knowledge and ability to its fullest, and be innovative.

At the end of my honour's year, I was awarded a scholarship to do a master's degree. I completed research for an external organisation, and, in the process, was awarded the degree with distinction.

During the year that followed, I was employed to perform a range of academic tasks, including research, teaching, and grading of papers and exams. I was at another transition period of my life, where, as it turned out, I left home and left the country on the same day.

I had been awarded a PhD scholarship at Victoria University in Melbourne. Although I was concerned with a range of issues (e.g., how would I cope living on my own, would I be able to succeed academically, would I be able to develop a new social network), I resolved to deal with issues as they arose, rather than trying to work my way through a great number of variables mentally. My first year in Melbourne was one of the best years in my life. I lived in student accommodation and was readily accepted by the somewhat younger students. In some ways, this was a reversal, in age terms, of my first year at university. I was now the older student, with a lot of younger students, doing many of the activities done by younger students. I was given an award at year-end for my contribution to college life, which I saw as a measure of how well I had been accepted into a new country.

Coming to Melbourne, I was eager to continue my gym training, and was delighted to find the campus gym in the building in which I was to study. After I had been training for a few months, I asked the trainer to write me a regimen, because I was getting bored with writing my own programmes. I was concerned when he prescribed exercises for me that I could not do by myself, or which I would find difficult. To compensate for my difficulties in performing the exercises, the trainer said he would assist me. He then got permission to set aside time each day to help me with the exercises.

I had been fortunate that, at the gym in New Zealand, a scheme had allowed me to be assigned personal trainers for about three hours per week. This scheme began a few years after I started training, and I relished the opportunity to

perform programmes that I would have otherwise been incapable of doing. I had not been expecting to be this lucky again.

To me, the value of my training, and the assistance I get, are immense. With my trainer, I am able to demonstrate competence in a field that would otherwise be hugely challenging for me. I am able to develop my body and offset the occurrence of debilitating functional and physical loss as I age with cerebral palsy. It provides me with a further source of social contact, primarily with my trainer, but also with other gym staff and patrons. Training is also a haven from my hectic PhD research. If this glimpse of my life is not a good case for people with cerebral palsy doing exercise, I do not know what is.

My pattern of achievement throughout my life was borne out of feelings of inferiority, which are omnipresent. The continuous achievement, some may say over-achievement, was founded in the perceived need to compensate for a disability that I viewed as abhorrent, and I struggled when people around me did not see it similarly. I did not have a part-time job during my school days or undergraduate education, and people expressed doubt over my ability to perform the jobs I finally did get, lecturing, tutoring, and grading papers, as a postgraduate student. I perceived that I would need above-average qualifications to be able to compete for employment with other people. To borrow words from Missy Higgins's (2004, track 3) song *Scar*, "I'm a little bit tired of fearing that I'll be the bad fruit nobody buys."

### *Procedures*

The Victoria University Human Research Ethics Committee gave approval for this study to be conducted. The participants were recruited in different ways,

and these methods are detailed within the life histories. One interview was conducted with each participant. On meeting each participant, the details of the study were reviewed, along with the risks of participation and the provisions put in place should these risks have eventuated. The participants were given an information sheet containing this information and were asked to sign a consent form before the interview began. Participants were interviewed about their participation, or attempted involvement, in physical activity. During the interviews, psychodynamic theory guided follow-up questions and probes. Although the starting point for each interview was the meaning and experiences of physical activity, follow-up questions and probes often explored other aspects of the participants' lives, which appeared related to their involvement, or lack thereof, in physical activity. The interviews were audio-tape recorded and transcribed verbatim. These transcriptions were used as the data for the analysis. Following the interviews, the participants were thanked for their involvement in the research. A summary of the findings of all four studies in this thesis was sent to participants once the research had been completed.

### *Analysis*

Denzin (1989a) described three interpretive formats: no researcher interpretation of the participant's life history material, researcher interpretation of a life history that has often been written by the participant (i.e., interpreting autobiographical material), and researcher interpretation of the participant's life history material. I used the last of these interpretive formats in the data analysis. Using this format, each participant's life is woven "into and through the researcher's interpretations of that life" (p. 58). The interview transcripts were

carefully read, and patterns of meaning and experience were extracted from the text. These patterns were then interpreted, using primarily psychodynamic theory (Freud, Erikson, Adler, and Basch, in particular), to gain insight into the meaning and experiences of physical activity for each participant. Freudian and neo-Freudian theories were chosen because of the developmental aspects of the life histories and the obvious dynamic and developmental material that emerged through the interviews. Although psychodynamic theory (in particular, Freud's work), has been criticised (most notably because many of the theories are not testable and, therefore, judged to be unscientific), several concepts have received research support (e.g., defence mechanisms, castration anxiety, penis envy; Maddi, 1996). Empirical evidence also supports recent developments in psychodynamic theory (Basch, 1988). Attention was placed on understanding the participants' ego-defence mechanisms and stages of psychosocial development. A review of the basic tenets of psychodynamic theory and the concepts I used in the present research is included as Appendix C. There is a need, however, to recognise that the term *self-esteem* is used with respect to Basch's (1988) conceptualisation. Basch considered self-esteem to be "a genuine sense of one's self as worthy of nurture and protection, capable of growth and development, [stemming] from the experience of competence, the experience of functioning appropriately" (p. 24). When one engages in "introspection and reflection, competence is experienced as self-esteem" (p. 25). Please refer to Appendix C for further description of how Basch conceptualises *competence*, and, therefore, how the term is used in the present study.

When reporting extracts verbatim from the interview, I have used parentheses, brackets, and italics, to help clarify the text. Parentheses have been used to add or replace words and names. For example, names have been replaced by pseudonyms or by words that show the relationship between participants and the people they were talking about. Parentheses have also been used to substitute the pronoun, “it,” with the noun, in situations when not doing so would have made the extract unclear. Brackets are used to describe how something was said, or any other relevant behaviour that occurred during the extract being cited. Italics has been used to highlight words or phrases that I specifically make mention of in the text that follows.

## Results

### *Judy's Life History: Seeking Social Connectedness*

#### *Meeting Judy*

Judy participated in Study 1, and indicated that she was willing to be a participant in further research. Because Judy had reported participating in minimal physical activity, I contacted her by letter, outlining the purpose of the present study, presenting what it entailed, and inviting her to be involved with the study. She responded to me in a brief email, saying that she would like to be a participant. I then telephoned her to arrange a time for me to meet with her. What struck me about these exchanges was their succinctness. Her willingness to participate seemed to contrast with her taciturn abruptness towards me.

As I drove to her house, I was conscious, more than usual, of the need to build rapport. Judy answered the front door after I had rung the doorbell. She was a well-presented woman. I wondered whether she had dressed up on my account.



Judy guided me down a short hallway, through a lounge area, to a small dining area beside the kitchen. Her house, or what I saw of it, seemed an extension of Judy. Everything was in its place. She seemed proud of her house and garden, and I complemented her on both.

Judy needed the assistance aid of a walking frame, to which I had not paid much attention. Before we sat down, Judy remarked that she had begun using the walking frame only in the last two years. I lodged the comment as an issue to explore during the interview. We sat at the dining room table and began the interview.

### *Playing with Dolls and Selling Mud Pies*

Unlike the other five life history participants (Study's 2, 3, 4) who were born in the 1970s and early 1980s, Judy was born in 1944. In Australia, at the time Judy was a child (the late 1940s and early 1950s), many people with moderate and severe disabilities were cared for in State-funded institutions, such as general hospitals, hospices, mental hospitals, nursing homes, and special institutions (Lindsay, 1996). Nurses staffed these institutions and were oriented towards caring for the medical needs of patients. Some people with disabilities were cared for by their families, and sometimes received support from nurses. Charitable organisations ran many of the schools for people with disabilities, but the value of the education they provided was often limited.

As a child, Judy was, of course, unaware of State provisions for people with disabilities. Her earliest memories are of playing for hours in the backyard of her home. She would spend time playing on her swing, playing with her dolls, and making mud pies to sell in her make-believe shop. Being an only child, Judy had

no sibling rivals, and was the centre of her parents' attention. Her interactions were mainly with adults, and she did not often communicate with children of her own age.

### *Learning to Walk*

Judy's cerebral palsy adversely affected her ability to walk. Although Judy could not recall memories of early attempts to walk, she could remember walking with assistance from the age of two. Given her impeded development, medical staff recommended that Judy wear callipers (i.e., leg braces designed to improve walking by preventing the typical cerebral palsy gait) to improve her ability to walk unaided. An intervention such as this one may have influenced Basch's (1988) developmental spiral at the behavioural stage. Through this intervention Judy may have improved her walking ability and gained self-esteem through reflection on her newfound ability. Walking would have also enabled Judy to take more initiative in her environment, as is desirable in the locomotor-genital stage of development (Erikson, 1985). I found little evidence to support or reject Basch's and Erikson's predictions, however, because Judy had trouble recalling some of her experiences with callipers, which had happened over 50 years ago. Judy's difficulty with walking may have restricted her attempts at more active forms of play. This limitation may also have inhibited her gaining a sense of pleasure from being mobile.

Although Judy's callipers may have assisted her to walk unaided, she was unable to perceive any gains in competence at this young age. Judy described how awkward it was for her to walk with her legs braced in an extended position, and how her mother had to lift her on and off public transport when they went to the

Children's Hospital for physiotherapy. Through reflection on these difficult experiences, Judy gained little self-esteem for walking. Judy did not understand why she had to wear callipers, and she described it as being a horrible experience. Her inability to walk unaided, and her difficulties walking with callipers may have discouraged her from activities that involved walking.

An individual experiencing such difficulties in one area may decide to limit their involvement or to abandon their strivings for competence in that area (Basch, 1988). Judy's family, however, entered her developmental spiral at the decision-making stage. She received support from her parents in her attempts to walk. Her mother encouraged her to keep wearing the callipers, and Judy could recall her father and uncle giving her feedback about her walking.

J: I can always remember an uncle of mine; he always (said), as my father used to say, "get off your knees," meaning that I walked with my knees bent all the time and they wanted me to stand up straight.

When Judy started school, she had new callipers, a pair that bent at the knees. With these callipers, Judy found it easier to walk. From her description of this experience, I gained the impression that Judy increased her sense of competence with walking. By the time Judy was in the fourth grade, she no longer had to wear callipers. Judy seemed to reflect positively on the time when she was able to walk without callipers, and, from this experience, she appeared to gain self-esteem for walking. I enquired about what it was like for Judy to wear callipers at school, and the perceptions of her classmates, in an attempt to judge whether she had any feelings of inferiority, but she could not recall any such experiences.

*The Head Physiotherapist was a Dragon*

Judy had physiotherapy throughout much of her childhood and adolescence. She made frequent visits to the Children's Hospital, and one of her strongest recollections was that she perceived the head physiotherapist to be a dragon. The head physiotherapist had Judy work hard to develop her physical abilities, and Judy did not perceive her favourably. Physiotherapy meant that Judy had to repetitively do difficult exercises. Although these exercises would have been prescribed to increase her competence at physical tasks, especially walking, Judy did not perceive she was making progress. Physiotherapy was, then, something to be endured, rather than activities that contributed to her sense of competence.

Although Judy disliked the head physiotherapist, she liked the other physiotherapists. Her positive perceptions of the other physiotherapists, however, had little to do with the therapy they performed with her.

J: They were nice, the (other) physios, because the ones in the Children's Hospital used to take us out on a weekend. They'd take us to things. I can always remember my physio coming and picking me up and taking me to the zoo. But there were other kids with her too.

Going to the zoo was an enjoyable experience for Judy. She was able to see the animals and to have a ride on an elephant. The visits to the zoo were also of physical benefit to Judy. She had to do a substantial amount of walking around the zoo to see the animals. This outing may also have enhanced Judy's commitment to physiotherapy, because physical activity was placed in a pleasant context (i.e., walking around the zoo, rather than performing difficult exercises) and because

she was able to spend time with the physiotherapists she liked in an enjoyable way.

The final sentence of this quote is perhaps reflective of Judy's experiences as an only child. As Adler (1932) discussed, being an only child typically results in the undivided attention of both parents. Judy may have projected this pattern of interacting with parents onto the physiotherapists, so the presence of children competing for the attention of adults would have been an unwelcome novelty for her. Possibly, Judy had problems with the other children vying for the adults' attention.

Another of Judy's memories of the Children's Hospital was of the Christmas parties, when wealthy businessmen would open their homes to the children. Like the visits to the zoo, Judy seemed to benefit from having enjoyable experiences with the physiotherapists, which contrasted with the experience of performing difficult exercises with them during physiotherapy. Looking forward to these pleasant experiences may have enhanced Judy's commitment to physiotherapy.

Judy also recalled having speech therapy at the Children's Hospital. Judy had speech therapy when she was young, but did not persist with the treatment for long. When reflecting on her speech therapy, she revealed her belief about the possibility for development as a person with cerebral palsy.

C: What about the speech therapy you mentioned?

J: Oh, I gave that away a long time before that. Once I left the Children's Hospital I never had that (speech therapy) again. I'm a great believer that if you can't improve (your physical ability) when you're young, well, you're not going to (improve) anymore.

This limited perception of the possibility for functional improvement beyond Judy's childhood may have been an acceptance of the views of the medical profession. Cerebral palsy has traditionally been regarded as a paediatric condition, and therapeutic interventions were developed accordingly (Bottos et al., 2001). Development programmes have typically been targeted towards children with cerebral palsy, with few continuing through adolescence, and even fewer available for adults with the condition. Judy's internalisation of this message may have contributed to her beliefs about physical activity later in life. That is, Judy may have thought that it was pointless to expend effort engaging in physical activity, because her physical condition was not going to improve.

*Screaming the Place Down: Physical Activity at Primary School*

Walking aside, Judy did not participate in physical activity when she was at primary school. Her first school was a small private school for girls. When her classmates did physical activity during class time, Judy rested for the hour, on one of the boarder's beds. She then rejoined her class when they had finished their physical activity. On one occasion, however, Judy was forgotten about following the physical activity.

J: They took me upstairs to one of the boarder's beds.

C: Okay.

J: And I had to lie on her bed, and sometimes they forgot me, and I screamed the place down.

C: What was it like for you to be forgotten about?

J: Oh, [pause] I screamed the place down, and I was never taken back. I used to just sit and wait for them, then they never took me back up there.

Judy was angry about being left in the boarders' room after her classmates had completed their physical activity. Although Judy could clearly remember this experience, she could not remember the reason for this angry outburst. A possible explanation for her behaviour, however, could be that she was angry about being isolated from her classmates when, following the physical activity, they were engaged in tasks with which she perceived she could be competently involved.

Judy's teacher decided to exclude her from participation in physical activity, presumably because the teacher was unsure whether Judy would be able to cope with being involved with the other children in this type of activity. Judy did not mind being excluded from physical activity, which may be indicative of low self-esteem in this area. Judy said that she could not remember what it was like for her to spend time alone in the boarders' room, when her classmates were performing physical activity, but she could recall her perceptions of physical activity. She did not like physical activity because she could not do it (i.e., lacked competence) and her attempts at physical activity were often negative experiences (e.g., falling over and hurting herself). Judy's reflections on her lack of competence at physical activity meant that she did not develop self-esteem in this area. Following Basch's (1988) developmental spiral, then, this lack of self-esteem resulted in Judy's progress being inhibited, and her decision not to try to participate in physical activity. This halt in her physical development seemed to require outside intervention for Judy to progress. The intervention, however, was not forthcoming, and she did not become involved in physical activity.

### *Early Social Isolation*

One feature of the latency phase (Erikson, 1985) is its emphasis on the development of skills and on the use of tools, which will be employed to become a productive member of society. If a child does not develop these skills, a sense of inferiority can develop. In one aspect of the school curriculum (physical activity), Judy was unable to show competence, which resulted in her isolation from her classmates when they were performing physical activity.

This isolation continued in the playground. At playtime, Judy's classmates were involved in physical activities (e.g., running, skipping) that she perceived were too rough for her. Judy did not play with her classmates at lunchtime, either, because she would go home for lunch. These circumstances meant that the opportunities for Judy to interact socially with her classmates were limited. Judy's cerebral palsy restricted her opportunities, both physically and socially.

The social isolation Judy experienced in the playground at school was replicated at home. There were four children next door to her, who played in the back yard. Judy regarded these children as good friends, but did not play with them because she perceived their games as being too rough, and that she would get in the way. Judy gained vicarious pleasure from watching them play, but wished she could be involved. Again, Judy did not feel competent to interact with her peers in physical activities.

Judy's lack of physical ability contributed to her difficulties in obtaining the skills necessary to interact successfully in the social milieu, which seemed to have led to a sense of inferiority (Erikson, 1985) in the social setting. Such inferiority may have contributed to Judy restricting her potential in the social



context in later life (see, e.g., *Aiming Too High: Husband Wanted and My Uneasiness with Judy*).

Inside the classroom, Judy disliked study. She said that she would rather have watched television than do schoolwork.

J: It was never a pleasure to go (to school). I used to like the holidays, y'know.

C: What didn't you like about primary school and middle school?

J: Oh I suppose I didn't like study for one thing. I hated to study and . . . I just didn't like school. I like doing my own thing. I always have.

Two factors that may have contributed to Judy's dislike of school were her experiences as an only child and anxieties in the social context of school life. As an only child, Judy had the undivided attention of both parents and was not used to competing for the interest of adults with other children, as would have happened in a classroom environment. Further, she had been used to directing her energies in play without having to cooperate with other children. The social situation may have been anxiety inducing for Judy, because she did not perceive herself as having sufficient physical competence to engage successfully in the activities of her peers.

### *Swimming: A Hopeless Case*

Judy's father encouraged her, and provided numerous opportunities for her to learn to swim. Here, Judy's father was entering her developmental spiral (Basch, 1988) at the decision-making stage. Judy's father seemed to want to help his daughter develop through exposing her to situations in which he hoped she

would demonstrate competence. Although Judy's father seemed well meaning and concerned for his daughter, swimming was not going to be an area where she would develop competence. In the following dialogue, Judy reflected on her lack of ability.

- J: It didn't matter how often I got taught, I just couldn't swim.
- C: The breathing was the hardest part?
- J: The breathing, yeah, the breathing. Yes, and I got very cold in the water.
- C: Did they have the heated pool?
- J: Oh yes, they had the heating. It's just the old Olympic pool. That was heated, but I still couldn't (swim).
- C: You still got cold?
- J: I still got cold, yes. I'm a hopeless case [laughs].

The mother of the four children, who lived in a neighbouring house, was a champion swimmer and tried to teach Judy to swim. Judy struggled to master the breathing methods for swimming and got cold in the pool, no matter how warm the water. Her father persisted and took her to swimming lessons on Sunday mornings. Judy, however, could not gain a sense of competence at swimming, and did not pursue the activity.

### *Gaining Competence Through Work*

As a nine-year-old, Judy started working in her parents' shop on Saturday mornings and, quite often, after school. She served behind the counter and, in the evenings, Judy's father would have her count the money as part of her homework. During their time together working in the evening, Judy's father taught her the

essentials of bookkeeping. Judy's father appears to have had a significant role in helping his daughter develop competence during this stage of her life. Although Judy's experiences at school may have contributed to her feeling a sense of inferiority among her peers, Judy's father gave his daughter the opportunity to develop a sense of industry and accomplishment. Judy seemed to have developed the belief that she could one day take her place in the workforce, beside her able-bodied peers.

### *Childhood and Perceptions of Parents*

Judy's description of her father sharply contrasted with what she said about her mother. Adler (1932) wrote that, with the absence of brothers or sisters as rivals, only children might take one of their parents as a rival. Judy described her father as a hard man who demanded obedience, and she painted her mother as a saint. Yet, there appears to be a degree of discordance between Judy's stories that featured her father, and the way she directly presented him. The stories told thus far described how Judy's father encouraged her to develop physical skills (e.g., swimming, walking) and provided her with opportunities to grow, such as learning the skills of operating a business. In response to the story about how Judy's father supported her in her attempts at swimming, I remarked that she must have loved her father. In the following dialogue Judy described her father.

C: You must really love your father.

J: He was a hard man. He worked very hard.

C: Hard in what sense?

J: Oh, I s'pose when I was young he made me do, you know, I wasn't spoilt, no way. I was never spoilt. I just had to be told, and I knew by the voice. If I was doing something wrong, he only had to speak [laughs].

In Judy's response to my first question, it appeared that she tried to modify the initial sentence, by giving the word *hard* perhaps more favourable connotations. My clarifying question brought out that it was the first sense of the word *hard* that Judy meant. Judy perceived that her father related to her in a strict manner. From Judy's stories, her father made her perform activities (e.g., swimming, walking, working) that she may have found difficult, but from which her father thought she would benefit. Judy's father also ingrained in her that to earn a fair day's pay, a fair day's work was required.

Judy's feelings towards her father were also represented in what she did not say. She did not use the word *love* in her responses to my questions, and did not use this word herself, in reference to her father, at any other time during the interview. Such an omission provides evidence of Judy's ambivalence toward her father. Judy seemed grateful for the opportunities her father provided, but disliked the authority he had over her and the difficult activities he required her to attempt.

Judy's father's dominant role in the family seemed to conflict with Judy's need to be the centre of attention, which perhaps was another manifestation of being an only child (Adler, 1932). She spoke of her father as being the boss, and, uncompromisingly, always needing to have his own way. In this respect, her father was a rival for Judy.

In contrast, Judy perceived her mother as someone who worked hard to make life easier for Judy. The next extract details the admiration Judy had for her mother.

J: She looked after me, took me to the hospital every week. It must've been hard on her because she nursed her mother as well. I don't know how. She had to get the family, had to keep coming to look after nana while she took me to the hospital. And then she always ran out of time. She worked very hard. She had a big house and garden. She loved her garden and, of course, she more or less ran the shop. My father was there, but my mum was the one that did it all. She did it all. She did all the buying and everything. She used to go into town to all the warehouses. I can always remember going into town with her to all of the different warehouses . . . Yeah, buying the stock and everything. Yeah, so she had a hard life. Tried to make it easier for me I'd say.

In this passage, Judy implied that it was her mother who did all the work in the family, and her father did little in comparison. These perceptions of her parents in the home and work settings probably would have contributed to Judy's ambivalence towards her father and identification with her mother. Judy may have perceived herself to be like her mother, in that they both had to work hard to please her father.

*Social Isolation, Physical Inactivity, and High School*

Judy went to high school in the late 1950s. The two features that were prominent in Judy's primary and middle school years (social isolation, physical inactivity) were present again during her high school years. The social isolation Judy experienced as a high school student, however, was more blatant than what she had experienced in the past.

J: I hated, I hated the high school because they used to hide from me, the girls at lunchtime.

C: That must have been tough for you. Do you know why that did that?

J: I've really got no idea. I'd like to meet them and ask them now. But the trouble was I used to wander around all lunchtime looking for them, and I

don't know where they hid, unless they were behind me all the time [laughs] and would see where I went and went the other way. But I had parents, they were older parents, and my father always used to say to me, "Don't worry about them, take a book, and read a book," but when we were kids you don't want to just sit and read a book. You want, y'know, friends.

Whereas, at the primary and middle schools, Judy removed herself from some social situations because of a lack of physical competence, the girls at high school excluded her from socialising with them. As Erikson (1985) described, young people can become extraordinarily clannish and exclude from their social groups others who are "different." Judy had difficulty walking and spoke in an unclear manner. Without any competing evidence, these manifestations of her cerebral palsy were probably the basis for her exclusion. The exclusion of Judy from school peer groups may have impaired her social development, and made her feel that she did not belong in the company of able-bodied people. Judy may have experienced a sense of role confusion, in that she did not fit within any of the social groups at school. Her later association with people who had disabilities, may have helped to clarify her identity. Although she wished to be with people who were able bodied, such experiences may have led her to believe that she should look towards other groups (i.e., people with disabilities) for social interaction.

The advice from Judy's father, in the dialogue reported previously, may have represented a frustration on his part with not knowing what he could do to help his daughter, rather than unconcern for her social development. His advice seems protective. He may have thought it better for his daughter to be engrossed in another activity (e.g., reading), which may have allowed her to develop in other

ways, rather than face the anxiety of not being able to find her classmates at lunchtime.

As a 60-year-old woman, Judy still reflected on the memories of how she was treated by her classmates. A recent segment she had heard on the radio about bullying in schools had caused Judy to reflect on her own experiences as a child and adolescent. Judy drew a parallel between her own experiences and what was being described on the radio. What Judy experienced was a passive kind of bullying. Although Judy consoled herself with the knowledge that her school days were in the distant past, it was clear that her memories of those experiences still affected her.

Even when Judy mentioned friends she had during her school years, the people she described seemed more like acquaintances than friends. The following dialogue encapsulates Judy's perceptions of her "friends" at high school.

- C: You mentioned to me that, at high school, the girls tended to run away from you, or hide from you. Did you have friends at high school?
- J: Oh, I had a few friends, but not friends that wanted to spend time with me really, y'know. I could walk (with them from school) or, as I said before, if Dad didn't pick me up from the station I had to walk (with them). I had to walk to the station, so I walked along with them, but I don't know how they felt about me being there with them, y'know.
- C: That must've been a fairly difficult time for you.
- J: Yeah, it was. Yes.
- C: What were you thinking at the time?
- J: Well I can't remember now, that's why I hated school, y'know.

Judy did not experience the intimacy of friendship. Her friends seemed to tolerate her presence or, worse, took pity on her. Along with the displays of outward avoidance of Judy, high school would have been unbearable for her. Judy's lack of competence in social life continued.

Judy typically avoided physical activity at high school, as she had done during her primary and middle school years. Two activities with which her classmates were involved were marching and rounders. Judy did not participate in the marching and was minimally involved in rounders.

J: I did do rounders, occasionally. I could run around the square of the rounders, but then, as I got older, I met girls that didn't want to do it anyway. So we used to go (away from) the girls at the rounders, but they could never find us. We used to hide [laughs]. So, really, I never did that either.

C: So what did you use to do?

J: We used to just sit on the ground and talk behind a shed or something. I can always remember, I think we had a go (at rounders), and then we used to go and sit and wait for the (time when) we could go home.

Judy loved her participation, and non-participation, in rounders. This enjoyment stemmed from her ability to show competence with some of the skills of rounders, and her social inclusion. The latter of these factors, however, was perhaps the most important to Judy because she took delight in avoiding rounders to go and hide with some of the other girls. It seems that Judy identified with the girls with whom she was hiding. Judy had regularly experienced what it was like to be the person from whom other classmates had hid. Now Judy was among the group doing the hiding, and she enjoyed the sense of belonging to this group. In the



previous dialogue, however, Judy creates the impression that she was closer to the other girls than was, perhaps, the case.

This experience may have contributed to Judy viewing physical activity in a negative way. In physical terms, her involvement in rounders was one of the few positive experiences she had with physical activity. Through identification with some of her classmates, however, she perceived that avoidance was more enjoyable than participation.

### *Physiotherapy and Adolescence*

Judy had physiotherapy throughout her adolescence, and although she liked the physiotherapist (not the dragon), she did not like doing the exercises she was requested to do. Her dislike for physiotherapy seemed to stem from not gaining competence through the exercises, and the treatment may have accentuated, for her, that she had cerebral palsy. With the physiotherapist, Judy continued to practice walking and did exercises (e.g., kicking her legs, while lying on a table), but felt that her walking was not improving.

C: Why did you want to give this physiotherapy up?

J: I didn't think it would do any good.

Although Judy did exercises with the physiotherapist, she did not practice the exercises in her own time. Through reflection on her physiotherapy experiences, Judy felt that she had not gained a greater amount of competence to walk.

Following the developmental spiral (Basch, 1988), then, the stalling of Judy's progress in physiotherapy contributed to her perceiving that the physiotherapy

was not benefiting her and to her decision to expend minimal effort performing the prescribed exercises. At the age of 20, she stopped physiotherapy, because that was the first time when she, and not her parents, had the choice of whether she would continue treatment.

### *Formal Bookkeeping Training and First Job*

At the start of the 1960s, Judy finished high school (aged 16), and went to a business college. She wanted to gain employment in an office, but did not know for what type of job she should focus her training. Judy attempted shorthand and typing but was not competent at these tasks. She was too slow and could not keep pace with her classmates. Judy then attempted bookkeeping and found herself more suited to this task. Her father's instruction in the finances of the family business had provided Judy with a good foundation of knowledge to build upon. Judy had found a profession at which she would be competent.

The growth that Judy experienced during the business administration course was diminished somewhat over the six months following the course. Judy described this period of her life as being quite disheartening, because nobody would give her a chance. Judy's development, however, progressed once more when she gained employment at a bakery, working with the dockets. Judy was proud that she was able to hold down a job, and loved her work. Judy appeared to have been receiving the message in social contexts and job interviews that she was not sufficiently competent to take her place in society alongside those who were able bodied. Gaining employment meant that she was the equal of people who were able bodied in the workforce, at least.

### *Searching for Social Connectedness*

At the end of her adolescence, and having joined the workforce, Judy increased her efforts to be socially connected. To this end, Judy enrolled in a dressmaking course, joined the YWCA, and started attending church.

C: So, what motivated you to join the YWCA?

J: Oh, I wanted to meet friends, meet people.

Judy's attempts at finding friendship succeeded. It was at church where she met a woman, who would later become her best friend. The friendship continued over the years. In the following extract, Judy described their relationship, as it was when I met Judy.

J: Yes, they come up about every three or four months. They come up nine times a year to a concert, and we go in and meet them and have lunch with them. She's got a family, a boy and a girl. And I had my 60th birthday the other week. And they came up and we had lunch together, and we talk on the internet, and we send emails to each other all the time. It's been a good friendship [laughs]. That was a bit wrong on my part, it's a bit sarcastic in different things because after, like she only lived around the corner, more or less, from me when we were young, and then she got married, and my father said to me, "Well, you'll never see her again," y'know, after the wedding, and of course about six weeks later she said come up for the weekend.

In a life in which Judy found it difficult to be socially connected, this friendship assumes importance, because it is one of two long-term relationships outside her family that she had during her life. I shall report on the other relationship later in the life history (see *Romance and Paternal Disableism*). When I spoke with Judy, she still seemed to be intimately connected with her friend from church. Although

her friend lived far from Judy, they typically seemed to see each other whenever her friend came up to the area where Judy lived. Her friend also made a special effort to go out with Judy on her birthday.

Two aspects of this extract that are particularly interesting are Judy's remark about her friend's family, and the interaction between her father and her that she described. The comment about her friend having a son and daughter may have been reflective of her wish that she had children. I will return to the topics of family and children later in the life history. The hostility that Judy felt towards her father was evident, once more, in how she described her interaction with her father about her friend. Given that Judy's father would have known that his daughter had struggled to find friends for most of her life, his comment seemed designed to prepare Judy for the reality that her friend was beginning a new part of her life in another town, and might not have as much time for Judy as she once had. Judy seemed to enjoy her father being proved wrong.

### *Social Isolation Overseas*

When Judy was 23, her parents closed their business and took her on a 12-month overseas trip to Europe and England. On this trip, Judy became socially isolated once more.

C: How was the trip?

J: Good, yeah, (but) it would've been nicer to be with younger people. Mum did suggest a couple of times that I go off on a tour of my own with young people, but Dad didn't like that idea, so I just stayed with them the whole 12 months. I sure realised it was good, but you know the down side was I was with them the whole time. I never really met young people.

C: Your Dad sounds like he was quite protective of you.

J: Yeah, he was protective. Yes, unfortunately, yeah.

There may have been several factors that contributed to Judy's father's decision not to let her go on a tour by herself. Parents are often over-protective of an only child (Adler, 1932). This over-protectiveness may have been exaggerated in Judy's case, because of her cerebral palsy. Further, Judy's father probably knew of her difficulties in social settings, and may have had doubts about whether his daughter could effectively interact with others without her parents nearby. In attempting to protect his daughter, however, Judy's father removed a potential opportunity for her to develop competence socially, which would have been of benefit to her when they returned home.

*Playing Politics (or Trying to Make New Friends)*

On returning home, Judy was given her old job back and continued on her quest to become socially connected. With social, rather than political, aspirations, Judy joined a political party. Judy enjoyed the weekly parties with other young people, and took part in a weekend away as a group. She met a few nice female friends in the group and went to movies and suppers with them.

J: And we used to have go out together and that, and there were four girls. We used to meet up, and (I) *stuck with them for a while*.

Judy's use of language in this extract resonated with how she described her friends at school. She depicted the atmosphere of the political group as a fun environment in which to be involved. It seemed, however, that Judy was tolerated, and probably liked, by other group members, rather than Judy being an important

part of the group. The words that I have highlighted in italics suggest affiliation rather than belonging. Judy's lack of experience with close friendships may have inhibited her from being closer to other people in the group.

*Aiming Too High: Husband Wanted*

Judy became despondent about her chances of finding a husband, which is further evidence that she was struggling to be fully accepted by members of the political party. A woman said to Judy that a person normally has a holiday overseas or gets married, but not usually both. Although this statement has no rational basis, it appears to have contributed to Judy's concerns over her chances of getting married. Concerned about her daughter, Judy's mother took her to a doctor who specialised in cerebral palsy.

C: Can you tell me about what happened when you went to see the doctor?

J: He said to me and my mum (that) maybe I'm aiming too high. Maybe instead of going out with able-bods all the time and (them) being up there and (you) down there, if you go with disabled people you might feel a bit more on top.

This advice elicited a strong reaction within me. My parents raised me to believe that, although I had cerebral palsy, I was the equal of people in the general population. Her retelling of this advice, forced me to confront my own fears, as a single person, that I was not worthy of having an intimate, romantic relationship with someone who does not have a disability. Her recalling of the story, without affect, suggested to me, however, that Judy felt differently than I did. I waited for Judy to finish the story before I asked her how she reacted to the doctor's advice.

- C: So how did you feel then when the doctor advised you that you were aiming too high?
- J: Well, I thought I could try what he was suggesting. Because I knew I wasn't getting anywhere with a load of able-bodied people, and I thought, well, maybe he is right.
- C: How did you feel about that?
- J: Oh well, you couldn't. I don't know really. I had the girls at work and all the men at work that I was still associating with the able-bods. So, I really wasn't, you know, going to not see them or be with them at all. I had my work and church, because they were able-bodied down there.

Judy appears to have internalised this disableism. She accepted that she was inferior to people in the general population, and, therefore, should seek a husband among those who were also disabled. It seemed as if Judy regarded herself as being able to keep up with people in the general population in some areas of life, but not in romantic partnership terms.

The doctor entered Judy's developmental spiral (Basch, 1988) at the decision-making stage. The premise behind his suggestion was that Judy would have more chance of finding a romantic relationship with someone with a disability, rather than someone who was able bodied, and that this experience would allow development to resume in this area. Judy took the doctor's advice, and began visiting a residence for people with disabilities. She had trouble being accepted by the residents, because she was able to leave and go home at any time, which seemed to make some of the residents jealous of her. Judy was able to build friendships with some of the residents, however, and was invited to go to a beach party with them. On the bus trip to the beach, Judy was asked if she was keen to meet anyone. She said that she was, and was introduced to Don, who would later become her husband.

*Romance and Paternal Disableism*

Judy knew when she first saw Don that she wanted to marry him. Judy's father did not approve of the relationship, as she described in the following passage.

C: So you met (Don), and a romance bloomed from then?

J: Yes, and that's when my father became very harsh. He didn't want us to be together.

C: Why was that?

J: Oh, well, he didn't think we could cope. . . . I don't know, but he was very dead against it anyway.

This episode in Judy's life seemed critical in shaping her perceptions of her father, and may have been the source of dislike for her father that was evident, and seemed somewhat unjust, in her early stories. Through disapproving of Don, Judy's father seemed to be protecting his daughter in the only way he knew how, but, in doing so, he was questioning her competence to function in a marriage. Given Judy's strong wish for social connection, she was determined to not let her father end the relationship. Judy's aunty was pivotal in changing Judy's father's attitude.

C: Please tell me how you worked through that difficult time with your father.

J: Oh, (Don) just wore them down, and in the end I . . . supposed they knew I wasn't going to give him up. So . . . my aunty stepped in. I can always remember her going down. Dad was down in the shed, and she walked down there, and after that he changed his mind. So, I always forgot to ask her what she said to him, but she must've said something to him that changed his mind.



Although Judy described her aunty as “a lovely lady,” it did not seem that she was particularly close to her aunty. When I asked Judy to tell me about what she used to do with her aunty, Judy related how their families would go to each other’s homes for dinner, and that her aunty’s daughter was an only child as well. Nevertheless, her aunty’s actions contributed significantly to Judy and Don being allowed to marry. Judy still seemed bitter, however, that they did not get married sooner.

### *Gardening as Physical Activity*

During Judy’s 20s, up until when she was married at 28, she did little physical activity. Her inability to demonstrate competence at this type of activity, and her motivation to involve herself in other activities (e.g., socialising, work), seems to have contributed to her not engaging in physical activity.

After Judy and Don were married, Judy’s parents went overseas for 18 months, and Judy and Don sat house for them. Judy had done little physical activity in her third decade of life, but her activity levels had to increase while she and Don were looking after her parents’ home. Judy had to work on the upkeep of the garden. She viewed this gardening as sufficient physical activity to maintain her health.

### *Back Pain*

During about the last 30 years of Judy’s life, she has had problems with her back. Periodically, Judy would fall, and sometimes the fall would cause her back to become misaligned. These problems may have been reduced if she had been involved in more physical activity. Certain types of physical activity increase strength and endurance, and reduce a person’s susceptibility to falls. For months,

however, she had chiropractic treatment twice per week. Judy then met another chiropractor, with whom she made appointments when necessary. The second chiropractor's approach to making appointments left her feeling that she had been duped by the first chiropractor, who had made unnecessary appointments for her. She resolved that she would not be "strung along" again.

### *From Work to Caregiving to Happiness*

When Judy was 45, she left the bakery where she had worked her whole life, and became the caregiver for her sick father. With regard to her employment, the transition could not have come at a much better time. A week before Judy was to give notice her position was retrenched.

The transition was not enjoyable for Judy. She was leaving work she liked to take up a care-giving role that she did not perceive favourably. Judy's ambivalence towards her father came through when he asked her if he could live with her.

J: My father took ill, sick and he had to go to hospital and then he asked could he come and live with us. We didn't want him to live with us, but we couldn't say no.

Up until her father's death, three years later, Judy felt as though he was still controlling them. Judy's father did not like her and her husband going out for dinner, saying that it was a waste of money. Judy attributed her father's attitude to him growing up in the economic depression. Even so, she did not appreciate his criticism. The last six months of her father's life, however, were different. Following a stroke, Judy said she could talk to him more. In particular, Judy said she could openly discuss finances with him. Judy seemed to interpret this

experience with her father as a validation that she had achieved competence financially, and in a wider sense. Her father may not have provided her with the reinforcement she was seeking at various stages of her life. In the final stage of his life, however, Judy's father seemed to acknowledge his daughter's competence.

Toward the end of the interview, Judy remarked that she was much happier now than when she was at school. I asked her when did she start becoming happier. Initially, Judy said she became happy when she met Don. Judy then changed her mind.

C: That happiness. When did you start getting happy?

J: When I met him (Don).

C: I see.

J: Yeah, oh, not (when I met Don), really I suppose when my father died, and we didn't have anybody to account to, because even then he tried to, y'know, keep trying to control us.

Throughout her life, Judy felt that her father had control over her. This situation may be viewed as an Oedipal story. Judy's father may have never accepted that his daughter had married a man with cerebral palsy. His sister had to persuade him to allow Judy to marry the man with whom she was in love. Judy's father's control over his daughter could be seen as him performing the role of a husband, in place of a person whom he thought was inadequate to perform that role. Her father's death meant that she was now married to one man.

### *Gaining a Walking Frame: Losing Independence*

Aged 58, Judy could no longer walk without a walking frame, because she had trouble keeping her balance. She attributed the loss of balance to medication

she was prescribed for depression. At times in her life, Judy had become exhausted and wondered if what she was experiencing could be depression. Judy described these depressive episodes as being temporary (lasting about two hours), and resolvable through sleep. What Judy described, however, may be more symptomatic of excessive physical tiredness, than depression. Thinking she may have had depression, Judy educated herself about the illness, and then went and saw her doctor. The doctor agreed that Judy may have had depression, and prescribed medication to help her. Judy experienced an adverse reaction to the medication. In the following extract, Judy explained the effects of taking the medication.

J: Now I never forget that night, the night I took the first one. It was like a bolt locking in my brain from there to there, in there I could feel it locking. And nobody would ever believe this, but that's what it felt like. Anyway, after that I had to go on a walking stick, and then it just progressed, and I ended up on this (walking frame), but the thing is people reckon it couldn't last that long, but now that I've got the internet I can look it up, and they do say it can cause walking difficulties after you go off them. Well mine happened when I went on them.

Judy's loss of competence to walk without an aid translated to a loss of independence, and anger towards her doctor and Beyond Blue, an organisation that promotes issues relating to depression. Throughout her adult life she had typically gone grocery shopping on her own. Having a walking frame, however, meant that shopping independently was too difficult for her. Judy now had to rely on Don for assistance when going out of the house. She appears to have rationalised that the problems she was facing with walking were the result of her doctor and Beyond Blue not warning her of the potential side effects of taking the medication for depression.

C: So, how did it feel for you to lose that independence?

J: Very, very frustrated. Very, very annoyed. Very annoyed, I keep saying why, why, why (did this) have to happen? Because even lay people, like the doctor gave me those tablets that lay people said to me, but, but your nervous system couldn't take tablets like that. You should never have been on them. Anything (that) affects the central nervous system we shouldn't be on. And this is what I get mad about because Beyond Blue, you know, that depression place, you often hear things on the radio and TV about people who shouldn't take them, but they never mention cerebral palsy. Never mention it, and people don't know, well you didn't know.

C: No I didn't know.

J: No, and now you've got the internet. Every tablet you get you should check whether it attacks your central nervous system. I do. If the doctor gives me a tablet, I go straight to the internet and make sure it's not going to hurt me, because they don't seem to care. I know I shouldn't be saying all of this, but oh.

Although antidepressant medication can sometimes have temporary side effects, such as those that Judy described, it seems doubtful that one dose of such medication could have caused the loss of function that Judy experienced. A more plausible explanation is that her cerebral palsy adversely interacted more with the aging process, than with the medication she took. The medication became an explanation for the loss of function she was experiencing. Rather than blaming herself for the loss of function, she protected her ego by rationalising that the loss was the mistake of others.

Aside from Judy's loss of independence, this experience seemed to re-emphasise how isolated she was. That is, she felt that not even the doctor cared for her well-being. Instead of showing sadness, however, like she had when she reflected on her lack of caring family and friends, she displayed anger. As Judy had done on an occasion when she was speaking about her father, however, her

criticisms vanished on further probing. Following her comments above, I asked Judy about her experiences with medical practitioners. Judy replied that she had had good doctors, but they had given her the wrong tablets. This ambivalence resonated with how Judy spoke about her father. Although she liked her father, doctors, and chiropractors, she had strong negative feelings toward them.

### *Social Isolation at 60*

On occasions throughout the interview, the material of Judy's past caused her to reflect on her current social isolation. Although Judy was happily married, she lamented the near absence of social connections with family and friends. One such instance occurred when we were discussing her relationship with her aunty.

J: We just used to go for tea at her (Judy's aunty's) place and she'd come over to Mum and Dad's place. I saw quite a bit of my aunt and uncle and her daughter, yes. She was an only child too.

C: Were you similar in age?

J: Yeah . . . there was four of us, six months apart, and I was the baby. Yes, so we are all 60 at the moment. Yes, and I remembered their birthdays, and they didn't remember mine. I sent them cards, and I never got (anything). So, you know, I just don't know why.

A further instance was when Judy was telling me about her best friend, and I enquired whether she had other friends in her late adolescence.

J: I haven't got many other friends [laughs]. Our families don't seem to worry about us either [laughs]. . . . *You hear about disabled persons and people being very close to their families, and their families look after them.* Well our family don't, don't worry about us [laughs], oh well.

C: Why do you think this is?

J: Oh they've got their own lives. They can't be bothered with us, I s'pose. We're probably boring to them.

C: How do you feel about that?

J: Oh, I get upset about it. But there's nothing you can do about it.

This social isolation continues the patterns of isolation that occurred throughout Judy's life. The sentence I have italicised may offer some explanation for the social isolation that Judy experienced from her cousins. The expectation that Judy needed to be looked after, because she had cerebral palsy, may have been communicated to her cousins during their lives, and may have impaired the relationships between Judy and her cousins. Judy's cousins may have had to adopt caregiver roles with Judy, at times in their childhood, and did not wish to do so in adulthood. The passing of their parents (Judy's aunties and uncles), who were good to Judy, made it easier for them to remove Judy from their social lives.

#### *Physical Activity at 60*

The functional loss that Judy experienced over the previous two years of life translated into a decline in physical activity involvement. Judy had tried to walk up and down her street, but found that she got extremely tired doing this activity. Rather than interpreting that this tiredness was occurring because she lacked fitness, Judy concluded that walking in the street could not be helping her. Judy decided that performing housework was sufficient physical activity. She also limited herself in how much activity she conducted, because of her loss of balance.

#### *My Uneasiness with Judy*

My uneasiness with Judy, which I experienced during my interactions with her before we met, continued throughout the interview. On listening to the audiotape and reading the transcript, I realised I had probably conducted a better

interview than I thought. I was able to use my humour to good effect on a few occasions. I was also able to identify the comments and questions from Judy that made me feel like I was not doing a good job. During interviews, with other participants, I often ask about their experiences with cerebral palsy, even when I perceive that I understand what they are discussing, because I have had similar experiences. I do not wish to assume that another person's experiences of cerebral palsy are similar to my own. They may not be. Neither have I had some of the experiences that the participants talked about, so I needed them to elucidate what they went through. This issue was encountered with Judy. On a few occasions she seemed mystified as to why I would ask such questions, because I surely should know the answers. An example of an experience that we both have had was physiotherapy. I asked Judy about what she did in physiotherapy; she began to explain, and the following dialogue occurred.

J: . . . I kicked my legs and put my leg out and the physio, you know.

C: Yeah.

J: Haven't you done, you must've done physio too.

C: Yeah, I did a lot of physio.

J: So I s'pose we've all done the same physio.

C: Physio changes over the years.

J: Yes, I s'pose it does.

C: So it'd be quite interesting to hear what, what you did.



In this dialogue, Judy identified with me as a person with cerebral palsy. This identification made my question seem unnecessary to her. Once I had explained why I had asked the question (i.e., she had physiotherapy 30 years before I had), she continued with her response. A further example was in our discussion of callipers.

C: Wearing callipers is something I'm not familiar with.

J: Oh, you never had callipers?

C: No.

In this extract, Judy seemed surprised that I had not had the same experience as she did. I felt this interaction did not enhance our relationship. A final example arose when she was discussing how physical safety was not an issue on public transport when she was young, and that she did not travel on public transport nowadays for fear of being “bashed.” After Judy had referred to the risk of being “bashed” on a couple of occasions, I directly probed this issue.

J: You know, and you just never thought of being bashed or, not like now, you wouldn't dare do that (take public transport late in the evening) now.

C: Obviously your physical safety is something that you really think about now.

J: Oh, you do now. I wouldn't go by train anywhere now.

C: Yeah.

J: You don't care, you don't worry about it either.

The differences in life experiences may have also contributed to my uneasiness with Judy. On a number of variables she was my photographic negative. Broadly speaking, Judy was a female, 60-year-old adult who was physically inactive, socially isolated, and married, whereas I am a male, 28-year-old adult who is physically active, socially connected, and single. These factors may have made it difficult for Judy and me to relate. We shared a medical condition, and little else.

I think it is worthwhile to consider why participants agree to be involved in this type of life history research. Like so often in psychotherapy, I had to wait until our time was almost up before Judy revealed what I perceived was her motive for participating in the study. Just before I was to leave, I was standing in the lounge with Judy and her husband. I sensed that they were not just there to bid farewell, but had a question to ask. To help them, I told them that participants typically wanted to ask questions, usually about the research and how it is progressing, and I would do my best to answer any questions they had. Judy said that she and her husband had wondered if I had come across any other people with cerebral palsy who, like them, did not have many friends. In essence, they were hoping that I could introduce them to other people with cerebral palsy. The issue of social isolation that Judy was confronting as a 60-year-old, was the same issue she had been coping with for most of her life. An interesting parallel can be drawn between her looking for love as a 25-year-old and seeking friendship at aged 60. That is, she lacked competence to form relationships with people who were able-bodied, so she turned to look for relationships with people who have disabilities. Just as the doctor helped her to resume social development when she was

younger, by suggesting that Judy visit a residence for people with disabilities, Judy appeared to be looking to me to assist her. I was unable to assist her, however.

### *Summary and Reflections on Judy*

A recurrent issue throughout Judy's life was her difficulties in forming social relationships. Although Judy found pleasure in her relationships with her husband and best friend, she wished to be more socially connected. Judy's position, as an only child, in her family may have limited early opportunities to form relationships with children of similar age and to learn how to cooperate with others. More decisive, however, was the effect of Judy's cerebral palsy on her ability to form relationships. Many of the children with whom Judy had contact (e.g., next door and at school) socialised through playing physical games, in which she did not feel sufficiently competent to be involved. Judy's perception that she was not capable of being involved in these activities meant that she would be watching on the sidelines.

This separation from her peers continued at school, where she was, albeit willingly, excluded from physical activity. In the playground, she was again isolated, through withdrawing herself from play, which she perceived as being too rough for her to be involved. Being isolated meant that she did not develop social skills necessary to be involved in the social milieu of her age group.

In addition to social exclusion, Judy's difficulties with physical activity meant that she was asked to perform physiotherapy and to wear callipers. Although these interventions were designed to improve her competence at walking, she did not perceive she had improved. Both interventions meant that she

had to perform awkward movements, which she did not enjoy. These experiences of physical activity seemed to contribute to her not seeking out physical activities during the rest of her life.

Judy's efforts to become more socially connected were successful in her late adolescence and mid-20s, when she met her best friend and husband, respectively. Although Judy cherished these relationships, she seemed to still want to form relationships with others, just as she had in her early stages of development.

Judy's physical inactivity seemed to affect adversely her physical and functional health. For the last 30 years of her life, Judy had experienced back problems, as a result of falling over, and recent functional decline, which meant she used a walking frame. The impact of these issues on Judy's physical and psychosocial health may have been reduced if she had been involved in physical activity throughout her life.

### *Alana's Life History: Quest for Normalcy*

#### *Meeting Alana*

Alana was a participant in Study 1 of this research. The responses to the items in the questionnaire showed that she was minimally involved in physical activity. I sent her a letter, in which I asked her if she would like to participate in the present study. Alana telephoned me and offered her assistance. During the telephone call, Alana seemed enthusiastic about the research. We arranged a time to meet at her house.

I conducted the interview on a Friday afternoon. I arrived at Alana's house, and she greeted me at the front door. Her cerebral palsy affected the left

side of her body, which meant that her walking was somewhat slow and unsteady, with a gait that is characteristic of people with cerebral palsy. Alana guided me through a small lounge area to a dining table, where we sat for the interview. Sitting at the table, it was difficult to notice her condition, apart from her left arm and hand being distinctly atrophied, and affected by spasticity, as compared to her dominant side.

### *The Early Years*

Alana was walking by the age of five. Although she does not have many memories of the development of her walking, Alana said her mother worked with her to gain that ability. Walking was a challenge for Alana, but she was determined to succeed, especially given that other people did not think she could walk.

A: (Walking) was something that I guess not many people thought that I could do, and I'm the type of person that sort of says, "Stuff what society thinks, I'm going to do this, I'm going to walk."

Alana was able to walk when she started school. Her early schooling occurred in the late 1970s and early 1980s when the Government promoted segregation, rather than integration, of people with disabilities in the education system. This segregation meant that Alana attended a school for people with disabilities (special school) rather than a mainstream school. Alana's mother promoted her daughter's cause, however, and, at age six, Alana began to attend a mainstream primary school for half a day per week. For the other school days, Alana attended a special school. Full integration was gradual, with Alana increasing her attendance at the mainstream school from half a day per week to

three days per week over a three-year period. At the end of three years, Alana started full-time attendance at the primary school. This method of integration may have proceeded for educational and physical reasons, but may have impeded her social development.

Erikson (1985) noted that the latency period can be the most socially decisive stage of psychosocial development. It is in this stage where children can gain a sense of differential opportunities based on factors, such as race, parental background, or the fashion of their clothes. For Alana, her gait, her affected left side, and her part-time attendance at the mainstream school may have been factors that contributed to other children's perceptions that she was different. The experiences that Alana had with these children seemed to increase her sense of inferiority.

Alana's description of the difference between the special school and the mainstream school was dramatic. At the special school, Alana's cerebral palsy was not an issue for the people around her, because all the students had various types of physical and intellectual disabilities. This school was a safety net for Alana. In contrast, Alana's cerebral palsy made her look and feel different among the students, at the mainstream school, who were able-bodied. The next passage captures how difficult it was for Alana at the mainstream school.

A: I was being, sort of, put in something that was totally foreign and totally different, and I felt different. I think that was my biggest thing. I was in a classroom of able-bodied kids, and I felt different, whereas at (the special school) I didn't because everybody had some type of disability. And it wasn't like your disability was focused on, whereas for me it was like I was plucked out of something that was safe and fine and, y'know, warm fuzzies, and put into something that was *cold as hell*, and you were being stared at.

The words I have italicised were particularly hard for Alana to say. The memories of her primary school years generated a strong emotional reaction from Alana.

Adler (1932/1979) argued that defective organs may intensify feelings of inferiority. Alana's cerebral palsy contributed to her feelings of inadequacy in front of her classmates. One aspect of her condition that she particularly disliked was that she had to wear iron callipers to improve her walking.

C: Can you tell me what it was like to wear callipers?

A: The callipers that I started with were the iron callipers. They were iron bars, and they attached to my shoes, and I hated them. I hated them with a passion. . . . I hated them because of how they looked. I hated them because of how they made me look, and I hated them because people saw me, and the first thing they saw was the callipers not me as such. So I really didn't like my callipers at all.

A principal source of her hatred of her callipers came from how other children at school reacted to them. A number of older children, and Alana's own classmates, teased her for wearing callipers, and referred to her as "iron legs." Alana found this name-calling distressing, but had empathy for the children that teased her, because they did not understand why she was wearing callipers.

Alana's feelings of inferiority were reflected back, from the children to her, in the way they behaved towards her (i.e., stared at and teased). This behaviour served as confirmation that she was different and did not belong at the mainstream school. Alana's inferiority feelings and her classmates' behaviour meant that it was difficult for her to socialise with them.

On occasions, Alana's older sister became a powerful ally in helping her to cope with the teasing. Although a support group, including teachers and senior school management, had been established to assist with Alana's integration into the mainstream school, they were ineffective at dealing with the teasing issue. Alana did not have the self-esteem to cope with the children who were teasing her, and her older sister sometimes came to "save the day." Alana's sister was much taller than Alana, and was an imposing figure for the children who were teasing her. I shall discuss Alana's relationship with her older sister later in the case (see *Faster, Daddy, Faster*; *Happiness at High School*; and *Further Identification with Older Sister*).

#### *Faster, Daddy, Faster*

Being so restricted in her mobility, Alana could not experience what it was like to run fast. She was, however, able to enjoy what it is like to move fast in her father's hot rod.

- A: My (older) sister had had a go (with Dad in the hot rod), and she'd screamed the whole way. Didn't like it at all. Then it was decided that I should have a go, but it was decided that I would sit with a helmet on, on my dad's knee, and be strapped in. . . . I don't know what speed Dad was going but I looked at dad as we're going around, "faster daddy faster, faster daddy faster," and by the time that we'd got back to my mum, I didn't know what G-forces we were going or whatever, but the look on my face was just, it was just one of, y'know, freedom and yeah. I guess that's where I get my love of speed from.

In addition to the pleasure that Alana seemingly experienced from doing something (i.e., moving fast) that she could not do by herself, this extract encapsulates an Oedipal story about Alana's relationship with her father and touches on her ambivalence towards her older sister. Alana may have felt inferior



to her older sister, because her cerebral palsy restricted the activities she was capable of performing. In her father's hot rod, however, Alana was able to please her father through being involved in an activity that her older sister did not like doing. This experience may have been one of the few times when Alana gained a sense of superiority over her older sister.

### *Physical Activity at the Mainstream Primary School*

Alana's lack of competence at physical activities was highlighted in the schoolyard. In the playground, Alana would be the person on the end of the skipping rope, rather than the person skipping in the middle. The inability to interact physically with others equated to social exclusion.

A: I felt very alone during my primary school years, simply for the fact that I wasn't included in a basketball match, or I wasn't included in the chasey game, or whatever. And I guess being alone for me, during my primary school years, was quite prominent and quite hard to deal with.

In coping with the issue of social exclusion, Alana was also coming to terms with the permanence of her disability. Adler (1932/1979) suggested that children with organ inferiorities may reorganise themselves to avoid or eliminate the issue.

Alana perceived that people did not understand her disability, however, and she did not know how to overcome the challenges it presented. She did not know how she could not feel so alone, when social inclusion meant being physically active, and she had a disability that reduced her opportunities to be physically active.

Alana did not appear to have resolved these issues during her primary school years. She seemed to neither avoid nor eliminate her cerebral palsy, but was stalled in her development.

In organised physical activity, Alana would be given tasks to do on the sideline, rather than being involved with the other children. Alana saw her friends and classmates participating in the activities, and resented that she was not out there with them. Although she quickly became used to being on the sidelines, she did not enjoy this role.

Physical education at school often meant that Alana would be taken out of school to do physiotherapy. She hated physiotherapy, because it involved the painful stretching of her muscles. Alana perceived that her physiotherapists did not understand how much it hurt her and the pain was such that she either wanted to cry or lash out at somebody.

### *Finding Freedom Through De-emphasising Disability*

During her primary school years, Alana was able to replace her iron callipers with plastic splints. Although she changed from being called “iron legs,” to being named “plastic legs,” the effect of this change on Alana was profound. Alana felt less disabled wearing the clear plastic splints than she did when wearing the iron callipers. The splints were less visually obvious than the iron callipers, and she was now able to choose any type of shoe she wanted. Alana also did not have to buy shoes that were two sizes too big. Alana said that when she got rid of her iron callipers she found freedom.

C: You said you found freedom. Freedom in what sense?

A: Freedom in the fact that I could go into a shoe store [and] say mum I like those shoes. I couldn't pick any type of shoe, but I could pick a runner. That I didn't have to buy two sizes too big, because I had to fit the splint in it. I could buy just an average pair of runners and it's nice just to not have to think, “Oh, I've got my splints on,” y'know. To have to do that for the first time . . . the feeling is amazing. You don't have to worry about it if

you don't have to think . . . for me I found I didn't feel as disabled as a whole.

### *Increasing Normalcy: The End of Splints*

At 12 years of age, Alana had a hamstring tendon release to lengthen her muscles. Prior to the operation, her walking became progressively worse, with her stature being lower to the ground and her knees coming together when she walked. Alana also had pain in her legs. One positive aspect of the hamstring release operation was that she no longer had to wear splints. This prospect excited Alana, because, like when she was able to give up her iron callipers, she felt as if she was less disabled without them.

Following the operation, Alana took 18 months to recover, due to her not regularly completing the prescribed rehabilitation exercises. Alana attributed this lack of motivation to not realising how important it was for her to perform these exercises. Alana's experiences of physiotherapy, however, may have been a factor of greater significance in her lack of motivation. Like the physiotherapy she did in earlier times of her life, performing the exercises was painful.

C: Can you give me a sense of what it was like to do those exercises?

A: Then I felt like it was a chore 'cos I'd go to physio, and I'd cry because of the pain I was in, and the stretches I was doing. So I guess that was a big factor. The fact that I knew my physio would cause me pain, so I just wouldn't do it. Yeah, so that was big.

Alana's younger brother helped her to cope with the pain of the exercises following the operation. She did exercises in the morning, before she went to

school, and her younger brother would help her by distracting her from the pain of the exercises. Alana was extremely grateful for what her brother did for her.

A: I'd often, y'know, lie there and cry, because it was hurting so much. (My brother) has a very wacky sense of humour. Extremely wacky, in fact. So I would often ask him to sit next to me and just make me laugh while I was doing these exercises, which he did just by being himself. Saying, cracking jokes or whatever, and it worked, y'know. I wouldn't concentrate on the pain, I'd concentrate on laughing, and I'd laughed so much that it'd hurt!

Few of Alana's stories featured her brother. She was closest to her older sister, but seemed to have a strong relationship with her brother. Although they did not do many activities together, it seemed that they could call on each other at any time.

### *Happiness at High School*

The transition from primary school to high school was a lot smoother than from the school for people with disabilities to the mainstream primary school.

Alana attributed the difference to her greater ability to articulate her needs to school staff.

During Alana's first year at high school, she got her first electric wheelchair. This event was significant in her life, because she gained greater mobility. That is, she gained competence at being physically able to keep up with her peers. Although she may have lost self-esteem in her ability to walk, this loss seems to have been more than compensated for by the added mobility she received from her wheelchair. In essence, Alana viewed the wheelchair as a positive alternative to walking. These two brief extracts reflect this interpretation.

A: I got my first electric wheel chair back in high school . . . finally I'd found my legs, as such.

A: I love my wheelchair. I love my freedom. I love being able just pick up the keys and drive.

In Adler's (1933/1979a) terms, Alana's experience may be understood in terms of her striving for the goal of perfection in physically keeping up with others.

Although not the primary force of Alana's strivings, feelings of inferiority, with regard to her mobility, may have provided impetus for these strivings. The freedom Alana mentions in the second extract seemed a reflection of the freedom she found in her father's hot rod when she was younger. Driving fast in her wheelchair was compensatory for the lack of ability to run fast.

Alana's quest for what she perceived as normalcy continued at high school. In her maths class, she did not have an integration aid (i.e., a person to assist her with work in class). Having an integration aid in other classes, meant that she had higher productivity, but precluded her from misbehaving with fellow students. Alana perceived misbehaving in class as a normal teenage activity, and maths was the only class where she could engage in this behaviour. In the next quote, Alana described her behaviour in maths class and her motivation.

A: We wouldn't concentrate on what was going on in class. We'd sit there and pass notes to each other.

C: So what motivated a maths rebellion?

A: I guess what motivated it (is a) good question. Because of my disability there are only certain things I could do and also because I had generally an integration aid in class. I couldn't get away with anything. I had to sit there and concentrate, but during some maths periods I didn't have an integration aid, so I'd be there sitting there on my own, and I'd be sitting next to my friend and, y'know, you'd sit there and pass notes to each other. So, y'know, I wouldn't get much maths done, but I'd have to go

home and do it all at home, but, y'know, I think in that regard, that really became for me a normal teenage type of thing. Not that I was rebellious in any way, but 'cos we never got caught.

As is evident from this example, high school was different from primary school in that Alana had friends. Whereas at primary school social inclusion was associated with physical ability, this relationship was not as strong at high school. Alana could be socially included without being physically active. The new social environment of high school (i.e., deemphasizing physical ability) meant that she did not have to resolve the issues relating to her disability that had been too daunting for her at primary school. Alana developed a friendship with a girl, which she still enjoyed when I met her. Alana and her friend had similar interests, and at school they used to sit together and talk. Holding conversations was something that Alana could do in the breaks during the day at high school, as opposed to the physical activities in which her primary school peers were engaged. Alana related that, to her friends, her disability was not an issue for them. They had accepted Alana for who she was.

A: They're cool with it. They help me through it, y'know, and the stick or the wheelchair or the whatever, they don't see that, they see me, which is what I want in life. I don't want people to see the stick or the wheelchair. I want them to see me, and with my friends it's like that, and that's why I'm so comfortable with them I think, yeah.

In hearing these stories I gained a sense that Alana was becoming increasingly comfortable with herself. At a stage of life when individuals face the conflict of identity versus role confusion (Erikson, 1985), Alana perceived her cerebral palsy to be part of her personality. Her friends and family reinforced this process

through their acceptance and love of her. Alana was becoming proud of who she was and wished other people in the community would be accepting of her for what she had to offer.

Although the earlier story of passing notes in class helped Alana to feel more like her peers, the activity had added meaning. After I had reflected back to Alana that she seemed pretty proud of never being caught passing notes, she revealed that, in this respect, she was better than her older sister.

C: You seem pretty proud of that.

A: Yeah I am [laughs], because my older sister used to get caught.

C: So you were one up on your sister.

A: Ooh yeah.

Alana's feelings towards her older sister were slightly ambivalent. For the most part, Alana strongly identified with her older sister. At high school, her older sister was involved in sport and physical activities. This next quote captures Alana's identification with her older sister.

A: My (older) sister, as a kid, was very involved in the local basketball club, and so I'd, y'know, muck around with (her) on the front lawn or out the front in the carport. But I could never get out there and enjoy a game because I wasn't physically fast enough, y'know. (My older sister), as a kid, often had roller skates. I would run up and down the driveway with my callipers on and (later) with my (splints) on and I'd pretend that I was skating, but I knew that I could never skate because I didn't have the balance or the co-ordination. (My older sister's) very fit, very athletic, so, *I guess she's all the things that I wanted to be but couldn't* [hurt laugh]. You get that.

Alana's identification with her older sister manifested itself in her involvement with the physical activities of her sister. The words I have italicised suggested that Alana wanted to "be" her sister. The closeness of their relationship was demonstrated in the older sister's inclusion of Alana in the physical activities she performed. With basketball, knowing that Alana could not play with her on court, the older sister said to Alana that she could head her cheer squad and mind her bag. These gestures made Alana feel important. Although Alana was once again on the sidelines, which she had not enjoyed at primary school with other children, her level of identification with her older sister made the situation easier for Alana.

### *Physical Activity and High School*

For Alana, physical activity at school still meant exclusion from her classmates. Alana was recovering from her hamstring-release surgery at the start of high school, and had further surgery during her second year. Physical education lessons meant, once again, that her mother would take her from school for physiotherapy sessions.

Alana's second operation was required to correct her left foot, because she was walking on its outside edge. To improve her walking, the ankle was broken and fused, so that the sole of the foot was flat to the ground. This surgery benefited Alana functionally, and it also helped to improve her self-concept. Alana was not as self-conscious about her feet following this surgery as she had been before the operation on her foot.

A: To actually take that first step and realise, "Hey, my foot is on the ground!" I thought that was huge.

C: So did your walking become easier?



A: Yeah, I could walk as normally as possible. . . . and, oh, I wasn't as self-conscious of my feet. Yeah, I mean it looks different now, but that's because it's had surgery. So, y'know, it's just part of growing up.

### *Finding Love*

Alana did not seem to face the difficulties of finding a life partner that many people with cerebral palsy face (Shuttleworth, 2000). She met her future partner, Joe, when she was eight, and he was 18, and they were friends for the first decade of their relationship. Given the age difference, Alana's mother and father did not mind that they were friends, but did not want the relationship to go past the friendship stage. These views, however, were not expressed to Alana. Possibly, her parents also did not want their daughter dating someone with a disability. Joe had an acquired brain injury, which manifests, predominantly, as a difficulty in transferring information from short-term memory into long-term memory. Here, Alana described her transition from perceiving Joe as a friend, to perceiving him as a potential partner.

A: So we kept it just at friends for a long time. Then I guess at 16, for me, I started having these thoughts, "Oh shit, (Joe's) attractive." I just looked at him one day and thought, "Man you're a fox." Didn't say that to him at the time.

When Alana was 17, they started dating. Falling in love during adolescence is one way in which identities are clarified (Erikson, 1985). Adolescents sometimes project an image of their ego onto their love interest and see it reflected back. For Alana, she seemed to have projected an image of a person with a disability, rather than that of a disabled person, and saw that image reflected back. Her friends accepted her for who she was (see *Happiness at High School*), and so did Joe.

A: Y'know, what (Joe) sees is he sees me as I am, but he doesn't see the disability, the stick, the wheelchair. He doesn't see any of that. He just knows that that's an extension of me, that I need that to function.

Dating typically involved spending time at each other's houses, or meeting at a local shopping centre for lunch, or a movie. I explore their relationship further later in the life history (see *Getting Married, Studying Disability – Personal Interest and Activism Reasons, A Marriage of Prejudices*).

#### *First Job: The Ups and Downs*

Alana, at 17 years of age, left school to take up a position as a receptionist. This event was huge in Alana's life. Alana stated the importance of catching public transport to and from work everyday, and her first pay cheque. In essence, like with achievements in her past, Alana's excitement seemed to be grounded in the further achievement of normalcy.

Alana's development was arrested, however, when she began having seizures. She had had epilepsy in her childhood, but she had been free of seizures for the previous 10 years, and had not been required to take medication. Workplace relationships soured, with her managers not happy to have someone on the front desk who could have a seizure, and who got messages wrong. Her managers were not prepared to accommodate her with her health issues, and she left the organisation after about 18 months of employment.

Following the termination of her employment, Alana launched what she referred to as one of the biggest battles of her life, to control her epilepsy. She went through tests at hospital to diagnose what kind of epilepsy she had. Her seizures were different from those that she had experienced in childhood. With the

loss of employment and the diagnosis of epilepsy, Alana became depressed. She felt that the world did not want her, and she was not good enough. In the following extract, Alana described her depression.

A: I guess depression, for me, was like I was in this big black hole, and I was getting further and further and further down into this big black hole, and I couldn't get out. I couldn't climb it, and that for me was just horrible because I was getting more and more and more despondent and depressed and you know my mum didn't, my family didn't know what to do 'cos I was still living at home at that stage. In the end I went to my doctor and I said, "Look, I think I've got depression, this is what's happening, I need to hear it [pause] for it to become real, and for us to do something about it. I need you to validate what I'm going through."

As highlighted in this extract, Alana had to cope with not only the depression, but also her family's reaction to her depression. Alana's father, in particular, did not understand depression and was against his daughter taking the prescribed antidepressant medication. Because her family did not understand what Alana was experiencing, they could not provide the support she needed. To treat the depression, Alana took medication for six months, and undertook counselling once a week, for 18 months.

Basch's (1988) conceptualisation of depression may be most applicable in Alana's case. According to Basch, there are several aetiological features of depression, including the self system's inability to mobilise resources to cope with a given stress; the retreat of the self system to a lower level of functioning; and the communication to the outside world that the self system is not operating to the same degree that it once was, and cannot be relied upon, and that help is needed from others. Alana was treated pharmacologically and psychotherapeutically, which, using Basch's typology, suggested that she had both forms of clinical

depression (i.e., endogenous and exogenous). The counselling that Alana undertook appeared to enter Basch's developmental spiral at the self-esteem stage. Alana seemed to have a poor self-concept, which may have been based on her beliefs about what it was to be normal. The material that Alana told me she had discussed with her counsellor was not only her inability to hold down a job, but went back to lost opportunities to do activities that were typical among her peers (e.g., running and playing games, working a part-time job during high school).

One such issue was that Alana never had a part-time job at high school. Getting a job was never discussed with her parents, but she sensed that they did not perceive that she would be able to get a part-time job. The lack of a part-time job not only meant that Alana remained financially dependent on her parents, but also delayed her development and explained the significance of getting her first job.

*The Mask of Normalcy: Alana and Her Parents*

Alana spoke about her parents with a lot of love. She acknowledged that her achievements would not have been possible without their support. Perhaps most importantly, in Alana's view, they had raised her as a normal child.

A: I've been pretty fortunate in that I was brought up pretty what I consider normal. My family and my parents never excluded me from anything. Sure there were things I couldn't do growing up, but I was given every opportunity to excel and to extend myself, and, you know, I was included in everything.

The key word in the first sentence is "pretty." Although Alana's parents cared for her similarly to their other children, there were times when her disability seemed to influence how they treated her. For example, Alana's parents were sometimes

overprotective of her. Alana described how she did not have the same opportunities to go out with friends, because she was reliant on her parents for transportation and they sometimes stopped her plans. A further example is that of Alana perceiving that her parents would not allow her to get a part-time job. Alana's dependence on her parents seemed to mean that she often did what made them happy. This next dialogue captures how Alana related to her parents.

C: Can you tell me a bit about your Dad?

A: About my Dad, where do I begin? What do you want to know?

C: Begin wherever you like.

A: Okay, Dad's worked in the engineering industry for all of his life. In fact, Dad and I, I guess we had the normal father daughter relationship.

C: Which means what for you?

A: For me it meant a lot more protection, a lot more "(Alana) don't do this because we don't want you to." Y'know, but it also meant, for me, that pleasing mum and dad meant doing what they wanted, particularly when I was young.

Although I started off asking Alana about her father, she told me something superficial about him, and then moved on to talk about both her parents. Alana felt that her father was always there when she needed him. Alana's father's assistance, however, seemed to be physical, rather than emotional. Her father's apparent discomfort with emotional issues was evident in his lack of support when Alana was depressed (see *First Job – The Ups and Downs*) and in his relating to her after her marriage (see *Post- Wedding – An Oedipal Story*). Perhaps Alana's father was supporting his daughter in the only ways he knew how (e.g., physically), rather than in other ways (e.g., emotionally).

Alana's mother was her main source of support throughout childhood and adolescence. The examples of her helping Alana to walk, advocating for her inclusion in the mainstream school system, and driving her to physiotherapy appointments have already been mentioned. At home, Alana's mother had her do chores, like her siblings. She was given tasks that she was capable of performing. These chores helped to increase Alana's feelings of normalcy.

### *Gaining Competence through Voluntary Work*

Aged 18, and receiving treatment for depression and epilepsy, Alana's vocational development continued when she began volunteer work at a local retirement village, on one day per week, and at a local primary school, on two days per week. Through performing this work effectively, she was able to demonstrate competence. In the retirement village, Alana helped to run a programme for the residents, and, in the primary school, she ran a reading programme for one of the teachers. Alana's self-esteem was enhanced through the positive feedback she received from the people around her and through reflection on her ability to perform these jobs.

A: (The work) became invaluable. It gave me a sense of purpose again. It gave me reason to get up in the morning

### *Second Job: Returning Home*

Aged 22, Alana got employed in the office of the high school she attended as a student. This environment was comfortable for Alana.

A: That was like coming home, y'know. I knew everybody, and I knew the corridors, I knew how to get around. I knew where everything was,

y'know, that was like going home because, yeah, I didn't feel foreign. I mean, I did because I was ten years older, and I had to call my teachers that had taught me in Year 11 by their first name or something, so that felt weird. But, as for everything else, it was just like I was home, you know.

Alana's second job seemed a good progression from her voluntary work. Gaining employment at the high school meant that she did not have to re-fight old battles to achieve normalcy. She was working with people who already knew her, albeit as a student, rather than a work colleague. Alana was gaining self-esteem through demonstrating competence in paid employment.

The beginning of the job was not without difficulties, however. Alana had got this job through an employment agency, and her consultant had certain expectations regarding how Alana should present herself. One of these expectations was that she should wear stilettos to work. Alana had never worn high-heeled shoes before, and her employer, the school, did not expect her to wear such shoes.

Alana was employed for two years, before she had to leave due to ill health. In this job, Alana spent a lot of her time looking at a computer screen, and she said that the flickering screen had triggered more epileptic seizures. She spent the next 18 months visiting hospital and trying certain medications to control her epilepsy.

### *Getting Married*

At age 24, Alana got engaged to Joe. The engagement was a significant factor in diminishing Alana's depression, which was still present. The following was how Alana described how she changed after she got engaged.

A: That shifted my focus totally from myself to suddenly (being) alive with someone who I loved and cared about, and who loved me and respected me for who I was, right then right there.

The, at least partial, alleviation of Alana's depression may be attributable to Joe entering the developmental spiral (Basch, 1988) at the self-esteem stage. Against a background of situations in which Alana was unable to show competence, with accompanying lowering of self-esteem, was her fiancé who accepted her for who she was. This acceptance and love seemed to have increased her self-esteem and to have reduced her depression.

Six weeks before her wedding, Alana had another seizure, which she attributed to the stress involved with organising her wedding. Stress seemed to be a common element that was evident in all her seizures in her adult life. I queried whether stress may have caused her previous seizures as well.

C: Do you think stress caused the seizures at work?

A: Definitely, definitely, because my bosses were making sure that I'd perform and they wanted me to perform. So then my body was saying, "Hey, hang on a second, maybe we can't," and me being me, I didn't want to give up, so I didn't, right until the last second.

Given the significance of Alana's first job to her, it is understandable that she persevered, and tried to suppress the messages she was receiving from her body. To accept that the job was too stressful for her would be to acknowledge that she was not competent to perform that role, which meant that she also was not normal.



*Post-Wedding: An Oedipal Story*

Three weeks after Alana was married, she received a phone call from her father. Such behaviour was rare for her father. The following extract was how Alana described the phone call.

A: I'll never forget it. We'd been married three weeks, and we were home. We were here, it was a Sunday afternoon, and the phone rings, and it's my dad. I knew something was up, because my dad never picks up the phone for a chat. I got to the phone, and it was just my dad ringing me to tell me that he'd missed me. That bowled me over. Because my dad's the type of guy that doesn't do that for a start, but the fact that he did it and that he wanted to see me, even if it was for just a cup of coffee, meant a lot. Because it meant that, y'know, he'd realized and accepted that I moved on with my life. My family think that (Joe) is just wonderful.

From the perspectives of both Alana and her father, this seemed an Oedipal story.

Alana's father missed having his daughter close by, and Alana was still seeking love and approval from her father. The last sentence stands out, because the feelings of her family members towards her husband were in contrast to how they initially viewed the relationship. Alana's parents initially did not want their relationship to be more than a friendship. Although, as I have stated, the age difference could have been a source of concern for Alana's parents, Joe's disability could also have been a concern. Alana choosing a person with a disability to marry may have forced her parents to confront their disableism.

For Alana, the need for love from her parents was still important. The significance of her father's phone call was that it sent the message that she still was wanted. As she had done throughout her life, Alana was still trying to please her parents.

### *Returning to Education*

A year after she was married, Alana returned to education. The structure of the education system in Australia meant that she had to complete the equivalent of a final year of high school (Year 12) before she could do tertiary study. She did this Year 12 study part time, over two years, at a Technical and Further Education (TAFE) institution (TAFE institutions are non-university tertiary education providers). Graduating from this course was momentous for Alana.

A: I did that part time and graduating from that was one of the biggest thrills of my life, because a lot of people when I was young said, “Oh, I won’t be able to do it. It’d be too hard,” all those type of things, and the fact that I went and did it, and (that) I got a certificate to prove it is huge.

Graduating represented public recognition of her competence at the knowledge and skills incorporated in the Year-12 course. She had demonstrated to everyone that she was able to achieve at the same levels as her able-bodied peers.

Graduating seemed to have also increased her self-esteem to do academic study, and may have contributed to her decision to continue studying (see *Studying Disability – Personal Interest and Activism Reasons*).

Studying the Year-12 course also gave Alana an opportunity to increase her independence. When she was in high school, her mother would advocate for her needs to school staff, to ensure that her daughter had the necessary assistance to perform schoolwork effectively. At TAFE, however, Alana had to articulate her needs to the staff of the disability unit operating within the TAFE. She did this successfully, which seems to have contributed to her feelings of competence as a student.

### *Lack of Physical Activity and Functional Decline*

Throughout her 20s, Alana was not involved in much physical activity, and experienced functional decline. Whereas in her childhood and adolescence Alana was involved in physiotherapy, she did not continue these treatments into the next decade of her life. Although she sometimes thought about being involved in physical activity, she did not have the competence to participate, nor the self-esteem to seek out the advice of people who could help her gain competence. This lack of self-esteem seemed to stem from her inability to show competence with physical activity as a child.

C: Were you involved in any physical activity?

A: No, and for the simple reason that I didn't know what was around. I didn't know what I could do. I didn't know what was accessible, or not, so I just didn't do anything. But it wasn't like I didn't want, y'know, I sort of thought occasionally it'd be nice to go to the gym, or do a workout of some sort, but I didn't know what was around. So I guess really, I'd need to go to a gym that was supportive, but that had people on hand that knew how to design a program for a person with CP, and that knew what they were doing, not pretended to know what they were doing, y'know, and I actually haven't found that yet. So, if you know of anywhere around here, let me know.

This extract illustrated Alana's lack of self-esteem with physical activity. I interpreted the final sentence as a request for help. To assist Alana, I offered to send her information about exercise prescription for people with cerebral palsy (Laskin, 2003), and to schedule a time for her to meet with a personal trainer and I, to explore what she could do in the gym environment. Alana accepted this offer (see *An Exercise Intervention*).

About a year after Alana was married, she was experiencing pain in the quadriceps muscles, and was finding it difficult to stand for long periods of time. In the next extract, Alana described the extent of the functional decline.

- A: It got to the point where I could hardly walk. Even cooking a meal was a challenge. So, y'know, we were eating out a lot, which I didn't mind, but y'know, I'd just cook whatever I could get my hands on, whether it'd be one of those freezer meals or, y'know, whatever. (Joe) didn't seem to mind, but I knew that I could cook. So I knew that I was deteriorating further . . .
- C: Can you tell me how it felt?
- A: Well I just, I felt awful, y'know. Not only was I in pain, I had to deal with the emotions of, "Oh my goodness, I'm getting worse, I don't know what to do, and so I just won't say anything," make everything seem okay.

Alana used denial to cope with the functional decline. She did not understand why her walking was becoming progressively more difficult, and had resolved that it was something she had to put up with. Such was her denial that Alana took two and a half years to tell her mother of the trouble she was experiencing.

#### *Studying Disability: Personal Interest and Activism Reasons*

Following the completion of the Year-12 course, Alana enrolled in a disability studies course. Her motives for studying disability were both personal and activist. With regards to personal motives, Alana was able to study about herself as a person with cerebral palsy. One aspect that she greatly benefited from was obtaining resources about disability and sexual functioning. Alana expressed her frustration with not easily being able to access information on this topic.

- A: I guess when it comes to intimate stuff if you like that was also very hard cause there's very little literature around for people who have disabilities.

You can't go into (a well-known book shop) and pluck a book off the shelf about the, "How to's," if you've got a disability. Try to do it. It's impossible.

Alana benefited from her course through one of the class's excursions to a family planning clinic. It was here that she found an entire section of material devoted to disability and sexual intimacy. In this quote, Alana described what happened.

A: I walked away from that excursion thinking I'm going to come back here on my own, y'know, go on my own time, chat to somebody, make an appointment, and yeah I did and it was probably the most helpful hour that I've ever had.

Alana obtained information from the staff at the clinic. She has used this information with her husband and said they were gaining more enjoyment from physical intimacy.

The activism motives for studying disability were born from the perceived inequalities that Alana and her husband have encountered as people with disabilities. Alana had strong opinions about the lack of support that the government gave to people with disabilities. She did not want to be a politician, but would like to be an advocate for people with disabilities.

A: We (Alana and Joe) often find that together and separately we're fighting for our rights, and, y'know, if the world's not fair, we've got to fight for that, and I guess I'm sick of people saying, "No, there's not enough funding." That's a phrase that I don't like. So, basically, I just want to get more equality for people with disabilities, more funding, more help, and, I figure, who better to do that than somebody who knows first hand.

When discussing the need for someone to advocate for people with disabilities, Alana's frustration with being treated as someone who was inferior came through.

In her adolescence, Alana had come to terms with her cerebral palsy. Although she had addressed the feelings of inferiority that were strong in childhood, she now was facing other people who saw her as inferior. This next quote further explains why she chose to study disability and how she feels people in the community treated her.

A: I'm there simply because I guess I'm sick of being put on the bottom of the pile, you know. I want to be up there. I want to have my voice heard not just for me, but for everybody.

An example of what frustrated Alana, was when she was shopping in her wheelchair, during the sales in the city, and people did not see her coming, and, consequently, did not move out of her way to let her past. Although many people have difficulties negotiating their ways through crowds of people, Alana's description of what happens when she is in her wheelchair suggested that she was invisible to many in a crowd. Her lack of height, because she is seated, might have meant that she was not treated as an adult.

Alana's activism behaviour was manifested in how she communicated with people who were standing in her way. Most people were apologetic when they were asked to move out of the way. It seems that they genuinely did not perceive that they were impeding Alana's progress. Some people even engaged Alana in conversation about her wheelchair and how fast it could travel. She relished the opportunity to educate people about what it was like to use a wheelchair, and other aspects of having a disability. Alana did not blame people for not knowing how to behave with people who had disabilities, but highlighted the need for people to be educated about disability issues.

Alana's desire to educate others about disability and her experiences of having a disability extended into the realm of public speaking. When I met her, she was undertaking a Toast Masters programme, and was enjoying relating stories of what it was like to have a disability. In essence, Alana's wish to educate others through telling her own story was probably a central reason why she consented to being part of the present research. My research may have represented a vehicle by which she perceived that she could educate others about what it was like to have a disability.

### *A Marriage of Prejudices*

The difficulty that Alana had finding material on sex and disability was part of a wider issue of prejudice that Alana and her husband faced. The way in which some people viewed her marriage was a source of worry for Alana.

A: This is going to sound strange, society (a) thinks it's strange that I'm married 'cos I've got a disability, and (b) they think it's even more strange that I'm married to someone with a disability. So you've got a double stereotype happening and when, I guess, the average normal Joe in the street won't or can't imagine two disabled people being married, let alone two disabled people having sexual intercourse. Y'know, that's weird to them. Except, y'know, (my husband) and I are like any other normal couple.

Alana appeared to have received the message, indirectly, from a range of sources that her marriage to a person with a disability, and their sexual lives were unusual and, possibly, distasteful. Alana did not provide any direct examples, but the effort she was required to exert to find material on sex for people with disabilities probably sent a message that it was not typical for people with disabilities to experience sexual intimacy. Alana viewed sexual intimacy as a healthy part of her

relationship with her husband, and was dismayed that some people may have thought otherwise.

More direct examples of how Alana and Joe were treated when they went out together come from when they ate out. One of the manifestations of Joe's condition was that he had accelerated speech, which meant that some people ignored him. In restaurants, some waitresses did not acknowledge his presence, and spoke solely to Alana. The reverse had happened as well (i.e., waitresses acknowledging Joe but not her) when Alana had been in her wheelchair. A further example of Alana's activism was when waitresses ignored her husband.

A: I guess that's where your education comes in, and it's just by saying something simple like, "Oh, (Joe) can order for himself" or he might tell me what he wants, and then I'll order if he's not comfortable with it.

#### *Further Identification with Older Sister*

Two years ago, Alana's older sister gave birth to her first child. Although Alana can have children, when I interviewed her she had no plans to do so in the near future. Alana was able, however, to experience pregnancy and having a child vicariously through her sister. Alana's older sister included her in her prenatal activities, which Alana appreciated. Alana had a photo of the child in her lounge and spoke fondly of her.

A: I just have this great relationship, y'know, great bond. She knows who Aunty Alana is, and that, to me, is very important

This story was reminiscent of Alana's involvement with her sister in basketball.

Alana was on the sidelines during the game, and may have also placed herself on



the sidelines when it came to motherhood. Through her identification with her older sister, however, Alana was enjoying the experience of what it was like to be a mother.

*Continuing Depression: Further Denial*

Alana continued to experience depression throughout her 20s. The previous year had been tough for Alana, with two deaths in her family. These experiences had intensified her depression. When I interviewed her, she felt that she was starting to feel well again after this most recent depressive episode. Alana was aware of the effect of her depression on her family and friends.

A: With a great GP (general practitioner) and good people around me to support me, I'm not letting depression ruin my life, that's for sure, because I can't, y'know. If I'm no good then my marriage suffers, then (Joe) suffers, then my friends suffer, so I've got to be good so that everything else is okay.

C: It sounds like you think of other people a lot.

A: Yeah, I do. I tend to think of how things are going to affect (Joe) before I think of how it's going to affect me. So, y'know, that's a classic example. So, yeah, but that's just how I am, just my personality I guess.

Alana seemed to be suppressing her depression when speaking with family and friends, so that they would not be concerned about her. This method of coping was reminiscent of how she adapted to her decline in function.

In these two instances, Alana was reluctant to tell family and friends of quite debilitating health issues: premature functional decline and depression. The reason for her suppression may stem from childhood experiences. Alana was the second of four children, and in this next dialogue she gave her perceptions of what

it may have been like for the two youngest siblings to grow up with a sister who needed extra parental attention because of her cerebral palsy.

A: I think, I don't know, but I think growing up for them (the younger siblings) may have been a bit more difficult, because I was sort of second in line and I needed all this attention, treatment the whole thing. They've never actually said it, but, y'know, you sometimes can't help but wonder, but yeah.

C: So how does that make you feel?

A: I don't know, sometimes, I try not to let it get me down, but there is sometimes you can't help but think about it, and we've never actually sat down and had a full on discussion about it. I don't think it's necessary, but, y'know, things sort of come up.

C: So how do you feel about those times?

A: I guess I can't help but feel a bit [pause] I don't know, guilty would be the word, because I needed a physio for treatment for care, and all of that to get me going and to, y'know. I guess you can't help but wonder how they would feel, and I've never actually said to them, "How did that make you feel?" But it's never come up. I don't think it will, because now that we're older, and, whatever I think, they realise what the treatment was for.

A degree of ambivalence, about the extra care she was given, is captured in this passage. Alana could rationalise her need for greater attention from her mother, than what her younger siblings received, through her having cerebral palsy. She harboured guilt, however, that she needed that care. The deep emotion that Alana felt can be seen from how hard it was for her to respond to my question about how she felt about having extra care. The first time I asked the question, she said that she did not know, and avoided the question. The second time I asked her, she took time to say that she felt guilty, and then quickly rationalised her need for extra care again. It may be these feelings of guilt that, possibly unconsciously,

contributed to Alana's decisions not to tell her mother about her functional loss, and not to tell family and friends about her continuing depression.

Corroborating evidence comes from how Alana described her relationships with her two younger siblings. Stories that included Alana's older sister occurred throughout the interview, and were mostly unsolicited by me. In contrast, Alana did not tell me any stories about her younger siblings until I asked her to talk about them towards the end of the interview. It was clear, however, that she loved her younger siblings, as is demonstrated in the following extract.

A: Y'know, their love and support, and their being there, y'know. Just made, y'know, life like any other normal kid. Just made it part of the family.

At least part of why she loved her younger siblings was that they helped her to achieve normalcy to a greater extent. The extent of Alana's love, however, did not seem to be reciprocated on the part of her younger siblings, especially her younger sister. The next dialogue embodies how Alana perceived her relationship with her younger sister.

A: So we don't really communicate that much, except on, say, family occasions or whatever, and that sometimes is hard to deal with for me, but I've just got to learn to accept that, and, y'know, some days it's harder than others.

C: Do you think it's hard for her as well?

A: I think so, I think, I hope it's hard for her as it is for me, but she's never actually said to me, "Hey sis, we need to sit down, we need to work this out." I've wanted to, I've even approached her about it, but she's always been too busy, which for me is code for, "I don't want to deal with this now," and that's just how she is.

Alana and her sister were not emotionally close when they were younger. They were involved in different activities. Alana loved her younger sister, however, and wanted to be close to her. It seems that Alana's younger sister had continued with her life, however, and may not have had the same need to reconcile her differences with Alana.

*Restoration of Function: Walking for Graduation*

Last year, the decline in function was arrested pharmacologically. When seeing her neurologist about her epilepsy, Alana mentioned the issue she had with her walking. The neurologist informed Alana that the muscles that were causing her trouble could be treated with botulinum toxin.

Alana was frustrated because she did not receive information regarding what to expect from the treatment. She did not know how the botulinum toxin would affect her body, and how much rehabilitation she would need to go through. Alana was also disappointed with the doctor who administered the treatment. His bedside manner was poor, and he spoke as though she was not in the room.

Alana had to have physiotherapy once per week for six months. She was motivated to comply with her physiotherapy treatment, because she had a goal of being able to walk at her graduation. This goal was a further example of her efforts to achieve normalcy.

C: What did that mean to you, to be able to walk at graduation?

A: It just meant the world. I was standing there. I was walking. I didn't want people to see me in my chair, even though my friends at school and my lecturers and all of that wouldn't have cared, because they were all cool with that. To me, it was just important to be able to walk, because I hadn't

done it for so long. And because the room was packed with people, I just wanted to be able to walk. I actually became obsessed with it. Yeah, because it was like I have to do this. I haven't done this for so long. I just have to do this.

C: Why did you have to do it?

A: I guess because I hadn't walked for so long and I hadn't felt, you know. When I couldn't walk I felt more disabled.

Her feelings of being more disabled through not being able to walk are reminiscent of her feelings when she had iron callipers. Alana's transition from finding it extremely difficult to walk, to being able to walk were similar, in terms of cognition, to her childhood transition from iron callipers to plastic splints. Feeling less disabled equated to achieving greater normalcy.

In the last extract, Alana seemed to be more concerned with the reactions of people she did not know in the graduation audience, rather than showing her friends and lecturers that she was able to walk. This concern could have been grounded in the distinction between a "disabled person" and a "person with a disability." For Alana's family, friends, and lecturers, her cerebral palsy was just one aspect of who Alana was, and they knew there was more to Alana than her disability. In contrast, Alana feared that people, who did not know her, would see her disability before they saw her. By trying to remove the manifestations of her cerebral palsy, Alana was increasing the opportunities for people to see her and not her disability. As Alana tells in this next extract, one of her lecturers provided confirmation of her normalcy as she was leaving the stage, after receiving her certificate.

- A: As I was making my way from receiving my certificate, back down to my seat, one of my past lecturers (who handed her the certificate and was conducting the ceremony) said, and I heard it, she said, "I'm just going to wait for the most inspiring person that I know." And I didn't look at her, I didn't even acknowledge her, but to think that she had enough patience and enough respect for me to wait until I was seated to continue, that to me meant the world, because, y'know, I was doing something that was difficult.

Still coping with depression, being referred to as inspirational seemed to have benefited Alana's self-esteem. The lecturer's actions also gave Alana the message that she was worthy of the respect given to her able-bodied peers.

To achieve her goal of walking at graduation, Alana did exercises during breaks in lectures at TAFE. Her friends would go down to the cafeteria, and she would ask them to get her a coffee. While they were gone, Alana practised her walking in the corridor. Her friends were not aware of what she was doing, but during the time they were gone, Alana did about 10 laps of the corridor. She would drive her wheelchair to one end of the corridor, and then walk the length of the corridor and then back to her wheelchair.

- A: So I'd do that (walking) about ten times, and to do that twice a day for six months, twice a day, twice a week, six months, that became, y'know, that was just part of it. And I think that's why on the night that I graduated. I felt so huge.

- C: Not only had you achieved academically, but you also had achieved physically.

- A: Not only have I achieved this, but *the rest of you guys in the room don't know this, but I'm bloody fucking walking, y'know!* Very few people in that room knew that. I mean there were people that did, my mum did, (Joe) did, my lecturers did, my friends did, but that was it. For the other 300 people, they didn't know.

- C: They didn't know that you'd been in a wheelchair.

A: They didn't, they didn't know, they didn't even think about it I'm guessing. To the people that mattered, they knew what I'd been through . . . and the look on my face as I got up to accept that award was just, "That was it, I've made it!"

Alana said the words I have italicised very excitedly. This intense emotion seemed to have resulted in her mixing her words. What she probably meant to say was that the people in the room, who did not know her, did not know that she had been in a wheelchair. Her satisfaction was that, through her efforts, she had presented herself to the audience in a way in which the disability may not have been as great an issue as it could have been if she was in a wheelchair.

Her reaction to finishing physiotherapy was reminiscent of her emotions when she had overcome other obstacles in her life (e.g., not having to wear splints). She had increased in competence and achieved greater normalcy.

A: (I) had to go to physio every week 'till I got, y'know, to the point where the physio said, "Right, you can now do it on your own," and that was big. Hearing that, it was like, "I've made it again."

Alana drew a parallel between her physiotherapy and an Olympic swimmer in training. For Alana, walking at graduation was her gold medal. Aside from these psychological benefits and an increase in her ability to walk, Alana received several functional benefits from the treatment.

A: I'm a lot steadier than what I used to be. I don't fall over as much. Pre-botox (botulinum toxin) I was falling probably three times a week in varying situations. I mean, I'd fall over here and I'd fall over in public. Anywhere that if I just didn't feel stable, bang, I'd go down. Whereas now, y'know, to have a fall for me is rare.

Alana was now able to do tasks, like making a cup of coffee, which she was not able to do prior to the treatment. Her mentioning of falling over prompted me to ask her about these experiences. From my own perspective, I have found falling over embarrassing, because it is a sharp reminder that I have cerebral palsy. Falling over made Alana feel frustrated and angry at herself. She also felt embarrassed when she fell over in public. People in the general population typically do not fall over, so falling over for Alana appeared to threaten her feelings of normalcy and to have made her feel more disabled.

Alana's friends used humour to cope with their friend falling over. This strategy may have also helped to ease the shame of falling over. Alana educated her friends on how to help her to her feet, so that they did not injure her or themselves.

A: It's very hard. I found getting older and falling over quite embarrassing as well, particularly if I fell over in public. You know my friends have developed the attitude, oh, they'd just something like, "Oh, she's drunk again". Y'know they'd make a joke of it.

### *Engaging in Physical Activity*

Following graduation, Alana persisted with her walking. The distance from the front door of her home to her letterbox was equivalent to the length of the corridor at TAFE. Alana replaced her walking in the corridor with walking to the letterbox several times each day. When we were conducting the interview for this life history, Alana excused herself and did that walk each time a side of cassette tape had been recorded. Alana also did exercises for her legs on her bed. Through a successful rehabilitation programme, Alana had achieved competence



at walking, developed greater self-esteem for this task, and, so, was persisting with her efforts to walk.

Although Alana's walking contributed to her development, her efforts to engage in other forms of physical activity have been unsuccessful. When discussing her exercises that she performed at home, Alana mentioned difficulties she had in finding a gym that she could attend. These experiences provided a possible explanation for why she had asked for assistance earlier in the interview. There were three gyms that were local for Alana. In this dialogue, Alana recalled what happened when she telephoned the first gym.

A: As soon as I said the phrase "I've got a disability" the person on the other end of the phone freaked out.

C: What did he or she say?

A: Basically made it very clear that she didn't have the programme that I was looking for. I thought yeah okay just cause I've told you I've got a physical disability it doesn't mean you have to shut down on me, yeah, and that happened.

Alana attributed the unfavourable response to the gym fearing how their customers might perceive a woman in a wheelchair attending their gym, and the inexperience of gym staff to accommodate people with health conditions. The first attribution may have resulted from the uneasiness with which the gym staff member spoke with Alana, after finding out that she had a disability. Alana was intimately aware of the prejudice that some people hold with regard to people with disabilities. The staff member may have been reflecting that prejudice, and projecting it on the gym customers. With regard to the second attribution, gym staff may not have experience of prescribing exercise for a person with cerebral

palsy. In my own experience, however, I have been able to work with gym staff to help them to develop effective programmes for my needs. Initially, joining a gym was confronting for me, as it seemed to be for Alana, but by exercising with regard to my functional limitations, I have found it possible to develop competence and self-esteem through performing exercises in gyms.

Alana had not contacted either of the other two gyms. She perceived that one of these gyms was inaccessible to her, because it had a steep driveway up to the main entrance, which would have been too difficult to negotiate in a wheelchair. Alana made a plan to read information about exercise prescription and cerebral palsy, and to have a session with my trainer, before contacting the third gym.

### *The Next Challenge*

Following Alana's successful completion of her TAFE course, she began studying at university. Alana intended to study disability-related courses as often as the bachelor's degree prescription would allow. Her motivation for studying disability continued to be the same as what drove her to do disability studies: personal interest and activist goals.

University was more of a challenge to Alana than TAFE. Not only was a higher academic standard expected, she did not have the same support that was present at the TAFE. Instead of receiving personal support from aids, she had to approach lecturers herself to get the class notes that made it easier for her to cope with the lecture mode of teaching. She also had to have special consideration on all her work. When I met Alana, she seemed to be starting to master this new system, and gaining self-esteem in the process.

C: How you handling the transition from TAFE to university?

A: Uni and TAFE are worlds apart. Yeah it's totally different.

C: Do you enjoy it?

A: I love it now that I've sorted all the crap out and that I've sorted out ways to do things I love it. I go and I have a ball. *When you're at uni, y'know, everybody can see me coming,* but yeah, to do something like that gives me a reason to get up in the morning, because I haven't had a job in such a long time. I needed a reason to get up.

The words I have italicised are a further example of Alana's acceptance of herself and her cerebral palsy. The foundations of this acceptance were in adolescence (see *Happiness at High School* and *Finding Love*). In these italicised words, Alana seemed to be saying that she was different, that everyone could see she was different, and that she was proud to be different.

#### *An Exercise Intervention*

In response to her request for help (see *Lack of Physical Activity and Functional Decline*), I decided to intervene by trying to increase her competence and self-esteem to perform exercise in a gym environment. First, I sent Alana information about exercise prescription for people with cerebral palsy. Alana seemed unsure of which exercises people with cerebral palsy could perform. Through providing this information, I hoped to give Alana a new perspective on the exercise potential of people with cerebral palsy.

Second, I scheduled Alana to have a session, with my trainer, to see which exercises she was capable of performing. From this session, I hoped that Alana would be able to show competence at several exercises. During this session, my trainer helped Alana to attempt several different exercises for each major muscle group. Although there were some exercises that Alana had difficulty with performing, she was able to do at least one exercise for each group. With this knowledge, my trainer was able to write the basis of an exercise programme, which she could take to a gym near where she lived. Alana was given my trainer's contact details, so that she could give them to a staff member of another gym, in case they wanted advice on how to prescribe exercise for her.

On leaving the gym, Alana was excited about her ability to exercise in a gym environment. Reflecting on her experience, Alana seemed to have gained self-esteem. She told me that she was proud that she could successfully use gym equipment, and was optimistic about her prospects of exercising in the gym where she lived.

Third, about two weeks after her session at the gym, I tried to contact Alana to find out what had happened when she approached one of the gyms in her area. I tried to contact her on several occasions, and left a phone message for her. Alana did not, however, contact me. There are many possible reasons why she did not contact me. It would be unfair of me to suggest why communication stopped between us. Although this brief intervention appeared to be successful in increasing Alana's competence and self-esteem, I do not know if it changed her behaviour.

### *Alana and Me*

My positive communication with Alana prior to our meeting set me at ease during the interview. She put me at ease, further, in the following extract.

A: Everybody's disability is different. I mean, you and I might have the same disability, but the degrees that we have it, our severity, is totally different. So everybody's experiences are different.

Although her words sounded as if they could have come from a Disability 101 lecture, her acknowledging that we were different was of great help to me. I tended to repress knowledge of any attempted identification with me by people with disabilities (see *David's Life History*, Study 4). The identification itself, however, tends to make me feel uneasy, even if I am not sure why that is, at the time.

Alana's quest for normalcy resonated with my own life. In the literature review, I wrote about the Pinocchio effect of wanting to be like a real boy. In social and vocational aspects of life, she was achieving this normalcy.

One aspect of our lives that sharply contrasted was our attitudes and involvement with people who had disabilities. This difference may be rooted in our childhoods. Alana socialised with other children who had disabilities, whereas I was typically kept away from them. Alana was clearly comfortable with both the able-bodied and the disabled, whereas I was only at ease with the former.

### *Summary and Reflections on Alana*

Alana's quest for normalcy was strongest in her childhood. She knew that she was different to other children, and desperately wanted to be like them.

Alana's adolescence, however, was a time when this quest seemed to no longer

hold the importance it once did, and, largely replacing it, was an acceptance of herself as a person with a disability. She became increasingly proud of her difference, and was determined to be involved with, and be successful at, activities performed by people who were able-bodied (e.g., education, marriage, work)

Physical activity had a number of meanings throughout Alana's life. In her first years of school, physical activity meant hard work, physical pain, and social exclusion. Instead of enjoying what her body could do, like so many of her classmates would have, Alana found physical activity difficult, including having to wear callipers, and performing challenging, and often painful, physiotherapy. Social exclusion resulted from Alana looking different from other children and from her lack of competence with the physical games they played.

These experiences with physical activity seemed to have resulted in Alana avoiding exercise, which contributed to functional declines in her early adolescence and mid-20s. Both of these functional declines were halted with medical interventions. After the first of these interventions (i.e., the hamstring tendon release), Alana took more time to recover than was expected, due to her not performing physiotherapy as regularly as was prescribed. After the second intervention, Alana, with greater maturity, was more motivated to perform the rehabilitation. Part of this motivation was to achieve greater normalcy, through walking at her graduation.

Alana's display of competence through walking at graduation seemed a potential catalyst for future involvement in physical activity. She tentatively approached further involvement in physical activity through enquiring about

attending a gym near where she lived. The reaction she received from the staff member who spoke with her on the phone, however, inhibited her development in this area. Although my brief intervention seemed to help her display competence and to increase her self-esteem, this assistance may have been insufficient to allow Alana to continue to develop her involvement in physical activity.

### Summary of Life Histories

Common features of the lives of these two women, who did minimal physical activity, were negative experiences with physical activity during early childhood. These experiences seemed to have established a lifelong pattern of avoiding physical activity. Specific similarities between Judy and Alana were that they had to perform difficult, and sometimes painful, physiotherapy; they wore callipers to assist their walking; they lacked competence at physical activities; they were socially isolated from their classmates at primary school; and they experienced functional decline.

For both Judy and Alana, physiotherapy seemed to have taken physical activity from being an enjoyable experience, in which individuals use their bodies for play and exploration, to being structured sessions aimed towards improving function. Although physiotherapy can improve the physical functioning of people with cerebral palsy, Judy and Alana, when they were young, did not understand why they had to undertake the treatment. They did not perceive that they were functionally improving, and the treatment sometimes involved the painful stretching of muscles.

Wearing callipers sometimes made walking difficult for Judy and Alana, and was a source of an unwanted difference between themselves and their

classmates. Judy found her first callipers made walking more difficult, because she was not able to bend her knees while wearing them. Technological advances made callipers easier to use, with the newer versions enabling the wearers to bend their knees. The adverse social impact of callipers seemed of greater issue for Alana, with her classmates teasing her for having to wear them. For Alana, a sense of normalcy was gained through not having to wear callipers.

Judy and Alana lacked competence to perform physical activity. As children, they watched others play physical games and wished they could be involved. The games the other children played involved, for example, the ability to move quickly and to jump, and the balance to withstand being knocked or pushed. Judy and Alana knew that they did not have the capacity to perform these activities. Having low self-esteem to become involved in the physical world of children, Judy and Alana largely excluded themselves from these activities. In formal physical activity, as part of the schools' curricula, the participants were also excluded, and were involved in physiotherapy, in Alana's case, or in resting, in Judy's case.

At a socially decisive stage of their lives (i.e., the latency stage; Erikson, 1985), Judy's and Alana's classmates largely excluded them from the social milieu. Judy's and Alana's abilities to build relationships with their classmates were adversely affected by their impaired physical functioning, their use of callipers, and their inability to be competently involved in playground games. With the de-emphasis of physical activity in social settings during adolescence, Alana was able to forge new relationships, and her competence in social settings developed throughout her adolescence and 20s. In contrast, apart from two



intimate, long-term relationships, Judy's self-esteem in social settings seems to have been impaired for much of her life. A significant point of difference between the two women appears to have been the presence of siblings in Alana's life, which were absent in Judy's life. Alana's intimate relationships with children close to her own age, her older sister in particular, may have provided Alana with the skills to socialise with others when the opportunities arose during adolescence. Judy did not, however, have a similar opportunity.

Both women experienced declines in physical functioning, aside from what would be expected due to ageing. Alana appeared to have more severe cerebral palsy in her lower extremities than Judy, which may explain why Alana experienced a decline in her ability to walk much earlier in her life than Judy. The onset of these declines may have occurred earlier in their lives than if they had been involved in physical activity during their lives.

Physically, the lives of the two women contrasted deeply with my own life. Judy and Alana's early, adverse experiences with physical activity seemed to have contributed to a life-long pattern of generally avoiding physical activity. In comparison, I can recall positive experiences of physical activity when I was a child, and I have remained physically active throughout my life. From these findings, it may be tentatively suggested that, for people with cerebral palsy, childhood experiences with physical activity influence their participation as adults. That is, adults with adverse experiences as children seem to avoid physical activity, whereas those with positive experiences would tend to be more involved with physical activity. This contention could be examined through investigating the lives of adults with cerebral palsy who were involved in physical activity.

In summary, the meaning and experiences of physical activity for the two women with cerebral palsy, who had minimal involvement in physical activity throughout their lives, were predominantly negative. Physical activity was associated with difficult, and sometimes painful, physiotherapy wearing callipers, a lack of competence at physical activities, social isolation from their classmates at primary school, and functional decline. Most of these experiences happened during childhood, and established a lifelong pattern of physical inactivity. On occasion (e.g., Alana's walking for graduation), however, physical activity was used to increase feelings of normalcy. Research is now required to investigate if, and how, the experiences of people with cerebral palsy, and who have been involved in physical activity, are different to those of the women in the present study.

## CHAPTER 6

### STUDY 3 – LIFE HISTORIES OF ADULTS WITH CEREBRAL PALSY WHO WERE INVOLVED IN PHYSICAL ACTIVITY

#### Introduction

Although many people with cerebral palsy have minimal involvement in physical activity (Heller et al., 2002; Longmuir & Bar-Or, 2000; Turk et al., 1997), others participate on a regular basis. In Study 1, the adults with cerebral palsy who engaged in exercise did so, on average, for over 30 minutes each day. Understanding the meaning and experiences of people who are engaged in a substantial amount of physical activity may be helpful in assisting others to become involved.

Few studies have investigated the meanings and experiences of physical activity of people with disabilities. In these studies, however, several issues relating to the physical activity involvement of people with disabilities were present, such as: compliance with advice from medical practitioners (Henderson & Bedini, 1995), identification with people who did not have disabilities, internalised ableism (Hutzler et al., 2002), poor self-image (Peganoff, 1984), and sexuality (Guthrie, 1999; Guthrie & Castelnovo, 2001). Through studying the lives of people with disabilities, deeper knowledge of these and other issues, and how they develop, may be gained.

In the present study, I explored the life histories of two adults with cerebral palsy who were involved in physical activity. The aim of the study was to understand the meanings and experiences of physical activity of these people.

## Method

### *Participants*

The participants were a woman and a man who both had cerebral palsy: Amy, aged 25, and Ben, aged 30. Amy had spastic quadriplegia and Ben had spastic hemiplegia. Both participants were involved in physical activity. The participants' life histories detail their characteristics and the method by which they were recruited.

### *Design*

As for Study 2, a life history approach (Denzin, 1989a, 1989b) was used in the present study.

### *Procedures*

The procedures followed those for Study 2.

### *Analysis*

As for Study 2, the participants' life histories were interpreted using psychodynamic theory.

## Results

### *Amy's Life History: Showing Competence and Being Socially Connected*

#### *Meeting Amy and her Mother*

Amy found out about our research through an advertisement in a publication of a major disability organisation in Victoria. Her mother contacted my co-supervisor and me and expressed an interest in my research. She told me that Amy had been involved in physical activity throughout her life and that Amy and she were interested in talking to me about Amy's life.

I met Amy and her mother at their home. Amy had severe cerebral palsy, slight intellectual impairment, and epilepsy. She used an electric wheelchair for mobility, but was able to walk, with assistance, for short distances. Amy's mother greeted me at the front door, and warmly welcomed me into the family home. Amy was seated in her wheelchair, and seemed pleased to see me and shy at the same time. Her mother and I were seated on a sofa each; Amy's mother was opposite her, and I was on Amy's right hand side. Amy was a tall woman and the seat of her wheelchair was higher than the seats of sofas, which meant that her mother and I had to look up to her, and, perhaps more strikingly, it made Amy the centre of attention.

Due to her cerebral palsy, Amy had difficulty speaking clearly. Although members of her family (e.g., mother, father, brother) could understand her speech, I had difficulty understanding all she said. Amy spoke in short sentences, which seemed to be an adaptation to her difficulty with physically producing words, rather than a reflection of her slight intellectual impairment. She had adapted to her communication difficulties by trying to convey each message in as few words as possible and through repetition when the listener did not understand what she said. This style of communication meant that I had to ask many more questions than I would usually do in an interview with a person who did not have communication difficulties. To questions that I was expecting Amy to provide a detailed response, I often got answers of only a few words. Additional questions were necessary to gain a deeper understanding of her life.

I had explained to Amy's mother, on the telephone, that I wished to conduct the interview with only Amy and myself present. After talking to Amy

and her mother on my arrival at their home, however, I found it very difficult to understand Amy's speech. At my request, Amy's mother was present throughout the interview to help me understand what her daughter was saying, and to elaborate on aspects of Amy's life.

Although having another person present in the interview could result in the nondisclosure of sensitive issues from a participant, I perceived that Amy had a very open and caring relationship with her mother. Although there were some topics where I felt her mother's presence may have limited Amy's responses, I felt that the information gleaned with the help of her mother was much richer than would have been gathered had she not been present during the interviews. Amy's relationship with her mother, and the effect of her mother's presence on Amy's responses will be discussed later in the case.

To give Amy the opportunity to express herself using a non-verbal medium, questions were composed after the interview, which were sent to Amy in a letter. I invited her to respond to each one using her computer. I used this approach, because, during the interview, I learnt that she used a computer, at times, to type notes to people, such as doctors, carers, and her mother. I also learned that she had completed English courses at TAFE (Technical and Further Education) and was capable of reading the newspaper and parts of the Bible. Despite asking Amy open-ended questions and encouraging her to expand on the answers with any subject matter that came to mind, her responses to these written questions were short (i.e., between two and four sentences long).

### *Walking With a Little Pink Trolley*

Amy was able to walk at a young age. By the age of five, Amy could walk with the assistance of a pink trolley, which she used to keep her balance while walking. Even though she found walking to be difficult and slow at times, she was able to competently walk when using the trolley or when another person could help her keep her balance. Amy enjoyed walking, but had trouble remembering what it was like for her to use a trolley.

This story was one of the first that Amy told me. The story resonated with me, because, as a child, I also pushed a trolley. As it was for Amy, recalling what it meant to be able to walk with a trolley was difficult, because it was so long ago. For me, as it probably did for Amy, having a trolley meant that I was able to move around independently, and explore my environment to a greater extent than if I did not have any assistance with mobility. The pleasure that Amy derived from walking seemed to have motivated her to persist with being mobile.

### *Being Late for Class*

Having mastered the oral, muscular, and locomotor psychosocial stages, children enter school life, where the nuclear conflict is that of industry versus inferiority (Erikson, 1985). Amy had not mastered the goal of ambulation, however, and this lack of ability was exposed at the mainstream school she attended. Amy walked slower than her peers, and the necessity to go up and down stairs at school presented difficulties. Her slow walking speed meant that she was consistently late for class. The teachers must have recognised Amy's mobility difficulties, and so did not question her lateness to class. Whereas her teachers punished her classmates when they were late to class, they did not behave

similarly when Amy arrived late. This situation was unsatisfactory for Amy because she perceived that the treatment she received from her teachers for being late was different from that of her peers. In essence, it was a no-win situation. Being late to class adversely affected her self-esteem to walk. If the teachers had disciplined her for being late for class, however, this treatment would probably have also affected her self-esteem negatively. Amy seemed to feel inferior to her classmates because of the teachers' double standards.

Amy seemed to have few ways of addressing this sense of inferiority. One situation when she did not appear to feel as inferior as she did at other times, and maybe briefly felt superior to her classmates, was in school photographs. Amy's desire to be like her classmates was evident in these photographs, where she is pictured standing in the back row, hanging on to the teachers to avoid falling. In formal photographs of groups of people, tall people typically stand at the back. Being a tall person, relative to her classmates, Amy expected to stand at the back. To not stand at the back would signify that she was being treated differently, like when she was late for class. Special treatment was something she was keen to minimise.

### *Changing Schools*

About the age of 8 or 9, Amy changed from a mainstream school to a school for people with disabilities (special school). She perceived this change as being a positive experience. Most of Amy's new classmates were also in wheelchairs, and the infrastructure of the school was designed to accommodate students with mobility difficulties (e.g., with ramps instead of stairs). In this sense, being in a wheelchair may have reduced Amy's feelings of inferiority,



because she was like most of her new classmates. Even so, Amy still liked walking.

C: Did you enjoy walking?

A: Yeah, when I could I enjoyed it [pause]. Time to get in the chair, I loved it 'cos I could go faster.

The first part of Amy's response suggested that she still valued her ability to walk, but not in situations where she could be perceived as being inferior to others (e.g., getting to class on time). Through the use of her wheelchair, Amy increased her competence in being mobile, because she could now keep up with other people.

### *The Trouble with Walking*

Although Amy started using her wheelchair during her childhood, she maintained her ability to walk around her house and yard. At the start of her adolescence, however, Amy began to lose competence with walking. Some of the muscles in her legs were shortening, due to spasticity, and walking became progressively harder. She still wanted to walk, but was not helped by public health authorities, who would not provide her with a walker, so she could maintain the ability to walk. As walking became harder, Amy began to fall frequently, which seemed to reduce her self-esteem related to walking. Not surprisingly, Amy did not enjoy falling over and, by the age of 14 years, she had stopped walking altogether. She maintained mobility, however, through crawling or using her wheelchair.

At this age, Amy had a surgical procedure that lengthened Amy's achillis tendons, which enabled her to place more of her feet on the ground when walking.

In short, this surgery made walking easier for Amy, and meant that Amy was able to walk again using a manual cart.

### *Unhappiness with Lack of Treatment*

Amy had physiotherapy throughout much of her childhood and early adolescence. This treatment continued after Amy's surgery, with the focus on developing her competence at walking. Amy was positive about her physiotherapy experiences.

C: Please tell me about your physiotherapy. What was that like for you?

A: It was good. The physio was good. The stretching was good [pause]. *I loved it, being tall.*

As I have italicised, one of the aspects of physiotherapy that Amy enjoyed was the opportunity to stand to her full height. This experience contrasted with much of her life, in which she was sitting. In this seated position people would have looked down on her. This "being looked down upon" certainly had a physical connotation in that other people, who were standing, would have to look downwards to make eye contact with her, but it also seems to have a psychosocial meaning in that some people may have perceived Amy to be inferior to them. When Amy was standing during physiotherapy, she may have felt less inferior than she did otherwise, and may have gained a brief sense of superiority over those people who were shorter than her.

At the age of 16, Amy's efforts to improve her walking were hampered when she had to stop physiotherapy treatment, because the funding for a one-on-one physiotherapist ceased. So often, cerebral palsy is regarded as a paediatric

condition, especially with respect to treatment (Bottos et al., 2001). The public health authorities seemed to hold this traditional view, and limited the funding available for Amy's treatment when she was in mid-adolescence.

Amy's physiotherapy, however, did not cease entirely. She started attending two aerobics classes per week, for people with disabilities, which two physiotherapists facilitated. About six people with disabilities were in each class. Amy did not like these classes because she was not able to practice standing and walking, as she had previously been doing, one-on-one, with a physiotherapist. In addition, she had difficulty in performing the skills that were practised in the aerobics class (e.g., throwing and catching a ball).

### *Sailing Away*

Amy was introduced to sailing at the age of 19 years. In her first attempt at sailing, with fellow students from her school for people with disabilities, she quickly became familiar with the operating system of the boat and managed to sail the boat, so that it was out of reach from her teachers, for an hour. To develop competence this quickly must have been a new and rewarding experience for Amy. Because of physical impairments, people with cerebral palsy typically take longer than people from the general population to develop physical skills. Some who are severely physically impaired may not even become competent at the activities of daily living. Amy quickly learned the skills of sailing the boat.

Sailing was one aspect of her life where she could display competence.

C: Tell me about what sailing means to you, what it's like?

A: It's freedom. I love it. No cares. No one pushing me.

In Amy's response, "pushing me" had a physical sense. When she was sailing, nobody had to push her, like they sometimes had to do when she was in her wheelchair. Amy expanded on the meaning of sailing for her in the letter she sent me in reply to my written questions.

A: I feel free on the water. I can go anywhere I want without ramps or a carer. It means I am free to go anywhere I want to without relying on other people. It is wonderful fun. It also gives me the time to pray to Jehovah in peace.

Amy could display competence on the water because the boats she sailed were designed in such a way as to allow someone with limited movement to control the boat. Her competence at sailing was not only demonstrated by her sailing on the water, but she also gained a sailing qualification. Amy sat an exam, passed, and was awarded her Training Level One Certificate by the Australian Yachting Federation. There was only one exemption; she could not jump on a keel to right an upturned boat. Not only had Amy demonstrated competence to herself, she had received public recognition of her ability.

Reflecting on these experiences as she was talking with me, Amy seemed happy and proud of her achievements. Amy sat taller in her wheelchair and had a big smile on her face. She seemed to possess a high level of self-esteem for sailing, which appeared absent from many activities in her life. Amy's self-esteem translated into a greater commitment to sailing, and a wish to perform the activity more frequently. Her family were supportive of her sailing, and bought Amy her own boat.

In the previous extract, Amy said that she would use sailing as a time for prayer. Amy was baptised into the Jehovah's Witness faith when she was 20. I discuss the importance of religion in Amy's life later (see *Religion: Social Connectedness and Hope*).

### *My Brother*

Amy had a close relationship with her 13-year-old brother. I had the opportunity to meet him, when he came home from school during my interview with Amy. Amy was excited to see him, when he came in the door, and he seemed pleased to see her. He struck me as a person who was mature beyond his years and was comfortable with having a sister with cerebral palsy. When I asked Amy to talk about her brother, Amy frequently said that she loved him. This closeness may have been partly due to the age difference between the siblings. Freud (1916/1991) suggested that if the age difference between siblings is eight or more years, then the older sibling's reactions to the younger sibling are likely to be solicitous and maternal, rather than competitive, especially if the older sibling is female. Amy's mother told of how Amy was excited at the news of her mother's pregnancy and when her brother was newborn, Amy grabbed him and wanted to take him home, but she (her mother) would not let her.

Amy's brother frequently helped her to show competence. His actions can be viewed as interventions at the behavioural stage of Basch's (1988) developmental spiral. Although throwing a ball was difficult for her in the aerobics classes, when she was 16 years of age, Amy's brother taught her how to throw and catch when she was older. Amy may also have been more motivated to practice these skills when she was older, because she wanted to do other things in

the aerobics classes and because of her relationship with her brother. Small balls remained hard to throw (she had difficulty releasing her grip on the ball at the right moment) and catch for Amy, but she had more success with bigger balls.

A more important aspect of Amy's life in which her brother helped her show competence was in her communication with others. Amy found it frustrating when people did not understand her, but was very patient when people did not comprehend her speech. During the interviews, Amy was extremely patient with me, and often had to repeat words several times, especially when she had started a new line of thought and I was struggling to interpret her words in light of the prior discussion. Her communication with others was a situation where family members, such as her brother, were of great assistance. An example of when Amy's brother's assistance has allowed her to show competence was at church. Amy would raise her hand to answer questions at church, and, if the person asking the question did not understand her, Amy's brother would repeat what she had said. In this way, Amy not only was a competent communicator, but could also demonstrate her knowledge of the Bible and its interpretation in her faith. Through being able to communicate with the person asking questions, and through correctly answering the questions, Amy gained a sense of achievement, and regularly raised her hand to answer questions.

#### *Religion: Social Connectedness and Hope*

Amy had strong religious beliefs, which, for her, incorporated her cerebral palsy. Her religious experiences not only allowed her to demonstrate competence, by answering questions in church, but also served social and ego-related roles. At a stage of life (young adulthood; Erikson, 1985) when engaging in close

relationships is a sign of mastery of the nuclear conflict of intimacy versus isolation, Amy's social circle was limited principally to her own family. Her mobility difficulties limited her opportunities to engage with others in social settings on her own. Going to church provided Amy with the opportunity to become more socially connected. Her mother described how Amy loved meeting people, being known by others, and people coming up to greet her when she was at church. Despite the difficulties that Amy faced with her cerebral palsy, she seemed motivated to make the most of what opportunities she had to be connected with others.

For Amy, religion had an ego-related role, which was similar to the narcissistic features of some of Niederland's (1965) patients. Although Amy did not display narcissistic pathology, her fantasies of rebirth, accompanied by castration of her disability, and of immortality are strong narcissistic features. The following dialogue, in which her mother "takes over" asking questions, illustrates these characteristics.

C: When you read the bible, what stories do you like reading about?

A: Good stories [pause] with pictures.

M: What's your favourite bible story?

A: The second one [pause] with a picture of the Garden of Eden.

M: Do you like that story? What do you like about it?

A: A beautiful garden.

M: What appeals to you about the Garden of Eden?

A: People live forever and there's no cerebral palsy.

Consistent with her religion, Amy prayed that she was going to be part of God's new world after Armageddon and the Great Tribulation, a world without cerebral palsy. In her prayers, Amy said that she gave her serious problems to Jehovah. When discussing the problems that Amy gives to Jehovah, her mother told the story of how Amy had turned down a marriage proposal because she felt that she could not care for a husband and the children that she would have wanted to have with him. I do not know Amy's mother's reasons for introducing this story, but it seemed as if she wished to provide a further example of her daughter's competence. This time, Amy was portrayed as being competent at making major life decisions.

M: You know, there's another thing. You mightn't want to talk about it if you don't want, but you've often said that (Amy) would dearly love to get married and have kids. And we've always said that's fine while we're around, but with the epilepsy and everything it's not going to be easy. And she's decided on her own bat to turn this friend down who was very interested in marrying her. That she just didn't feel she could look after him [pause] and that must have been really hard to do.

A: Yip [pause] Jehovah knows how important that was.

M: You made that decision without any pressure.

A: I couldn't look after myself and him, and kids. I can't do it, I just can't do it.

The importance of this story lies in the impairment of Amy's psychosocial development and the influence her mother had in her life. Young adulthood is the stage of life in which true genitality can develop fully (Erikson, 1985). For Amy, turning down the marriage proposal effectively amounted to denying herself the opportunity to achieve the goals of genitality. Failure to form intimate



relationships with others may lead to isolation. That Amy would want to avoid a long-term intimate relationship seemed peculiar, however, when her stories about going to church suggested that intimacy was something she desired. Amy had often said to her mother that she would like to get married and have children, and I listened to several stories of Amy's maternal instincts. One instance was her loving relationship with her brother, and her behaviour when he was new born, which I have already mentioned. Another time was when her mother was flat on her back for four and a half months, while waiting for surgery. Her mother said that Amy helped around the house to support her mother. A further example was that Amy loved holding babies. When Amy held babies they would go straight to sleep.

C: Tell me what you like about doing this.

A: Giving back as a mother.

At this point I felt deep sadness for Amy. The pressure exerted by her family seemed to be the main reason for Amy turning down the marriage proposal. Although her mother stated that Amy made the decision on her own, Amy's parents exerted substantial pressure on her by expressing doubts about her ability to cope when they were not around. Because Amy was dependent on her mother to help her to perform most of the activities of daily living, it would have been difficult for her to make a decision that was contrary to her mother's wishes.

I asked Amy, via letter after the interview, what her opinions were regarding alternative forms of relationships (i.e., getting married but not having

children; getting married and looking after other people's children for periods of time; getting married and helping, or being employed, at a children's day centre), which may have met Amy's needs for romantic and maternal relationships. In her response, Amy stated that she did not want to discuss this matter any further.

This suppression lends itself to several interpretations, all of which may have some relevance. First, discussing the subject of romantic and maternal relationships could have evoked painful memories of the time when she was deciding whether to accept the marriage proposal. Second, it seems likely that these issues were fresh in her memory, but Amy dealt with them in the relative safety of her fantasy life, rather than in reality. Talking about different forms of relationships would make Amy aware that having a long-term intimate relationship, and children, was still possible. Third, vocalising her concerns to me may have meant that her mother would find out that she still harboured hopes of having a family of her own. From the use of language in Amy's written responses, I suspected that her mother had helped Amy to articulate her answers to my questions. Although Amy's mother seemed to believe that her daughter had dealt with this issue, Amy's fantasies suggest that Amy was still processing the issue, possibly at an unconscious level. In regard to this matter, I felt Amy's mother's involvement inhibited the interview process. Fourth, Amy's religious beliefs may have discouraged her from seeking alternative kinds of relationships. In the Jehovah's Witness faith, the prescribed role for a wife is to help her husband, to assist in the training and teaching of their children, to lovingly care for her family, and to deeply respect her husband (Watch Tower Bible and Tract Society of

Pennsylvania, 2000). Amy seemed to feel that she was unable to be a wife and to help in child rearing in the way her faith prescribed.

### *Riding . . . and Falling Off*

For the past three years, Amy had been involved in horse riding and going to the gym (see *Going to the Gym* for stories of this latter activity). These have been further physical activities in which she could experience competence.

C: Why do you like horse riding?

A: I love it [pause] it's fun [pause] I love horses.

C: So it's fun for you to be up there.

A: Being in control.

Amy gained a sense of competence from being able to ride horses. Unfortunately, Amy fell off a horse after it misunderstood a signal she gave and started trotting when she was not ready. The fall resulted in injuries that disrupted her daily routine for 10 weeks. Although Amy had not ridden since her accident, she was still keen to pursue horse riding in the future.

Amy could also display competence through volunteering in the programme, Riding for the Disabled. Here, while in her wheelchair, she led a horse, that was being ridden by a young child with cerebral palsy, with a carer either side of the horse. This volunteering provided her with the opportunity to help people, and to give back some of the assistance that other people had given her. Like the sailing qualification, being a volunteer for Riding for the Disabled

was public recognition of her competence. This experience of “taking care of another person” seemed to also partially satisfy Amy’s maternal instincts.

### *Going to the Gym*

Amy went to the gym once a week, with the assistance of a personal trainer. She also had been doing exercises at home two days per week to complement her gym programme. Like my trainer in the gym, Amy’s trainer could be viewed as intervening in the behavioural stage of Basch’s (1988) developmental spiral. Having assistance in the gym meant that she could demonstrate competence at activities that she otherwise could not perform.

This activity helped Amy in various aspects of her life. Having previously been quite sedentary, and having atrophied muscles, her body responded well to training, as reflected by the associated muscle growth. This growth was a bodily representation of her competence at her gym programme. Reflecting on this growth, Amy was especially proud of herself, and she did a bicep pose early in the interview to show off the gains in muscle mass that she had achieved. Amy also stated, in response to various questions, that she loved muscles. That is, she loved the muscles that she had developed through training. In particular, Amy was proud of her biceps, abdominal muscles, and shoulders. Amy had gained self-esteem through performing exercises in the gym, and seemed excited and proud when telling me of the weight she was lifting for some of the exercises and of her personal best on the rowing machine. In the following dialogue, Amy’s mother takes over the interview, again, with her own questions, which were directed towards showing that Amy is competent.

- C: How do you like the rowing machine?
- A: I love it.
- M: What's your personal best?
- A: 84 strokes per minute.
- M: She comes off, she's shaking, she's jelly, she's red, she's happy.
- A: Yeah.
- C: So you really like exerting yourself?
- A: Yeah.
- M: And on the pec deck, how much were you lifting?
- A: 18.5 kilos.

Amy attributed medical and psychological benefits to going to the gym, but the functional benefits seemed to be of greatest significance to her. Functional benefits came primarily from strengthening the muscles in her legs. Amy did not think she would have been still able to stand if it were not for the work she had been doing in the gym. Amy associated standing with being able to maintain some independence in her flat, which is out the back of the family home. When Amy was standing, she was able to stabilise herself in a corner of the flat, where she was able to wash and rinse the dishes. By wedging herself into the corner she was also able to prepare her breakfast and lunch. Competence in the gym produced strength gains, which allowed Amy to preserve her physical function and maintain the ability to perform household activities in her flat.

With regard to medical benefits, over the time that she has been going to the gym, Amy had not been to hospital due to epileptic seizures. She said that the

gym has helped her to control her epilepsy, because the gym was a place where she could get rid of frustration. Amy's experiences are consistent with the medical literature, where it has been found that physical activity can reduce the frequency of epileptic seizures (Howard, Radloff, & Sevier, 2004).

C: Do you think gym has helped your epilepsy?

A: Yip.

C: Why is that?

A: Because I like gym, I get rid of frustration.

C: Gym can be good for that. Tell me about some of the things that frustrate you.

A: When people don't understand.

Amy said that her communication difficulties were the reason for her frustration. Although she attempted to be patient with people, who are trying to understand her, she became inwardly frustrated with this difficulty. I enquired as to other sources of frustration, but Amy said there were no others, which I found difficult to comprehend due to the number of challenges she faced. Amy had possibly repressed other frustrations, or suppressed them during the interview, because of her mother's presence.

### *Staying With My Family: The Importance of Walking*

At the time I met Amy, she had been practicing walking every day by pushing a manual cart beside the house. A few weeks prior to us meeting, she had

managed to descend and then ascend 84 steps with the assistance of a carer on each arm. Walking was important to Amy at this stage of her life.

C: Can you tell me why it is important to you to stay walking?

A: To stay here, to stay at home.

Amy may have been anxious about the possibility of, one day, having to live at a home for people with disabilities. This anxiety was not allayed by her mother's insistence that she would not have to go into a home if she lost her ability to walk. This issue seemed to be of great importance in Amy's life when I met her, because she brought it up again in the letter she wrote to me in response to my written questions.

C: Could you describe for me some situations in the past when you would have liked to have been standing, rather than sitting in your chair.

A: I was standing in my school photos because I liked to be standing tall. It is good to be able to still stand because if I couldn't I would no longer be able to be at home because it would be too hard for Mum and myself.

Although my question was directed towards Amy's past, she quickly returned the focus to one of the main issues she seemed to be facing. Amy's concerns seemed to be grounded in the nuclear conflict of young adulthood (intimacy versus isolation; Erikson, 1985). Amy had intimate relationships with few people, and feared being isolated from them. Although Amy mentioned various people during the interviews, the relationships with her mother and brother were the most intimate and enduring. She gave the name of one close friend from school, but

said that she did not see her any more, because her friend had moved to a different suburb, and the taxi fare to get there was expensive. Amy's chance at achieving long-lasting romantic intimacy and having a family of her own was, at least partly, thwarted by her parents' concerns over her ability to care for her family, if they (Amy's parents) were not around.

Amy's concerns over being isolated from her family may have had its roots in how her family had treated her in the past. First, Amy spent a short time in respite (i.e. a home for people with disabilities) every eight weeks to give her parents a break from the intensive care-giving role they provided for Amy. Although Amy had always been brought home from respite, she, nevertheless, had fears that her parents would leave her there, if her function deteriorated. Second, Amy appeared to have strong memories of the period of her life when she turned down the chance of having a long-lasting romantically intimate relationship. Her parents' concerns over her ability to cope with a family of her own, if they were not around, could have also brought Amy to the realisation that her parents would, someday, be unable to care for her, due to their own functional deterioration with age. Maintaining her ability to walk provided insurance for Amy against the possibility of leaving the family home.

### *Amy, Her Mother, and Me*

Amy's mother had a significant role in the interview process. Her mother's initial telephone contact with my co-supervisor and me, and the seating arrangement when I interviewed Amy, gave me, in hindsight, an indication of her mother's agenda for the interview that was about to occur. That is, Amy was on show.



Amy's mother telephoned one of my supervisors in response to a flyer we had circulated through a disability organisation newsletter, which advertised that I wanted to recruit, for the research, adults with cerebral palsy who were doing minimal physical activity. She stated that her daughter had been doing physical activity, and that they were willing to share Amy's experiences with us. Amy's mother was obviously proud of what her daughter had achieved. When I interviewed Amy, she was sitting in her wheelchair, and, therefore, elevated from the level at which her mother and I were sitting. This positioning was subtle evidence that Amy should be a person that people looked up to for inspiration.

Although I started the interview without Amy's mother's presence, I quickly found it difficult to understand her speech. Amy's mother was in the kitchen, and Amy had previously said to me that it was all right if I wanted her mother to help with interpreting her speech. When I realised that the interview was going to be too difficult for me to do on my own, I asked Amy's mother to join us.

Amy's mother adopted several roles during the interview; she assisted in interpreting Amy's speech; elaborated on her statements; prompted responses from her daughter, to the extent that, on a few occasions, she took over the role of interviewer; told stories; and provided testimony of Amy's competence, progress, and strength of character. The elaboration of Amy's statements took the form of providing a fuller response to my questions. Amy's responses were typically brief, and so her mother fleshed out these responses. Amy's mother's prompting of responses from Amy seemed to me to suggest that her mother was helping Amy to provide more complete responses to my questions. For example, when Amy said

that she used to trot on a horse, her mother asked her why she was not currently going to horse riding, to which Amy could tell me that she had fallen off, injured herself, and had to stop riding for several weeks. At times, as in the previously stated dialogue about what bible stories Amy liked (see first extract in *Religion: Social Connectedness and Hope*), her mother took over questioning completely. Often her mother introduced new topics that she thought Amy should discuss. In these instances, it seemed that the introduction of topics highlighted other areas in which Amy had achieved competency. Sometimes Amy's mother told stories apart from what Amy had said. For example, when talking about why Amy liked babies, her mother told the story of how helpful and nurturing Amy had been during the several months when she was flat on her back waiting for surgery. Amy's mother often provided examples of Amy's competence, progress, and strength of character. The examples of competence often focused on physical tasks (e.g., gym work, sailing, walking), but sometimes included major life decisions. Amy's decision to turn down a marriage proposal was seemingly viewed by her mother as competent and responsible, given her cerebral palsy and epilepsy. Her mother prompted Amy to mention her progress, in reference to her physical achievements. For example, she asked Amy what her personal bests were on the pec deck and rower, at the gym. Amy's mother seemed to infer that her daughter had a stronger character. This perception of strong character appeared to be linked to how admirably Amy copes with having cerebral palsy (e.g., Amy's patience with people who do not understand her speech).

An understanding of why Amy's mother behaved as she did would involve investigating her life history, which is beyond the scope of this research. How she

behaved towards Amy, and comments she made about herself during the interviews, may give some insight to her present functioning. Principally, she inferred that she did not have good genes; she scoffed at people who thought she must be a nice mother, because God gave her a baby with cerebral palsy; and she endeavoured to represent her daughter as having achieved competency, at several tasks, despite her cerebral palsy. From the first aspect, it could be inferred that Amy's mother felt guilty that Amy was born with cerebral palsy. Although I do not know the story of Amy's birth, it is unlikely that her cerebral palsy has a genetic aetiology. Genetics are rarely a cause of cerebral palsy, with the risk factor being greater when consanguineous families are common (McHale et al., 1999, 2000). Her purpose in telling me that some people thought she must be a good mother, because God had given her a baby with cerebral palsy, was unclear. Perhaps she would like to project her guilt over the cause of Amy's cerebral palsy onto an outside object (e.g., God). She could not blame God for Amy's cerebral palsy, however, because this blaming would bring further guilt. Therefore, the guilt about Amy's cerebral palsy rested with Amy's mother. This guilt seems to have decreased through Amy showing competence at various tasks. Amy's mother was eager to discuss areas in which Amy had demonstrated competence and, through her body language and what she said, I could tell that she was proud of her daughter's achievements.

A feature of this life history is the relative absence of myself. During the interview, I felt I was an "other" in a production, in which Amy played the starring role, and her mother was a support act. I was allowed to ask many questions, but my primary role was to observe and listen to what was being

presented. Although this role may not sound too different from what would be typical of an interviewer, my role was more removed than was the case with other participants in this research. Amy's mother partially took over my role as the interviewer by asking her own questions, prompting Amy, and introducing new topics. This presentation seemed directed by Amy's mother, with Amy the star, and myself playing a minor role, and sometimes that of a keen audience member.

### *Summary and Reflections on Amy*

In looking over Amy's life history, I've come to see a remarkable young woman. Of the participants that I interviewed for this thesis (six people for Study's 2, 3 and 4), Amy appeared to have the most severe cerebral palsy. Despite her physical and slight intellectual impairments, Amy had applied herself with admirable aptitude to tasks directed towards meeting the challenges of psychosocial development.

The meaning and experiences of physical activity throughout Amy's life were closely associated with her psychosocial development and her strivings to show competence. With her little pink trolley, Amy was mobile and could show initiative in her environment through walking around at home. On entry to school, however, Amy was not as skilled at walking as her classmates were. Her lack of walking speed meant that Amy was constantly late for class. By not punishing her for being late, Amy perceived that the teachers were treating her differently to her classmates, which seemed to contribute to Amy's sense of inferiority. Amy made attempts to reduce her feelings of inferiority through the use of a wheelchair, which increased her mobility, and through behaviour, such as standing in school photographs. After surgery to improve her walking ability, in early adolescence,

Amy was persistent in her efforts to stand and to regain the ability to walk. She enjoyed going to physiotherapy, and through this treatment she seemingly addressed some of her feelings of inferiority. In physiotherapy she practiced standing and loved being in a position in which other people could not, literally, look down on her.

Because of the severity of Amy's cerebral palsy, she did not have control over many aspects of her life. Engaging in physical activity (especially horse riding, sailing, and working out at the gym) was one area of her life where Amy could exercise control. Amy was extremely proud of her achievements through physical activity, which was ever-present in her body language when she was speaking about her experiences. Amy's reflections on these experiences increased her self-esteem and motivated her to continue to engage in these activities.

When I met Amy, she was performing tasks to meet the challenges of the young adulthood stage of psychosocial development (intimacy versus isolation; Erikson, 1985). Through engaging in physical activity, Amy perceived that she was improving her chances of remaining close to the ones she loved. Amy feared that if she lost her ability to walk she would have to leave the family home. Retaining, and improving, her physical function through physical activity helped to allay these fears. In areas where her psychosocial development was impeded (e.g., getting married and having children), Amy coped through finding substitute areas to direct her energies (e.g., being a volunteer for Riding for the Disabled) and through, seemingly as a last resort, narcissistic fantasy (e.g., being reborn without cerebral palsy and living forever). Amy's family, in particular her mother, provided her with an abundance of love and support, which allowed her

to successfully meet many of the psychosocial challenges she faced. Amy's mother's support for her daughter was evident during the interview, in which her participation was invaluable. Although her involvement influenced the direction that the interview took, the stories that she provided enabled me to gain insights into Amy's life, which possibly could not have occurred any other way. Amy's mother appeared to be helping her daughter in the best way that she knew how. This assistance contributed to Amy developing both physically and psychosocially. Amy's involvement in physical activity played an important role in that development.

### *Ben's Life History: Developing Through Sport*

#### *Meeting Ben*

Ben contacted my co-supervisor and me after searching the Internet and finding an article about my research on the University website. In the email that he sent, he provided some background to his involvement in physical activity, which was intriguing and prompted me to invite him to participate. Ben indicated that he was obsessed by sport, and seemed proud of his achievements as a swimmer at state and national levels, and his other involvement in exercise. He included in the email a link to an Internet page at the tertiary institution where he worked, which had a news article about some of his more recent successes in the pool. Two facts in the email were particularly striking. Ben had only started swimming at age 23 and he said that it took six months for him to pluck up enough courage to enter a gym. My perceptions of him, from his email, were that he was a high achiever, but getting to where he was could not have been easy for him. Given this interesting, but brief, snapshot of Ben's involvement in physical

activity, I decided to ask him to participate in this study. He readily agreed, and we made arrangements to meet.

I met Ben outside the building in which he worked. The first thing that struck me was how functionally unaffected he seemed to be by his cerebral palsy. Apart from a typical cerebral palsy gait when he was walking, there was nothing I noticed that suggested he had the condition. His greeting was friendly and he invited me to go up to the offices where he worked.

During our walk to his office, we passed a few of his colleagues who were working. They all seemed pleased to see Ben, which left me with the impression that he was a respected member of staff, of whom his colleagues were quite fond. We did the interview in a small conference room, with a window that overlooked other buildings of the institution. Ben made himself a cup of coffee, which further illustrated that he had a high level of physical function.

### *Isolation from Family*

Ben had good knowledge of the events that occurred around his birth. The weekend before I met Ben he had spoken to his parents about his birth, in preparation for our meeting. When Ben was born, his parents lived in a small rural town. Ben's mother went into labour prematurely, but was told to go home, because her doctor did not think she was going into labour. The doctor inferred that she was stupid. The harshness of the doctor's evaluation of the situation may have reflected his inexperience in recognising premature labour, but it may also have been endemic of people's attitudes to teenage mothers, in small country towns, in the 1970s. Ben's mother was 18 when she gave birth to him, and he was her second child.

Ben's hometown had no facilities for premature babies. When the doctor realised that Ben's mother was in labour, she was rushed to the nearest city to give birth.

B: I was 8 weeks premature, and in hospital for the first 6 months. I don't think the relatives could cope with it so they basically just wouldn't come near me or Mum, which obviously wasn't hard for me, because I didn't know, but for Mum it must've been very hard.

This extract encapsulates two themes that are discussed in this life history. The first theme is the close bond between Ben and his mother. I will elaborate on this relationship later in the life history (see *The First Competition*). The second theme is the lack of support from extended family and friends during periods of Ben's life (e.g., when he was a child). One of Ben's mother's grandparents was the only family member to visit Ben and his parents in hospital.

Ben's grandmother, on his mother's side of the family, appeared to have been angry that her daughter was pregnant. Ben explained that his grandmother was a deeply religious woman, and to have her daughter give birth to two children out of wedlock may have been unacceptable to her. She may have also perceived that she had lost standing within her community, because her daughter was a teenage mother. In coping with this predicament, Ben's grandmother withdrew support from his mother, and blamed his father for the situation in which they were involved.

### *Prejudiced Diagnosis*

Ben was diagnosed with cerebral palsy when he was two years old. The advice from doctors and specialists was pessimistic as to Ben's prognosis.



B: My parents realised that I couldn't sit up and, y'know, right from then, too, it was a case of every doctor, every specialist, just saying, y'know, "Just put him in a home, he's not going to amount to anything."

Ben told me that the doctors, whom he saw as an infant, were inaccurate in their reporting of his functional capabilities. In one instance, a doctor recorded that Ben could only count to three, and only knew the first three letters of the alphabet, when he apparently knew all the letters in the alphabet and could count far beyond three. The doctors' attitudes may have been reflective of those of their peers in the medical profession at that time. In the 1970s, it was common practice to institutionalise children with disabilities. Although Ben, as an adult, could tell this story to me, he would probably have been unaware of the doctors' recommendations at the time.

*Fragile: Handle with Care*

Ben's parents were not satisfied with the advice the medical practitioners had given them, and did not institutionalise their son. His parents were adamant that Ben would go to a mainstream school. This part of Ben's story resonated with my own life. I was the first person with a disability to attend my country school. From what I can recall, both staff and my classmates supported my attendance at the school. Ben's story, however, was different to mine in terms of the extent of support he received from others at school.

Although there was a special unit for people with disabilities at the school he attended, Ben was the first child to be fully integrated into mainstream classrooms, and faced a variety of challenges. Erikson (1985) proposed that, at this stage in life, a child faces the task of demonstrating industry, with the risk of

showing inferiority. It is at this stage when children learn that aspects of themselves (e.g., disability, race, socioeconomic background) can influence their worth in society. For Ben, his cerebral palsy made him sufficiently different from his classmates. Ben indicated that his teachers were uncomfortable to have a child who had a disability in their classes. His first teacher would carry him around, because she feared that he might fall, and break a bone. Academically, Ben was struggling to succeed, and received report cards with a number of failing grades. Socially, Ben's classmates typically avoided him. The other children seemed to be mirroring their teachers' behaviours towards Ben. Further confusion may have been created for Ben's classmates through the existence of the special unit, which provided education for five children with disabilities. These five children were not integrated into the mainstream classrooms. Ben was not part of this unit, but may have displayed some of the physical characteristics of the people within the unit. Ben's classmates did not associate with the children from the special unit, nor did they socialise with him. Ben's limited academic success may have been due to his difficulties with integrating into the school system. He was frustrated and angry, because he was not like his peers, and because he perceived that he was not given a chance to reach his potential.

Ben had no male friends. Boys teased him, because he was different.

When I spoke with Ben, he had empathy for these children. They did not understand why Ben was different. The main avenue to socialise with boys was involvement in sport and physical activities. Ben perceived himself to be inferior to the other boys, in terms of his ability to compete at sport, and did not participate in their games.

### *Special Friends*

Despite many of Ben's classmates not associating with him he did have two close female friends. These two friends played an integral part in Ben's early life. Ben said that his friends would often tell him that they would like to marry him. He fondly recalled how they would spend a lot of their free time together, especially during weekends. They also spent their lunchtimes together, when they would sit, talk, and eat their lunch.

B: Every weekend we would do everything together and they were very, very special because they were the only two friends I had, and they didn't care that I was disabled. They, y'know, didn't really give two hoots, y'know. We were just friends together and they were really, really supportive, and they were great. I've lost contact with them many years ago, but, y'know, I don't know what they're doing now, but, yeah, they helped a lot, and just keeping me, y'know, above water, so to speak.

Through their friendship, Ben seemed to have received the message that he was worthy of affection from people outside the nucleus of his family and that he could play with his friends like he saw other children of his age doing. For Ben, having people not view his disability as a sign of inferiority must have been a powerful influence in his life. Against the backdrop of school life, where teachers and some of his classmates accentuated his difference, his friends provided Ben a haven, where his disability was not an issue.

Ben's friends tried to get him involved with physical activity. On separate occasions, his friends got him to ride a bike and roller skate down a hill, all rather unsuccessfully. It is difficult to know what effect these attempts to be active had on his perceptions of physical activity. These unsuccessful attempts at demonstrating competence may have contributed to lower self-esteem associated

with physical activity. The attitudes of Ben's friends towards his involvement in physical activity, however, may have challenged his preconceptions that he was unable to be active.

At the end of each school year, the three friends would listen to the class lists for the following academic year being read, and hope that they would remain together. For one year, however, Ben was separated from his two friends. He was being academically held back a year. Ben described this event as particularly traumatic. Although he was not losing his friends (they remained friends for several years to come), he was losing their support in the classroom. To use Ben's words, he needed to have his head kept above water. Ben had feelings of inferiority that were grounded in his cerebral palsy and people's reactions to his condition.

B: I was very down on myself [pause], y'know, I thought, "Well, why am I here? What's the point, y'know? No one likes me, so why am I here?" I was just trying so hard on my school work to get somewhere, but I wasn't, y'know, getting past getting Ds and Es and Fs, and I just said well [pause], I was just so frustrated and so angry that, y'know, "Why aren't these people giving me a go? I just want to be like everyone else. Why am I not like everyone else?" I didn't understand why I was disabled. I didn't know what disability I had.

In terms of Erikson's (1985) latency stage, Ben was becoming aware that he was being judged in terms of his disability, rather than his potential to take a productive part in society. The despair evident in the previous extract could have contributed to feelings of inadequacy and mediocrity.

The frequent use of the phrase, "y'know," in the above extract could be interpreted in at least two ways. First, as simply a common phrase, to elicit

whether the listener has understood the speaker's words, and, second, as Ben trying to identify with me, as an adult male with cerebral palsy. Although my condition may have been an important factor in Ben participating in this research, Ben said nothing further that would allow a case for identification to be made (cf. *David's Life History* in Study 4 of this thesis).

Ben's feelings of inferiority at primary school seemed to pervade other areas of his life. He had developed a sense of worthlessness that influenced his interactions with family members. Although, as demonstrated in the next extract, Ben's parents were trying to convey the message to him that his input was valued, the contrary message from his school life was somewhat overwhelming.

- B: I never used to talk, which was really sad. I remember my parents, they got so frustrated with me one time they said, "Right, every night at dinner time you have to pick three things to talk about." That's how bad it actually got to, because I just would not talk. I wouldn't open up. I would close myself up and wouldn't let anyone know what I was feeling, and it would've been very frustrating for them. So they actually got to a point where they said, "Okay, at dinner time, three things you've got to talk about each night". And that was very hard for me. I didn't know what to talk about because I didn't think I had anything to talk about. I didn't think anyone wanted to know what I was thinking. I didn't feel important enough to feel that anyone wanted to know what I was thinking at that young age. Just quite sad.

### *People Like Me*

Ben's other source of social activities, with children his own age, was on camps, and on a horse-riding programme for children with disabilities. At these activities, Ben found kindred spirits. At this stage in his life, he did not know what disability he had, but he knew he had a physical condition, and he identified with other children with disabilities. Ben felt they were like him, and they understood

what he was experiencing. In the next extract, Ben drew a distinction between what he experienced at school, and what he enjoyed when associating with other children who had disabilities.

- B: I actually used to go on camps . . . quite regularly. I used to go horse riding for the disabled quite regularly every weekend, and I felt very comfortable then, because I was around kids, like me, who were disabled. And they understood, and I integrated great with them. But just when I was at school, I was different. I was the one who (was) singled out, y'know, it was a noticeable difference, and I didn't want to be different, and I couldn't cope with it.

### *In This Life Together*

The strength of the nucleus of the family was a theme that often came up as we spoke. The foundations of this relationship can be traced back to family members' reactions when they were told that Ben's mother was pregnant, with her first child and then with Ben. Ben's mother and father seemed to be isolated from support from their families, and so a reliance on each other developed. This close mutual support then extended to their sons. An example of this "we" (i.e., Ben and his parents) can be seen in Ben's discussion of his first school.

- B: We really hated that school, and I really think they had a vendetta against me and my parents.

The use of the word "vendetta" demonstrated the strength of Ben's negative feelings toward the school. The school staff were not trained to accommodate a pupil with a disability, and did not seem to know how to integrate him into the classroom environment. This lack of training, and possibly lack of motivation to

assist Ben, was shown in their behaviours towards him where physical activity was concerned.

*Physical Activity at School: Why Bother?*

In the small country school, physical activity involved competing in the national sports. For boys, physical activity meant playing cricket and swimming in the summer, and playing rugby in the winter. Ben was not competent at competing in these sports, and was not aware of any other options, in terms of physical activity. Through unfavourable reflections on his experiences with physical activity, Ben seemed to have developed low self-esteem. The significant adults in Ben's life at that time further contributed to his low self-esteem through not positively reinforcing his attempts at physical activity. This low self-esteem meant that Ben's developmental spiral (Basch, 1988) stalled, which manifested as an avoidance of physical activity.

C: When your class played sport, what did you do?

B: I avoided it. I didn't do it. I thought, "Why bother? They're always going to beat me anyway. So why bother?" I wasn't doing my exercises, either, that all the physiotherapists wanted me to do, because, y'know, it hurt, it's painful. I didn't want to do it. Why was I doing it? Why do I have to do it? I didn't understand. Obviously, when you're that young, you don't understand why you're doing it, and unfortunately I do now. But I just would avoid physical activity at all costs. Swimming carnivals, I just wouldn't go.

The teachers' comments on his report cards showed that Ben was not at ease with his environment. His behaviours were those of a child who had accepted his inferiority, and did not regard himself as being in a situation that he could change. The teachers wrote that he was not applying himself to his work, and was

being disruptive in class. Ben's inability to show competence socially affected his academic performance. As is revealed in the previous extract, this lack of competence was also evident in physical activity. Physiotherapists prescribed exercises to assist Ben to develop physically. For Ben, these exercises were punishing, because they were painful to perform. Physical activity at school was also a type of punishment and was avoided. Swimming was a negative experience for Ben. When he was in the swimming pool, Ben used to stand in the water, beside the pool, until he became cold and was taken out of the water. He did not swim, and his teachers did not expect him to perform this activity. Like physiotherapy, swimming was punishing.

Ben could not demonstrate competence in these physical activities, and performing them would have represented a public display of his inferiority. Understood within the developmental spiral (Basch, 1988), the inability to show competence contributes to a lowering of self-esteem, which, in turn, affects the decision as to whether to keep engaging in the behaviour in which competence could not be demonstrated. Ben felt that his teachers did not even want him to attend sporting events, so he avoided being present at them.

### *Changing Schools, Changing Fortunes*

When Ben was 11, he and his family moved to another small town, which meant that he started attending a new school. This move marked a new beginning for Ben. Academically, he was able to show competence at the new school.

B: When I left (my first school) and went to my next school my marks improved dramatically. To As and Bs and, y'know it was amazing. To pretty much, y'know, above average and also average, average, average,



was nice to be average for a change. But yeah, it was a dramatic improvement compared to (my first school).

Ben believed his improvement in academic performance to be the result of the change in school. It was not only Ben's grades that changed. Ben's stories were reflective of a boy who was more at ease in his environment, and with himself. Ben felt that he was treated more as a person at the second school. Ben's repetition of the word "average" in the previous quote sounded like he was relieved that he was normal, like his classmates.

For the first time, Ben had male friends. Having male friends meant that he was involved in physical activity during playtimes and lunchtimes, instead of conversing, as he had done with his female friends at his previous school.

B: I was being included, and that was something I craved more than anything was just to be included, and I finally was, and I had some great friends, and I absolutely loved it. I got into sport a bit more even though they only played rugby still [Ben accentuated this last word].

Ben's recollections of his time at the second school illustrated his ability to cope with adverse circumstances. Given his experiences of the first school, it would have been understandable if he had restricted his horizons to such an extent that he saw no point in trying to achieve at his second school. This transition between schools, however, seemed to have been a pivotal point in Ben's development. The change gave Ben the opportunity to develop a sense of industry in the latency stage (Erikson, 1985), which contrasted with the sense of inferiority with which he had left his first school. At the second school, he gained the knowledge that he

could be effective in the school environment. He was able to master the coursework and cooperate with others.

These newfound levels of competence, however, did not extend to his performance during organised physical activity. In physical education classes, he was required to engage in activities that were beyond his capabilities. For example, he was asked to walk on a balance beam in gymnastics and to run cross-country races. Ben, begrudgingly, was involved in these activities, and, when it came to swimming competitions, would revert back to his pattern of avoidance, and sit on the side of the pool.

Like his perceptions of his teachers from his first school, Ben felt that his physical education teacher did not like him. Here, Ben may have been projecting his own negative feelings about his involvement in physical activity onto his teacher. The teacher appeared to treat Ben in the same way as other children. In doing so, however, Ben was required to participate in activities where he could not show competence, where he had low self-esteem, and where his inferiority to his classmates was exposed.

### *Moving Forward, Regressing Back, and Sport*

At 16, Ben and his family were on the move again, which meant that Ben had to adapt into another school environment. It can be difficult to fit into a new school during adolescence, when friendship groups are firmly established, and sometimes operate on the basis of exclusion, rather than inclusion, to protect the developing identities of group members (Erikson, 1985). In social terms, Ben regressed back into the days of his first primary school. He had only one friend, a female, with whom he spent most of his time.

Through this latest move, Ben was exposed to a slightly different culture. Freud (1927/1991b) suggested that people readily place cultural ideals among the culture's psychical assets. Cultural ideals represent the achievements that are most valued and are most striven towards. In Australia, achievement in sport is commonly valued and pursued, often pathologically so. At this time in Ben's life, he became more aware of televised sport. In contrast to his avoidance of sport in the past, Ben began to start following, and enjoying sport. Perhaps more importantly, however, he seemed to begin to identify with the sport people he saw.

### *The Best Days of My School Life*

A year later, Ben and his family moved again, which presented Ben with one more school to attend. Ben was held back a year, because of curriculum requirements in this new state, and so spent two years at this school. Ben regarded these two years as the best school years of his life, because he had the most friends he had ever had. He attributed this change in fortune, with regard to the number of friends he had, to the increased maturity of his classmates, as compared to his classmates in previous years. Children, however, can be extraordinarily accommodating of diversity, as can be seen from Ben's experiences at his second school. It seems a crucial part of his acceptance at this last school was that he was quickly invited to join a group of students for lunch. If that invitation had not occurred, Ben's feelings of inferiority, grounded in childhood experiences, may have resulted in him avoiding a group of people, and preferring to seek friendship with those on the periphery. As at the second school Ben attended, having a group

of friends seemed to soften his sense of inferiority and allow him to feel, in his words, normal.

B: Those were probably the two best years I've ever had during my schooling in terms of, I had so many friends. I had 30 or 40 friends for the first time. I was actually included in this huge group of people, and I was just one of the gang, and it was great to be just one of the gang, and, y'know, we'd go and play basketball during lunch, y'know. Here I was doing some sport at lunchtime, and we'd go to parties. I'd go to friends' houses. I'd be doing everything that everyone else had been doing for years. And it was great to be included. OK, I did nothing of schoolwork. I used to, y'know, go to school to eat my lunch. But, y'know, and play basketball at lunchtime, but (it) was great. I had 30 or 40 friends, a huge group, which we all hung out together. We all looked out for each other and, and that was great.

For Ben, one aspect of normalcy seemed to be participation in sporting activities.

Like in his second school, when he had male friends, he was involved in lunchtime sporting activities. Playing sport, then, also presented the opportunity for social connectedness.

### *The Man with One Leg*

Ben's identification with sports people grew stronger when, in 1992, he saw the Paralympics, for the first time, on television. This event made Ben aware that people with disabilities could be involved in sport. Even so, Ben did not attempt to engage in any physical activity.

B: I saw a bit (of the Paralympics) on TV and thought, "Gee, that's weird, that guy hasn't got a leg and, ooo, what's this, and they'd been televising for Barcelona, and gee that guy's disabled yet he's competing in sport." And it was the first time that I've ever seen anyone compete on TV or anywhere in sport with disabilities, and I thought, "Ooo, that's quite bizarre," but I didn't really think any more about it.

*Being Alone Versus Being Dead*

After Ben had finished high school, he and his family returned to live in the area where he went to his third school. There, he rekindled his relationship with his female friend, with whom he had gone to school. Greater issues, however, were pressing. The school days were over, and he was seeking employment in an area that had high unemployment.

Ben was enthusiastic about the possibility of getting his first job. He did not disclose that he had a disability in his job applications. He figured that if could get to the interview stage, his merits would overshadow his disability. The reality, however, differed from what Ben had envisaged. Ben would go to job interviews, and he perceived that he did not have a chance of getting the jobs as soon as he walked in the door, and the employers saw that he had a disability. He was frequently asked what was wrong with him.

Ben responded to this anxiety of repeatedly getting job applications rejected in two ways: through anger and depression. Anger manifested in his attempts to seek assistance from an employment agency.

B: I actually went to, what they call, the employment agency (and) said to them, y'know, is there any extra assistance I can get. I'm not looking for financial (help), I'm looking for any assistance that I can get to help me find a job, because I am disabled. And they said, "Oh no, you're not disabled enough." And I said, "Well, what is this?" Y'know. I tend to get in a rage, I can't control my rages, so I let fly. I really had a go at them and I said, "Okay, what constitutes being disabled enough?" And they said, "Oh, being in a wheelchair or being, y'know, intellectually disabled." So even you wouldn't be disabled enough. And I said, "But that's ridiculous, have you ever been to an interview with someone who's disabled and seen the look on the employer's face?" And they said, "Oh well, I'm sorry, but that's the way it is." And I just said, "Well great, well I'm never going to be employed." Y'know. So that was very hard also.

The rages that Ben talked about seemed like expressions of frustration with the apparent hopeless circumstances in which he was finding himself, rather than verbal attacks on other people. He could not secure a job, and could not get help from people who, he believed, provided assistance for people with disabilities.

In the main, however, Ben became depressed through being unable to find work. Basch's (1988) conceptualisation of depression, as the possible result of an inability to cope with a given stress, fits better, in this case, than Freud's view of depression as the ego's cathexis of hostility towards others turned inward.

Depression manifested itself as increased feelings of inferiority and reduced motivation to seek employment.

B: Every rejection letter (that) came, I took it personally as, "Okay, they don't want me because I'm disabled," and so, in the end, I just got very lazy and thought, "Well, why bother? I'm, y'know, I'm living at home. I'll just, y'know, just do nothing." So I didn't have any other avenues to let my frustration out either, and so it was all piling up on me, and I just thought well, y'know, after a year or two, why bother, y'know. Why am I here? Y'know. No one wants me. Obviously I'm not, I haven't got any skills to offer anyone so why am I here? And it was a case of, y'know, I don't want to live anymore. I don't have any purpose in life. Like, y'know, I can't earn my own money. I can't be independent, and so I may as well just end it all, and that was really, really sad.

As in previous stages of Ben's life, his feelings of inferiority came through. The letters of rejection seem to have confirmed Ben's feelings of inferiority, and brought into focus other issues he was facing. Ben was angry that he had cerebral palsy. He revisited the question of why he should have this disability and why he should have to prove himself to an unaccommodating society. The rejection by employers seemed to bring to the fore previous rejections by teachers and classmates. Once more, Ben felt alone and unwanted. Ben also felt his hopes of

living independently, like his brother, diminishing, and he faced the undesirable prospect of living with his parents for the rest of his life.

Understood within the developmental spiral (Basch, 1988), Ben did not show competence in his job hunting, and experienced a loss of self-esteem. His parents kept him seeking work by strongly encouraging him to persist with the task. To gain a sense of normalcy in his life, Ben sought refuge with his friend during most weekends. She supported him and was someone, other than his parents, to whom he could talk about his difficulties.

The support from his parents and friend, however, was not sufficient to compensate for his feelings of inferiority and lack of competence in finding work. Ben's development had been substantially inhibited. Basch (1988) suggested that, in such cases, professional help may be required. In Ben's case, he attempted suicide.

Using Freud's (1917/1991b) terms, there seemed to be a strong cathexis between Ben's ego and his ideal of independence. This object-cathexis was shattered by the frequent rejection by potential employers and the employment agency. Rather than the free libido being displaced onto another object, the ego cathected with the object that had been abandoned. Alongside the identification with the ideal of independence came the cathexis of the anger, frustration, and rejection he had experienced with the employment agency personnel and potential employers. Ben's suicide attempt was an attempt, in some ways, to do harm to these people.

Such was Ben's despair that he drank some cleaning fluid, and then went to sleep. The liquid appeared to have had little effect on Ben, apart from waking up with a sore throat.

B: I would often (find) it would consume me that, oh, no one likes me. I don't want to be here. I want to end it all. I (would) feel better off dead. I'd rather be dead than alone. At least I wouldn't have to deal with all these problems, and that's scary.

Ben interpreted his survival from his attempt to poison himself as a sign that he was meant to live. He continued to be depressed after this attempted suicide, but did not have further suicidal attempts or ideations.

### *First Job*

To improve his skills, Ben completed a bar course, where he finished near the top of his class. This extra training, however, did not immediately result in a job. It was not until he was 21, and he and his family moved once more, that he gained employment.

Ben's first job was for three hours per week as a glassier at a bowling club. His job was to pick up drink glasses. From that beginning, he increased his competence and self-esteem. Ben's desire to prove himself was strong. After the rejections of the past, he was well aware of the typical perceptions that people had in regard to his ability.

B: My goal, from those three hours a week, my goal was to make this work and as a challenge to myself to basically tell me that yes you can do it. *The only reason you couldn't do it is because you wouldn't let yourself do it, which I've done for twenty years, y'know.* I just thought, well, every opportunity you get to learn new things you do it. You learn it, because it's only going to be beneficial for you in the long run, and get as many



skills as you can, because you're going to have to get out there, and if you need to get another job it's going to be on your skills.

There may be several processes underlying the sentence I have italicised. First, it could be the super-ego in operation. Ben would have internalised parental messages to the effect that he was a normal person, yet there are several examples throughout his childhood and adolescence of him avoiding certain activities because of his cerebral palsy (e.g., swimming). Second, although Ben did not always participate in physical activity, he enjoyed sport. Ben did not participate, unless he was encouraged, because of his sense of inferiority for involvement with physical activity. Third, his ego's identification with the ideal of independence, and with it the rejections he faced from employment agency personnel and potential employers, may mean it seems to him like the barriers that other people put in place are of his own making.

In general, the staff and patrons of the bowling club were supportive of Ben's employment. Many, however, were unconvinced that he would have the ability to do the job. In a more extreme case, Ben said that there was one employee who did not like him and tried to get his employment terminated. This issue came to a head in the manager's office, where the employee accused Ben of using his disability as an excuse for not doing certain tasks. The issue was resolved two weeks later with the termination of the employee's work at the club.

### *The Turning Point of 23*

Ben defined his life in two temporal phases. That is, pre-23-years-of-age, and post-23. He referred to the pre-23 phase as psychologically damaging, where he erected barriers to his development. These barriers (e.g., difficulties at school,

problems finding employment) do not seem as if they were entirely his construction. The prejudices of other people, Ben's internalised disabilism (brought about by, for example, identification with the ideal of independence), and a severe super-ego, all seem to have contributed to retarding his development.

The origins of this turning point (i.e., age 23) probably lay in his growing awareness of sport during adolescence. Ben seemed reasonably unaware of these connections and was concrete in his splitting of his life into two phases. As I have described, however, Ben's increasing interest in sport developed when he was 16, and he was exposed to a range of different sports on television. Ben seemed to begin to identify with sports people at this age. The sports people were what he was not, but what he wanted to be. They were fit, active, successful, and accepted by society. Ben, however, was physically inactive and had only a small social network. At 19 years old, through watching the Paralympics on television, Ben became aware that people with disabilities were involved in sport.

Huge inspirations in Ben's life were the Olympics and Paralympics in Atlanta. Ben's awareness of people with disabilities involved in sport had been sparked four years earlier with the Paralympics from Barcelona. Four years later, he was determined to watch as much of the Olympics and Paralympics from Atlanta as he could.

B: I wasn't as obsessed as I got when I, y'know, started taping all the (Atlanta) Olympics, and everyone would ask, "Why are you taping all the Olympics?" It's like, "Well I don't know, I guess I am, I just love it." So, y'know, I was working at the bowling club and, of course in Atlanta, the swimming events were in the morning, and I would stay up all night, lie on the floor and watch, tape, edit out all the ads, and just watch it and just follow Australia . . . and just love it. And now that I knew that disabled people could compete in sport, I had a greater interest.

In this quote, it was interesting that Ben specifically mentioned swimming. People sometimes become fixated with past traumas (Freud, 1917/1991c). Ben's childhood experiences with swimming seemed to have been particularly devastating for him. Through watching swimming, Ben seemed to be going back to a time when he was hurt. Ben was able to articulate what he saw when he watched the Olympians and Paralympians perform. He deeply identified with these people and wanted to be among them. Olympians and Paralympians represented everything that Ben wanted to become.

B: I thought, "Well, okay, if they can do it, so can I." And I just admire them, because they're people who have set themselves goals, like I was now doing, and they just wanted to get out there and achieve. I saw these people who were goal setters, people who have a positive mindset, and I only wanted to be around people who were positive now. I didn't want to be around negative people, and I saw Olympians and Paralympians as the ultimate people. That positive thoughts, positive energy, and positive outlook on life, and that's now what I wanted, and so I would often watch sport every day and every night. Just to see, just to watch them, and follow them, and admire them, and, because Australia is obsessed by sport, just to be a good Australian.

### *Six Months to Join the Gym*

Seeing Paralympians on television motivated Ben to engage in physical activity. He wanted to join the gym, but it would be six months before he went through the doors of the gym and took out a membership. Motivating him to join the gym were his continued interest, following the Games, in Paralympic sport, his desire for normalcy, and his poor body image. Ben's internalised disableism, together with being self-conscious and fear of being hurt by others, however, kept him from joining the gym.

Following the Paralympics, Ben was interested in finding out all he could about the Games. He wanted to know the history of the Games, the sports that were involved, and the classification system used to grade the level of function impairment. In essence, he was probably trying to find out how he could participate in sport for people with disabilities. For Ben, involvement in physical activity was something he associated with being healthy and normal. He wanted to do activities that other people were able to do, such as running and swimming.

Ben described his body, at that stage in his life, in negative terms. He had internalised others' perceptions of how a body should function. Ben's body did not function with the same precision as the perception of ideal body function he had internalised. His perceptions of his body were a catalyst for change.

B: I hated my body. I hated everything about it, and I just woke up and said, "Well, you hate it, do something about it."

C: What did you hate about your body?

B: I just hated the fact that, y'know, I'd trip up all the time, or I was weak. I was sickly. I, y'know, had no energy. I just, y'know, wasn't strong enough to lift certain things, and I just didn't like it. I wanted to be like everyone else.

Ben's internalised disableism and being self-conscious about his movement abilities, however, were barriers to him joining the gym. The people who had expressed doubts in his ability, and prevented him doing activities in the past, now formed part of his ego, which was preventing him from engaging in the gym environment. Ben also felt inferior, with a body that did not move in the same way as other normal bodies did.

- B: I just put up these amazing boundaries where I just wouldn't let myself do anything. "Oh no, you can't do that because you're disabled. You might hurt yourself," or, "Oh no, y'know, don't go for those jobs, because, y'know, people are going to reject you, so don't even bother," and (the) same with the gym. I'd walk past, and I'd look in the window and think, "Yeah, I'd like to do that, but, y'know, people might stare at me, and I don't want people staring at me."

The self-blame for not doing certain activities, which is evident in this quote, is reminiscent of the same thoughts he had when he got his first job. After achieving (e.g., getting a job, becoming a gym member) he harshly criticised himself for not having achieved sooner. As I have suggested, this pattern could be evidence of a severe super-ego.

A further aspect of the boundaries that Ben erected was his fear of being hurt by others. In his life, he had been punished for trying to be included with others (e.g., at school, gaining employment). These experiences contributed to Ben's reluctance to associate with others, who might hurt him further.

- B: I look back on it, and I think, "What was going through my head? Why was I, y'know?" Like I blame myself more than anyone else throughout my whole life, because I had put up these incredible boundaries to myself, y'know. Like, okay, I don't want to be hurt, so I'll put up boundaries so that, y'know, okay, I will look after myself. I don't want anyone else to come near me, y'know. No one else likes me anyway, so I'll just, y'know. I look back on it, and I think, "Why did I do it?" Y'know, they weren't the problem, I was the problem.

Ben approached the gym in the same methodical way in which he had started work at the bowling club. That is, he started with the basic tasks and worked his way from there. In the gym, this approach meant that he started off with lighter weights and gradually increased the weight he could lift. For example,

he started the bench press by lifting the bar with no weight on it. Ben also focused on his own progress, and not on the weight that other people were lifting

*Do the Sport You Hated Most*

Still 23 years old, and doing training in the gym, Ben decided to learn to swim. The choice of sport in which to participate seemed at odds with his feelings toward swimming, and may have represented a fixation with a past trauma (Freud, 1917/1991c). Ben hated swimming because of bad memories he had from when he was at his first school. The decision to learn to swim at this stage in his life may have been an attempt to try to heal his past, and to prove to his teachers, at least in his mind, that he could swim.

B: When you don't see yourself walk, you don't think, you don't see how bad it is. So, when I see myself walking I think, "Oh, okay so that's how everyone else sees me," and I think, "Oh, okay it's quite confronting." And I just got to a stage where I just didn't like me. And I woke up one day and said, "I've had enough. It's time to do something with your life," and I said, "You can either go down two roads of just being mediocre and just, y'know doing your 3 hours a week and, and being the way you are, or you can choose a sport which you could never do and go out there and do it, and choose a sport you hated most," which was silly.

C: Why a sport that you hated?

B: 'Cos I always remember (my first school), and standing in that pool every day during summer. No one wanted to teach me how to swim, and I'd just stand there and shiver, be freezing, and I thought, "Right," and I always thought, "I couldn't." My parents actually, one day, threw me in the pool, and said, "You're going to learn to swim," which was probably the wrong way to go about it, but they were frustrated too, because, y'know, I could never swim in our pools that we had at home.

At the start of this dialogue, Ben's body image issues come through once more.

There seemed to be a large incongruence between Ben's amount of bodily function and his internalised ideals regarding bodily function. These issues

seemed to affect his self-esteem in approaching new physical activities. Part of the motivation to swim came from a Paralympic swimmer, who had greater physical impairment than Ben. He rationalised that if someone, who was more physically impaired than he was, could swim, then so could he.

Learning to swim was confronting for Ben. He was in a class with children, who asked him why he could not swim, or walk as they did. In some ways, he was back at his first school. This attempt at swimming was more successful, however, than his experiences as a child. After six swimming lessons, Ben was able to swim a lap of the 25 metre pool unaided. From that point Ben was determined to set new benchmarks and to swim further. One of Ben's underlying motivations to swim was to change, because he did not like who he was.

B: I wanted to know what my capabilities were and what my limits were, and I wanted to push them, because I no longer wanted to have those barriers at all. I was sick and tired of being who I was, and I wanted to make changes and everything else overrode that. Everything was towards improving myself physically and mentally. But I think mentally, I needed to improve myself mentally more than anything else.

Ben felt he gained physically, socially, and psychologically from exercising in the gym and pool. His goals were primarily directed towards getting aerobically fitter and increasing strength. In time, he had increased his fitness to that of an elite marathon runner, and had dropped his body fat to 5%. This percentage of body fat is unhealthy, and falls at the lower end of the range of body fat percentages of national and international class athletes who compete in sports where leanness is desirable (e.g., body building, gymnastics, wrestling; Nieman, 2003). Ben's

concerns about how other people would perceive his involvement in the gym did not come to fruition. Ben experienced a supportive environment, in which some people openly admired his gym training. He met other gym members and would spend time conversing with them during each workout. The gym and pool became places where he could relieve stress, especially when he experienced difficult days at the bowling club.

### *Crossing the Paths of Olympians and Paralympians*

In a short space of time, still when Ben was 23 years old, he met several Olympians and Paralympians who inspired him to keep swimming and to take up the sport competitively. Given Ben's level of identification with these sports people, he did not need much encouragement to dedicate more time to swimming.

In the pool at which Ben swam, an Australian Olympian was training. Ben spoke with him one day and found out that the Olympian was covering a far greater distance in his training than him. This meeting inspired Ben to increase the distance that he swam from 50 to 100 laps per day. To be like an Olympian or Paralympian, Ben had to begin training like one.

As a member of the Olympic Club for Sydney 2000, Ben took the opportunity to travel to Brisbane to meet another Olympian swimmer. On the train ride to Brisbane, Ben experienced something like an epiphany.

B: I went up to Brisbane, and I hopped on this train to go up to Brisbane, and a very weird event happened, where this guy who is disabled, I'm not sure what, he had cerebral palsy because he was a soccer player, a Paralympic soccer player, and he came and sat across from me and started talking to me. And it was sort of like a weird moment like, I don't know if you ever have them, where things happen for a reason or you just have those moments in your life which are profound. And this was one of those



(moments), and here I was going to see an Olympian, but who should I meet first but a Paralympian.

The reason that this meeting was profound for Ben was that he interpreted it to mean that he was on the right path through life. The experience seemed to be quite spiritual for Ben. Although Ben described himself as agnostic, he believed there was something or someone who was looking out for him.

About two months after meeting the Paralympic soccer player, a new manager was appointed to the gym where Ben trained. The new manager was a Paralympic gold medallist in swimming. Meeting this Paralympian was to be another profound moment for Ben, and further evidence that he was experiencing something spiritual. Ben and the Paralympian, however, did not speak with each other for a while. Ben felt too embarrassed to approach one of his idols, and also projected his feelings onto the Paralympian. Ben would sometimes see the Paralympian watching him swim, but nothing was said until the Paralympian approached Ben.

B: One day I was finishing swimming and he walked out and he said, "Do you know who I am?" And I said, "Yes, I do know who you are," and he said, "Have you ever considered going competitive?" And I said, "No, because I'm too old, because, y'know, they retire at 26, 27." So I said, "No, look I'm too old," and he said, "Well look I'm 31 and I'm going to compete in my third Paralympics, and I think you've got a bit of talent, and I think you should, y'know, give it a go and get in there and start competing." And he (then) said, "If you can do the tumble turns, you're half way there".

Interpreted using Basch's (1988) developmental spiral, the Paralympian entered Ben's spiral at the self-esteem, and then behavioural, segments. The conversation, in the previous extract, enhanced Ben's self-esteem. The Paralympian, with whom

Ben identified, was telling him that he may be good enough to swim competitively, and possibly be a Paralympian himself. Ben practiced performing tumble turns in the pool and received some assistance from the Paralympian to improve his technique.

### *Getting a Coach*

Given his age and disability, Ben was unsure whether a swimming coach would include him in a squad. At this stage of Ben's life, however, he seemed to have more self-esteem than he did when he was contemplating going to the gym, so it did not take him long to approach a coach. In the summer, a new swim club was started in the town where Ben lived. Ben approached the coach and was invited to join the squad. This inclusion, however, presented a further issue for Ben. He knew that the other swimmers in the squad were children, and he was uncertain as to how they would react to him being in the squad. Given that he had difficulties making friends with children when he was a child, Ben was unsure whether the children would accept him. Ben's concerns, however, were not realised. The children in the squad were enthusiastically supportive of his inclusion. Initially, Ben did not want to swim competitively. His purpose in being coached was to improve his technique. Exactly six months after joining the squad, however, he went to Sydney to get his disability classified so that he could swim competitively.

### *Confronting the Past*

The trip to Sydney gave Ben an opportunity to see the Olympic Village and Olympic Park. More important, however, was that he got to be a spectator at the Australian National Athletic titles. It was at this competition where Ben first

saw live events that included athletes with disabilities. He saw wheelchair athletes and the Australian cerebral palsy relay team.

B: (Seeing these athletes) was another profound moment, because it was the first time I've seen disabled athletes competing in sport.

C: So what was that like?

B: I broke down emotionally [pause]. It was amazing. I just thought, well, a mixture of anger and, y'know, relief, but, y'know, it had been a huge year. All these things had been happening within 12 months, and I just thought, "Well, I've just got to keep going."

C: Tell me what you were angry about?

B: The thing that I was angry about was I was sort of angry at a lot of people, but also myself. Y'know, I had put a lot of barriers up for me. Saying that, "Oh no, I can't do that, because I'm disabled," y'know, "Why was I not told about the Paralympics earlier?" I didn't find out until '92. And, y'know, if I'd known about this at school, it would've solved a lot of problems. I probably would've got through it a lot better, y'know, but that was the 70s.

This dialogue encapsulates many of the themes that I have previously discussed (e.g., others' prejudices, internalised disabilism, identification with sports people, spiritual guidance). Significant in this dialogue was that Ben's anger was not solely directed at himself, as it had been during his descriptions of other parts of his life. Although admitting that he had restricted his own growth, he also acknowledged that the behaviours of others had delayed his development.

Ben thought that if he had known about the Paralympics when he was at school then his situation would have been better. He did not think that the issues that he was having at school would have changed. Rather, participation in sport would have allowed him an outlet for his frustrations with school life. It would

have also given Ben an opportunity to demonstrate competence, during childhood and adolescence, when he spent a lot of his time feeling inferior.

### *Increasing Competence*

From the age of 23, Ben experienced strong development in many facets of his life. Not only was Ben demonstrating competence in the gym and pool, he also took opportunities to extend his hours of work, and learn other operational aspects of the bowling club. Ben learned to perform a range of tasks, including bar work, cellar duties, handling promotional material, and running the gaming machines. Ben also took on managerial roles, including cash handling, managing staff, and opening and closing the club. Ben relished the authority that he had in his managerial positions at the club. The managerial roles that Ben undertook helped him to develop greater competence in the work environment. Ben's self-esteem was enhanced through being able to demonstrate competence, and through the compliments he received from patrons. He was loved by the elderly ladies, for whom he would call the bingo numbers, and the men congratulated him on how good the beer tasted, of which Ben was proud because he cleaned the beer lines.

Earning his own money meant that he had the resources to leave home and live independently of his parents. He now could fulfil his wish to be independent that he had had since leaving school. At this stage of his life, Ben had everything he wanted. He had a place of his own, a job, and a full life with his gym training and swimming. Two years later, however, the relationships between staff and management at the bowling club started to become strained, and the union was brought in to support staff claims of being underpaid. Although the staff were successful in gaining the money they were owed, management reacted by

changing the hours that staff worked. Ben's hours were halved, and new staff were hired to perform roles that were superior to his, and which he had previously fulfilled.

### *The First Competition*

Another of Ben's profound moments occurred at his first swimming competition in March, 2000. The competition was held at the new Olympic pool in Sydney, which was significant for Ben, because he knew that the Australian Olympic and Paralympic teams would be racing in the pool later that year. For Ben, being at the Olympic pool and seeing his name on the main scoreboard was a huge moment.

Ben may have been overawed by the significance of the occasion, because he was disqualified from his first race. On two occasions, during the 400 metre freestyle race, he did not touch the wall when he was performing the tumble turns. During the race, Ben realised that he had made those errors, but kept swimming to prepare for his next races. Ben sorted out his tumbling issue, and went on to win his next four races.

B: And, y'know, where the Olympics were going to be held and the Paralympics. My name. I was just so proud that I had done it myself. I had stuck with it. I had not given up, and I was keeping going, and here I was in the Olympic venue, swimming. And then I won my next four races, and, y'know, I was so pleased. I rung my parents up straight away and said, "Look, I've won four races," and, y'know, they were very, very proud, and Mum was in tears. She cried over the phone, I said, "Don't do that, 'cos I'll start".

Ben had a close relationship with his mother. She had supported him throughout his life, and had fought for his rights when he was a child and an adolescent. Ben

said that she did not consider herself to be a strong woman, as illustrated, for example, by her asking him on several occasions throughout his adult life whether there was something more that she could have done for him. Each time, he replied that there was nothing more she could have done, and that the best thing she did for him was to treat him as a normal child. From Ben's early life (see *Isolation from Family and Prejudiced Diagnosis*) his mother did not receive support from family members, medical practitioners, and schoolteachers, from which other mothers may typically benefit. It seemed to me that Ben's mother had done the best job she knew how, and that Ben appreciated all that she did for him

Apart from the competence that Ben demonstrated through swimming, he benefited from the social support he received at the swimming competition. Ben felt at ease being around other people with disabilities, which was reminiscent of how he felt when he participated, as a child, in a horse-riding programme for people with disabilities. Being known and supported by a large group of people also reflected his experiences during the best days of his school life.

B: (On the) first day (of) my first competition, the thing I'll never forget was that this young girl came up to me. She was blind. She was a blind athlete. She gave me a hug and said, "It's great to see you here and we hope to see you later on at other competitions." So, I was finally amongst other people like me, and it was a huge moment and, y'know, I had all these people coming up to me on the first day and they didn't know me. They said, "Oh look, it's great to see you here. We hope to see you at many, many more, and we hope to see you at state titles." And, y'know, it was great. So, now I haven't missed a swimming competition, and I'm always there. I'm known by everyone, and so it's great camaraderie.

### *First Trophy*

Ben received his first trophy at the annual awards evening, which his swimming club held. This moment was significant for Ben. He had recently won four competitive races, but, up to this point in his life, he had never won a trophy for his involvement in physical activity. Ben received a small trophy from his coach, which was for the swimmer who had put in the most effort for the year. Winning this trophy caused Ben to reflect on how, at his first school, the teacher had handed out awards for those students who had swum specific distances (e.g., 50m, 100m, 200m). Ben did not receive a certificate, because he could not swim. Telling the story to me, I could sense that Ben was particularly proud of this achievement. This trophy represented public recognition that he had displayed competence in a physical setting, and had done something of which other people did not think he was capable.

### *End of First Job*

At 27 years of age, Ben had become frustrated with his job. He was not getting opportunities to perform other roles, which was restricting his development. Finally, he quit his job.

B: I didn't want to leave, but it got to the stage where I would just come home (and) I'd be emotional. I'd be ringing up my parents and just ranting and raving. I'd be so frustrated, and, in the end, I just woke up one day and said, "I've had enough. I can't deal with this anymore. I don't care. I'll live in the gutter if need be, but I can't work here anymore." And they got their way in the end. I did leave, I walked out, and it just felt like a great relief off my shoulders.

### *Going to the Games*

The day after Ben quit his job, he received a letter from the Sydney Olympic Games Organising Committee (SOGOC), which invited him to work in the Athlete's Village at the Sydney 2000 Olympics. This invitation was a dream come true for Ben, for it provided him with the opportunity to be around the athletes with whom he identified so deeply. The chance to go the Games was a long time coming. Back in 1993, when it was announced that Sydney had won the bid to host the 2000 Olympic Games, Ben was determined to be at the Olympics and Paralympics, but he did not know how. Ben regarded receiving this invitation as another profound moment.

B: (When I received the letter) I was actually on my way to the gym to do some exercise and once again, as you've heard earlier on in the piece where *things happen for a reason, you just think someone's looking over you*. I actually just stopped, sat on the ground and cried, because my dream was about to come true. As, y'know, as you've heard, I'm fanatical about my sport.

The emotion that Ben expressed in this extract is further evidence of his identification with sports people. Ben was overwhelmed with the thought of being close to these people. The passage I have italicised seemed to have spiritual overtones, which were reminiscent of his meetings with Paralympians when he was 23 years old.

Going to Sydney for the Games, however, was a decisive stage in Ben's life for another reason. He had decided to continue to live in Sydney following the Games. To Ben, this move represented the biggest risk he had taken in his life.



Ben had 10 weeks of work guaranteed, during the Games, and was determined to find a job after the Games had concluded.

Ben was extremely proud of his involvement in the Games. His description of his journey to the Games seemed to resonate with an account that an Olympic or Paralympic athlete might give. This description appeared to reflect his inferiority feelings, which were stronger in his younger years, and his deep identification with sports people.

B: No one ever thought I would achieve anything, and you're now at the Olympic Games.

C: What was that like?

B: I had achieved [pause]. Oh, it was just profound. It sort of hit me right then and there, that, my God, *you've done more than most people, able-bodied or disabled*. You've now been put in this position that, what I called, "The Journey [pause]." This has sort of come, well, not to the end of the journey, but this was sort of a big moment. From learning to swim, from (my first town), from all the way through, and everyone that had said, "You would never achieve or do anything or be employed, you'll never get a job, you'll never, you'll never do anything" [pause]. Here I was at the Olympic Games meeting the American Olympic Team [pause]. And I was once again crying. I had tears coming down my eyes. *I just thought like, y'know, this is huge*. You've got to keep going for Athens. I haven't got there, and I never will, but it was huge, y'know. It was sort of like someone was guiding me throughout those, that last, well, my entire life I guess, and I still think that today, that I'm still, y'know, sort of, I'm being guided by something [pause] to keep going. . . . Some people say, "You should be an ambassador or help out people with disabilities," and I say, "Well, no, I'm just getting on with my life." And *I don't think it's huge to me*, but to other people, standing outside sort of saying, y'know, "You've done a lot," and I just sort of say, "Well, no, I'm just living my life". It's, you know, not special, y'know. *I don't consider myself to have achieved anymore than anyone else*, but, y'know, I had achieved my dream.

My purpose in quoting Ben at length is to point out an example of the later censorship of his thoughts. Ben's initial reflections on his involvement in the

Games were that it was huge for him and that he had achieved more than most people. Soon after, he had moderated his words to indicate that it was not a huge moment in his life, and that he had not achieved more than anyone else. Such censorship could have reflected a need to portray a socially desirable impression. The first two sets of italicised words may have also represented feelings of inferiority and narcissistic compensation, which would have originated from times, in his earlier life, when he did not feel accepted by others. From the second two sets of italicised words, however, Ben's development throughout the latter years of his life was evident. The reality for Ben probably lay between these words. Being at the Olympics was huge in his life, but was neither better, nor worse, than what others had achieved.

The significance of the Games for Ben can be seen from his description of one of his first days at the Olympic Village. Ben's job was to work in the main dining hall, checking the rubbish bins. At one point in the day, Ben had the head of the SOCOG sitting behind him, and the American team walked into the hall. These were some of the athletes with whom Ben so heavily identified. At this moment, Ben reflected on how far he had come, from the first town in which he had lived. This moment was emotional for Ben, because he felt he had achieved.

Two weeks after the Olympics had concluded, Ben was back at the Olympic Village for the Paralympics. He became angry, however, when he was told that he only had five shifts during these Games. Ben's name, however, was put on a list of workers that could cover shifts if other people could not work, and he ended up working the entirety of the Games. His anger, at originally being given a small number of shifts, manifested because he was being prevented from

attending the Games with the sports people with whom he identified. Ben felt that these were *his* Games, and he was determined to be a part of them.

B: I personally saw them as my games, y'know, . . . but it was a huge experience, and I often said that, y'know, "I'm going to experience a Paralympics before hopefully competing in one," *which probably won't happen now, or I didn't make happen*. But, y'know, it sort of encouraged me to keep going with my sport. Seeing those athletes and seeing how they've achieved their dream really pushed me onto maybe, y'know, trying to achieve some of my (goals) in sport and also in life. I mean, they don't just inspire me in sport, but also in life as well. Just to see the confidence that they had.

In addition to Ben taking personal ownership of the games, in the first sentence of the extract, Ben's severe super-ego (italicised) and identification with sports people comes through again. His super-ego seems to be punishing him for not being a fast enough swimmer to compete in the Paralympics. Although Ben had swum times that placed him within the top 50 in the world, he did not feel these times were good enough, because they could not earn him a position in the Paralympic team. Ben said that only swimmers ranked within the top 16 in the world were eligible for selection.

Ben benefited from his identification with Paralympic athletes with regard to the support the Paralympics received from the Australian public. Many people, who did not go to a large number of Olympic events because of the cost of tickets, went to the Paralympics to watch sport at the elite level. The support and acceptance of Paralympic sport by the Australian public seemed to translate as approval of Ben and his swimming. Ben, vicariously through the Paralympians, received some of the acceptance from people outside of his family that he had been looking for as a child and adolescent.

*Going for Gold: Getting a Job in Sydney*

With the Olympics and Paralympics now past, Ben set about finding a new job. He wanted all that he had before moving to Sydney. That is, to live independently and to work. Ben initially applied for bar work, but was not successful at gaining employment. He was able to draw a Government disability pension, which allowed him to live independently, but he wanted to be employed. Unlike where he had previously lived, Ben had access to an employment agency that specialised in finding jobs for people with disabilities. Ben was unemployed for about a year when the agency found him a job doing a variety of administrative work within a large organisation. His days were now occupied with full time work and training, either in the gym or pool.

Using Basch's (1988) terms, Ben was once again experiencing growth through displaying competence. Through gaining employment, he continued to perceive himself as a person with ability, rather than a person with a disability. This change in thinking had first occurred at the age of 23, and was further strengthened through demonstrating competence in the new job. When I met Ben, his manager was also encouraging him to take up part-time university to increase his skills and to gain the knowledge to perform a greater number of roles in the future.

B: A lot of people are looking out for me. Just sort of (to) give me good career prospects within this (organisation) and I've got to take those opportunities. They are fantastic opportunities to finally [word emphasised] get a career, not just a job, but a career going, and that's also just as important to me as my sport. I want to, sort of, use the application and the drive and the success that I have achieved through my sport to also do it academically and in a career, because I think I've got a lot to offer career-wise as well. That's why, when I found out about your research, I

was very interested, because it's a sort of area that I too [word emphasised] am interested in, and I'm also very interested and basically fighting for the rights of people with disabilities.

This extract encapsulates a number of themes. First, Ben spoke about himself using terms (e.g., application, drive, success) that he had previously reserved for sports people. This change represents a manifestation of Ben's development since his early 20s. Ben, as I saw him, had greater self-esteem and seemed more at ease with himself than how he described himself throughout his childhood and adolescence. Second, at least part of Ben's motivation to participate in this research could be seen. That is, he was passionate about the value of physical activity in the lives of people with cerebral palsy. Third, his interest in the politics of disability came through. During the interview, Ben's dissatisfaction with some elements of Government policy, with reference to people with disabilities, was exposed. Ben had strong views on the unfairness he perceived there to be in some policies, such as employment and funding of Paralympic athletes.

The politics of disability is an issue that warrants further investigation. Ben's interest in advocating disability issues seems to have its origins in helping himself through assisting others. Through his involvement in swimming, Ben met many children and young people with disabilities. Ben did not want to see these people exposed to the same injustices that he had experienced while growing up. By advocating for others, especially young people, Ben appeared to be helping himself to mend his own past. Ben acted on his views through becoming involved on the clients' committee of the employment agency that found him the administration job. In the next extract, Ben spoke about becoming the chairman of the clients' committee and about his reasons for advocacy.

B: Because I was the one with probably the best job that they've got throughout their clients, they wanted me to be in that position (as chairman). So, people are sort of not pushing, but sort of coercing me into areas where, y'know, that they want to see me in, sort of helping people with their disabilities. And, yeah, and I would love to do that, because I see a lot of injustices and I'm very passionate about sport for people with disabilities. I want to see them achieve their dreams. I want to see them have equal rights with, y'know, Paralympians with Olympians.

Ben perceived that there was a potential role for him in advocating for people with disabilities, but he wished to obtain a university degree first.

B: (Advocacy's) the kind of area I'd probably like to go into later on in life. I sort of see myself heading down that path eventually, and so I think that, y'know, getting my uni degree and doing those kind of things will also help too, because, as with your research, I'd probably like to go down the same way too, eventually. Because I do see a lot of injustices, and I want to see them stop.

In this extract, another possible motive for Ben's participation in the research was revealed. Ben seemed to perceive that my research would help to educate others about what it was like to live with a disability. Through his participation in the research, Ben was helping with that education. In that I was conducting the research, Ben was identifying with me. He wanted to perform a similar role in society to that in which he saw me, although perhaps he did not want to advocate through conducting and presenting research.

Ben also seemed to be preparing himself for the psychosocial stage of adulthood (Erikson, 1985), in which attention is turned to the establishment and guidance of the next generation. Through his focus on helping others with disabilities, Ben seemed to be skipping the psychosocial stage of young

adulthood. Further evidence for Ben's avoidance of intimacy is provided shortly (see *Sexuality*).

### *Revisiting the Past*

The year before I met Ben, he went back to the area in which he first lived for a swimming competition. He had some unfinished business with his first school, and wished to swim in the area once in his life. Ben wanted to demonstrate his competence to those people who had made him feel inferior. Although the people who contributed to his sense of inferiority, as a child, probably were not at the competition, swimming in the area was enough for Ben.

B: So, to finally have, y'know, those (area's) medals is a huge achievement. To show, y'know, to basically show everyone in (the area) that, yes, I could achieve if you'd given me the opportunity, but you never did. So, y'know, here are my gold medals, and here are my silver medals to prove that I could do it. So, yeah, so that was quite important.

While in the area, Ben also went and visited his first school. Being at this school again was emotional for Ben.

B: In September last year, I actually went back to my old primary school . . . and there was no one there thank goodness, but I actually stood by that pool and screamed. Because I, y'know, I (was) just sort of letting out frustration, like, y'know, "You didn't think I had the ability, and now I've done it."

B: I just stood in the schoolyard and just yelled out, y'know, "I've done it, despite what you thought."

There is a strong theme of resentment encapsulated in these quotes. The pool was significant as a place where Ben could not display competence when he was a

child. He had received little support from the teachers, who were there to guide his development. Yet, as a young adult, Ben demonstrated his competence at swimming in emphatic fashion, by winning numerous medals at State championships. On that day, the pool represented those people who had restricted his development and expressed doubt over his potential to achieve. Ben seemed to be, indirectly confronting his first teachers. More broadly, his release of frustration also seemed to be directed at the doctors and extended family members who had negatively appraised Ben's future.

*Swimming: Working Out Its Role*

The role of swimming in Ben's life was multifaceted. In one respect, swimming, as I have presented, was an aspect of life where Ben could show competence, enhance his self-esteem, and deal with his frustrations. A further aspect, which I have not mentioned, was the functional benefits that Ben received from being involved in physical activity.

Ben perceived exercise as a way in which he could prevent early functional deterioration, which is common in many people with cerebral palsy. Through training, he could delay the time when he would need walking aids, or a wheelchair, for mobility. Through exercise, Ben was able to maintain greater competence, in terms of his mobility.

- B: My exercises are extremely important. It's probably turned into one of the most important aspects of my life, because I see it as prolonging (the onset of) a lot of pain later on, and basically not only just to achieve some personal goals in my swimming, but, y'know, if I didn't do it. In fact, Mum asked me the question, "What if you hadn't done your exercise, what would you be like now?" And I said, "I'd probably be in a very bad state. I'd probably be walking with a walking stick, y'know. I don't know, but I know I'd be a lot worse off."



Ben used to get pain in his right arm, which was affected by cerebral palsy. This pain would return when he took breaks from swimming, but would ease once he resumed his training. Although exercising was ultimately effective in reducing the pain, Ben had to swim through the pain, initially, before the pain eased.

B: When I came back from three weeks of holidays I noticed that my right arm, which has (been) affected by (the) cerebral palsy on the right side of my body, that it was very, very sore, to the point where I nearly stopped. I just thought, y'know, I just couldn't cope with it, and I just thought, "No, I will train every day regardless of the pain just to see what happens," and it came good after two and a half weeks, thank goodness, and since then I haven't swum in pain at all this year since then, and I think that's due to the fact that I do train every day.

Performing exercise may also have medical benefits for Ben. He has a rare genetic blood condition, for which other family members take medication. Ben, however, did not need to take medication for this condition. He attributed exercise as the reason why he could cope with the condition without medication.

In another respect, Ben's swimming became a new outlet for the work of his super-ego. Although Ben used sport to help himself psychologically, the underlying motivation to be one of the sports people with whom he identified remained strong.

B: What I set out to do was to basically improve my self-esteem, my confidence, and to just, y'know, basically build myself into a better person. That has always been the aim and the goal, and whatever I achieve along the way is great, but my main focus is to always, and still everyday when I train, is to basically just keep going never give up, because giving up is failure. If I miss a training session I get very angry with myself, because I'm letting myself down. If I use a stupid excuse like I'm tired or I'm sore [pause]. So it's basically also a mental battle to just

keep pushing, keep fighting yourself, and other people, and just keep going, and I'll do that every day until, I don't know, until I drop dead. I'll keep going and I actually, this year, I made a commitment that okay I'm not good enough to go to the Paralympics, but I really haven't put in what was needed to go. I haven't really put in a lot of effort. I mean, a lot of other people think, y'know, think that I have, and they ask, "Well, what's your training schedule?" And I tell them, and they go, "Geese, we couldn't do that."

C: What was lacking in your preparation?

B: I wasn't putting enough effort in. I wasn't swimming hard enough. I wasn't putting enough effort into my training. I'd often miss sessions just because I was tired or, oh, y'know, "I won't swim today 'cos, y'know, I've got to catch the train and that's, like, an hour." So, y'know, I will miss a session. What's one or two here or there, and I thought, "Well, y'know, you're letting yourself down." So this year, my New Year's resolution was (that) we're going to train every day, or 6 days a week, just to see where I am by the end of the year.

From this extract, swimming seems to have become a metaphor for Ben's life post-23-years-of age. That is, to give up on swimming would be giving up on life itself. Ben thought that if he missed an exercise session he would be letting himself down. Any lack of effort in swimming would mean a possible return to how he was pre-23. Ben's severe super-ego is, once again, present in this extract.

The extent to which Ben drove himself to swim suggests that Paralympic participation, rather than gaining self-esteem, was the underlying motive for involvement. The intensity with which Ben seemed to be training supports this interpretation. Although Ben was getting sore and tired from his training, he wanted to train harder. Ben's reference to the importance of getting faster times in the pool also supports the interpretation that he was still aiming for Paralympic representation.

## Sexuality

Although relationships with females were important at different stages of Ben's life, he had not had a romantically intimate relationship. The lack of such a relationship did not seem to concern Ben, who was more consumed with his sporting endeavours. A significant reason for the lack of a romantically intimate relationship was his avoidance of intimacy for fear of getting hurt. This fear had been present in previous attempts at engaging with others (e.g., joining the gym). Ben was aware of how this fear prevented him from becoming close to others.

B: Actually, I've really never looked for a partner. I've sort of been obsessed with me rather than looking out for anyone else. I've always been very me, me, me orientated. I'm sort of, I am very selfish in that respect. Because people didn't like me as a child, I sort of think that, "Okay, I'm the only one who can look after myself." I don't let people get close to me if I can help it, which is sad but it's just the way I am. That I'm sort of on this mission in life to basically improve me before I could go out and find someone, but hopefully it will happen one day.

B: I'm quite prepared to forego a relationship to achieve that goal (of making the next Paralympics). I've always been a loner. I always enjoy my own company more so than, y'know, having a partner. I am very selfish. I do think of me, me, and me. I always have done because of those barriers that I set up, y'know. *"I've got to look out for me 'cos everyone else is probably going to hurt me," is sort of the thinking that I had pre-23.* So, it's been a battle to try and let people into my life, but it's changing slowly.

These quotes represent examples of Ben's difficulties in addressing the nuclear conflict of the young adulthood psychosocial stage: intimacy versus isolation (Erikson, 1985). Ben's thoughts about intimacy pre-23 (*italicised*) seemed to be still in his present functioning. Erikson warned that the avoidance of intimate relationships could result in isolation and self-absorption. In Ben's stories, there

was evidence for both of these outcomes. In essence, Ben's mother was the only person who had a long-term intimate relationship with him. She appeared to be the first, and sometimes only, person Ben would call on to share his joys and sorrows (e.g., winning events at his first swimming competition). Although Ben mentioned names of friends at times, there seemed to be no longevity and regularity in communication with these people. Ben's self-absorption is clearly reflected in the preceding quotes and in the scheduling of his time. Swimming and work were central parts of his life. As I signalled earlier (see *Going for Gold: Getting a Job in Sydney*), Ben seemed to be preparing himself for the adult stage of psychosocial development, rather than attempting to master the conflict of young adulthood.

*Ben: Where He Was At*

Through hearing Ben's stories, I could tell that he had come a long way, from a person feeling inferior in the world, including an attempted suicide, to a person who was competent in a number of different areas of life, and who was a valued member of several communities. Sport and exercise provided a means by which he could demonstrate competence, gain self-esteem, and improve the image he had of his body. Through his identification with sports people, and, more significantly, sports people with disabilities, he was able to increase his acceptance of himself. Ben seemed to come to accept that people with disabilities need not be regarded as inferior to those with able bodies. After feeling inferior to those people with able bodies, throughout his childhood and adolescence, Ben began to feel comfortable with who he was.

B: I wanted to feel good, and this (gym work), I was doing it for me, so that I could have confidence finally in myself, and be able to say one day that, “(Ben), you like your body, you’re happy with who you are, and what you are,” and I can finally say, “I’m proud to say I am disabled.” If I hadn’t taken this path, I would never have met some of the most amazing people I have met, who have inspired me to go on and do other things. And I think having a disability, this might sound bizarre, but it actually does force you to maybe do things that maybe an able bodied person wouldn’t even consider, because you are trying, well, I know I wanted to try and prove to myself that I could do it. So I would go out and do all these different things, whereas an able bodied person probably wouldn’t, because they’d probably feel good within themselves.

In this extract, I don’t believe that Ben was trying to be dismissive of the issues that people with able bodies face. Rather, he was suggesting that the presence of a disability might result in greater feelings of inferiority, and might require larger amounts of compensation, to cope with the disability. Throughout his life, especially much of his childhood and adolescence, Ben had significant feelings of inferiority, for which he tried to compensate. This compensation manifested itself most strongly in participation and achievement in exercise and sport.

B: I’m very hard on myself. I set very high standards. I expect PBs (personal bests) in all my races, personal best times, and when I don’t get them it’s a bad day. Even (when) I get four PBs and miss out on the last one, even though I win all my races, which my parents can’t comprehend. No one can comprehend, y’know. I’ll ring up and, “Oh, how did you do at state titles?” “Oh I won. I won all my races, I won all gold medals, but I’m not happy” [laughs]. ‘Cos I want to be the best. I want to do better, y’know. I know I can do better. I know I can push myself harder. I know I can. I know my capabilities. I want to push them and I just want to go further and faster and harder, and I know I can and, y’know, that’s great. I mean, what more do you want in life but to be the best and to finally be considered the best? Y’know, it’s great. I’ve won 15 state titles in New South Wales, which is fantastic. Unfortunately, all my competition is in Queensland, and they’re a lot better than I.

Even though Ben said that the main goal of his sport and exercise was to prevent functional decline, the need to compensate for his disability and to achieve in sport seemed powerful underlying motives. As is evident in the previous extract, Ben was concerned with decreasing his times, with the hope of making the next Australian Paralympic team to Beijing in 2008. Although Ben had achieved in sport at an elite level, he wanted to achieve more.

### *Ben and Me*

In many ways, Ben was my ideal person with cerebral palsy. That is, he did not seem to have cerebral palsy at all. Sitting, doing the interview with Ben, he showed no obvious manifestations of his disability. Ben's "lack of cerebral palsy" made this life history intriguing for me. I found it natural throughout these life histories, especially when participants had similarly functional capabilities to myself, to compare their lives to mine. Listening to Ben's story, I felt deep sadness for him and some of the challenges that he had had to face during his life. The person I saw before me was, physically, far less affected than myself. Yet, Ben seemed to have travelled a much tougher road than I had. In making this judgement, I have been conscious of not trying to view my own life with rose-tinted glasses. I, too, have had to face challenges, almost every day, which are due, in part, to my cerebral palsy. Since interviewing Ben, I have thought about how our life experiences could be so different, and, which is more, inconsistent with the severity of our conditions. The only (tentative) conclusion I have reached is that I was luckier than Ben, in terms of meeting people throughout my life who saw my potential before my cerebral palsy.

### *Summary and Reflections on Ben*

Ben's life history resonated with Buddhist teachings of the realm of hungry ghosts. In these teachings, hungry ghosts are described as having insatiable hunger (Epstein, 1995). Attempts to satisfy this hunger result in more pain and suffering, and more intense cravings and hunger. In psychodynamic terms, hungry ghosts may find their parallel in Adler's (1933/1979a) writings on inferiority. Like hungry ghosts, some people feel deep senses of inferiority, for which they may attempt to compensate. No matter how much they try to compensate for their perceived inferiorities, however, their feelings of incompleteness remain, and often deepen because of their latest unsuccessful attempts to eliminate these feelings. Throughout much of Ben's early life, his classmates, extended family, teachers, medical practitioners, and probably others treated him in an uncompassionate manner, which seemed to deepen his sense of inferiority. Ben wished to be normal like his classmates, and, in essence, developed into a hungry ghost. His hunger came from his feelings of inferiority, and he was searching for nourishment in the form of acceptance from others and achievement.

Ben sharply distinguished between two periods of his life, pre- and post-23. He viewed his struggles during the pre-23 period in a harsh light, and considered the troubles that he had were of his own making. There were many factors that seemed to impede Ben's development, over which he had little or no control. Throughout childhood and much of adolescence, physical activity, swimming in particular, was punishing. In some ways, Ben seemed to have severed his past, and he preferred to focus on his successes post-23.

Although Ben's division of his life into two phases was perhaps less delineated than he perceived, his watching of the Atlanta Olympics and Paralympics, at 23, seemed to have been the catalyst that promoted the changes in his behaviour. In elite sportspeople, Ben saw achievement and social connectedness personified, and strongly identified with the athletes on television. Ben seemed to perceive that through becoming one of them, he too would be seen as someone who was competent and well liked by others.

Ben's involvement in physical activity began with performing exercises in the gym, and then expanded to include swimming, which was the sport that seemed to be the source of some of his childhood trauma. Ben appeared to go back to a time when he was hurt to try to heal his past. Like the hungry ghost, Ben seemed to have a fantasised wish of being completely free from the pain of his past. In psychodynamic terms, Ben seemed to have been fixated with childhood traumas (e.g., attempting to swim, social isolation from classmates). Ben seemed to be still trying to address the nuclear conflict of industry versus inferiority in the latency stage (Erikson, 1985) of psychosocial development. Through his swimming, Ben was able to show industry.

With physical activity, Ben achieved what he initially set out to do. He was physically fitter, more socially connected, and less stressed. As with the hungry ghost, however, these achievements did not compensate for his sense of inferiority. To compensate further, Ben progressively set more difficult goals for himself. In Ben's life post-23, there was a distinctive pattern of setting goals, achievement, elation with his display of competence, recognition of the ever-present feelings of inferiority, and setting more demanding goals. This pattern was



most evident in his physical activity participation. When I met Ben, participation in the Beijing Paralympics was his next major goal. Following his long-standing pattern, however, it is doubtful that even performing at international level would allay his inferiority feelings.

Ben's feelings of inferiority also surfaced in his relationships with others. Although he had many friendships, Ben did not seem to allow others to get too close to him. The longest and most intimate relationship of Ben's life was with his mother. Ben's mother had supported Ben his whole life, when many others did not want to socialise with him. As a young adult, Ben continued to seek intimacy from his mother, and did not endeavour to try to forge close relationships with other people. Ben seemed to be focusing on himself, rather than facing the challenges of the young adulthood stage of psychosocial development (Erikson, 1985). He was also preparing himself for the next stage, adulthood, where he could help children with disabilities to achieve their dreams and to reduce the negative experiences that are sometimes associated with growing up with disabilities.

After reflecting on Ben's life, I felt slightly ambivalent about the role of physical activity. Being involved in physical activity seemed to have resulted in many positive changes, such as delayed onset of functional decline, improved ways of handling stress, greater fitness, improved body image, increased competence and self-esteem with exercise and sport, and more social connections. The extent of Ben's physical activity participation, however, meant that he could more easily avoid trying to form intimate relationships, because he perceived himself as too busy with swimming. The increasingly ambitious goals that he set

for himself, however, may ultimately prove to be too challenging for him.

Although physical activity was of great benefit to Ben's life, it did not represent the panacea that he may have thought it was.

My own perceptions of Ben changed while I was working with the stories he provided. Although I still wish that I had the functional abilities that Ben had, I do not envy the road he has travelled or how his life experiences had affected his psychosocial development. I have grown to see how Ben's adverse social experiences seemed to have manifested themselves as an insatiable appetite for social approval and an aversion to becoming close to others, for fear of getting hurt. Whereas I began this life history envious of Ben's functional ability, I conclude it with feelings of sympathy for him and how his life could have been quite different if he had received greater support from people outside of the nucleus of his family throughout his childhood and adolescence.

#### Summary of Life Histories

Amy and Ben were sharply contrasted in terms of functional ability. Amy had severe functional impairment, whereas Ben's impairment was mild. Even so, there were many common issues that emerged in the life history data.

A prominent theme was the use of physical activity to become, or remain, socially connected. For Amy, being involved with physical activity allowed her to preserve her physical function, which meant that she had a greater opportunity to stay living with her family. For Ben, through physical activity he hoped to be accepted by the wider community.

Amy and Ben had dissimilar childhood experiences with physical activity. Although both participants had punishing experiences with physical activity, Amy

positively reflected on her involvement in some settings (e.g., at home, during physiotherapy). This finding suggests that it is possible to get people with cerebral palsy into physical activity when they are adults, despite these people having negative experiences earlier in life.

For both Amy and Ben, physical activity became an area where they could display competence. Although attempting to develop control over their bodies and over objects in the external world was sometimes a frustrating and punishing experience, Amy and Ben found physical activities in which they could excel. These experiences benefited them through the development of self-esteem through their reflections on what they had achieved. Conversely, stalling or retarding of development can occur when the physical activity is too demanding.

Common to both Amy and Ben was the use of physical activity to delay further loss of physical function. By performing physical activity, Amy and Ben seemed to have substantially slowed this rate of decline. Amy perceived that the preservation of her physical function was a critical factor that increased her chances at remaining living at home, whereas for Ben, maintaining his level of function meant that the potential onset of pain was delayed. Through the retention or improvement of their degrees of physical function, they were able to continue performing their activities of daily living, and, therefore, sustain their levels of independence.

These two life histories illustrate some of the difficulties that people with cerebral palsy face when trying to negotiate the social world. One of the earliest issues identified in the life histories related to Amy and Ben's entries into school life. At this stage in life, Amy and Ben struggled to cope in an environment that

required the prior mastery of the organ modes and ambulation (i.e., latency stage; Erikson, 1985). Their lack of competency to perform physical activities meant that they had difficulty with many tasks at school and that their relationships with classmates were impaired. This adverse situation contributed to feelings of inferiority. Whereas Amy's sense of inferiority may have diminished when she changed to a school for people with disabilities, Ben's inferiority feelings seemed to have been continually reinforced, and resulted in him achieving progressively more challenging goals in the attempt to fill his void of inferiority feelings.

During late adolescence, people typically prepare themselves for entry into the workforce or further education, which means examinations and job or tertiary education applications. The repeated rejection of Ben's job applications reinforced his sense of inferiority, and contributing to his feelings of being unable to cope with the stress in his life. Ben felt the situation in which he found himself was hopeless, and he attempted suicide.

During the young adult stage (Erikson, 1985), Amy and Ben's psychosocial development was inhibited. At a time when the focus is on the formation of intimate relationships with others, manifestations of their cerebral palsy impaired their development. For Amy, the severity of her cerebral palsy meant that she was restricted, by her dependence on others, in her attempts to form intimate relationships. Amy coped with her disappointments through fantasy and through finding alternative ways to become socially connected. For Ben, however, the fear of others hurting him, as they had in the past, had led him into isolation, self-absorption, and preparation for the following stage of psychosocial development.

In summary, both Amy and Ben spoke of the meaning and experiences of physical activity in their lives in predominantly positive terms. Both had punishing experiences with physical activity in their childhoods, but had nevertheless engaged in these activities as adults. Ben's life history is perhaps the more surprising in this respect, because of his childhood traumas with physical activity, in particular swimming. As adults, Amy and Ben engaged in physical activity to achieve primarily social goals. These life histories have shown that, despite negative experiences with physical activity as children, people with cerebral palsy can begin, and benefit from, such activity as adults. The present study, however, considered Amy and Ben's experiences of beginning, and being involved with, physical activity retrospectively. Research is now required to investigate the experiences of people with cerebral palsy who had been involved in minimal physical activity throughout their lives, and then had participated in a physical activity intervention.

## CHAPTER 7

STUDY 4 – LIFE HISTORIES OF ADULTS WITH CEREBRAL PALSY WHO  
HAD MINIMAL INVOLVEMENT IN PHYSICAL ACTIVITY AND WHO  
THEN PARTICIPATED IN WEIGHT-TRAINING AND WARM-WATER  
AEROBIC PROGRAMMES

## Introduction

Many people with cerebral palsy do not participate in sufficient physical activity to gain associated health benefits from such involvement (Heller et al., 2002; Longmuir & Bar-Or, 2000; Rimmer, 2001; Study 1). Negative experiences with physical activity in childhood may discourage people with cerebral palsy from engaging in these types of activities as adults (Study 2). Although some adults with cerebral palsy may start participating in physical activity despite adverse childhood experiences (see *Ben's Life History*, Study 3), many choose not to become involved. These people may, however, become involved in physical activity with the encouragement and support of others. Understanding the meaning and experiences of physical activity for people who had minimal involvement in physical activity, and then participated in such activities, may be helpful in designing programmes to get other people with cerebral palsy engaged in physical activity.

Two physical activities in which people with cerebral palsy may be able to successfully participate are weight training and swimming. Weight training may be a viable physical activity option for people with milder forms of cerebral palsy. Recent studies (Allen et al., 2004; Blundell et al., 2003; Taylor et al., 2004) and a review (Dodd et al., 2002) have concluded that people with cerebral palsy can

develop strength through weight training. This type of training can also increase function in people with cerebral palsy (e.g., Blundell et al., 2003; Damiano & Abel, 1998) and can increase adolescents' self-perceptions of their physical appearance (Darrah et al., 1999). Aside from the Darrah et al. study, little is known about the psychological consequences of weight training for people with cerebral palsy.

Swimming may also benefit the health of people with cerebral palsy. For people with severe cerebral palsy, swimming may be one of the few physical activities they can perform, because these people have limited abilities to move some, or all, body parts in a coordinated fashion. Specific advantages of exercising in an aquatic environment, for people with cerebral palsy, include the buoyancy of water, the high viscosity of water, the rapidity of heat transfer in water, and the hydrostatic pressure that provides extensive stimulation of exteroceptors and proprioceptors, and increases the pressure on the lungs (Hutzler et al., 1997). There is limited information (Peganoff, 1984), however, about the psychological outcomes of participation in water-based physical activity for people with cerebral palsy.

In the present study, I explored the life histories of two men with cerebral palsy who had done minimal physical activity throughout their lives. Embedded within these life histories, I report on their involvement in a weight-training programme and a warm-water aerobic programme. The inclusion of these two types of programmes within the present study allows for the investigation of diverse types of exercise, in terms of the exercise mode (aerobic and non-aerobic) and takes into account the severity of the participants' cerebral palsy (mild to

severe for swimming and mild or moderate severity for weight training), both of which may have the potential to enhance the lives of people with cerebral palsy. The aim of the study was to understand the meanings and experiences of physical activity in general, and of these programmes, in the lives of these men. A secondary aim was to investigate the effect of these programmes on their HRQL and psychosocial functioning.

## Method

### *Participants*

The participants were two men with cerebral palsy: David, aged 27, and Tim, aged 24. Both participants had spastic quadriplegia. David and Tim had engaged in minimal physical activity throughout their lives. The participants and their recruitment are described within the life histories.

### *Design*

The design incorporated Denzin's (1989a, 1989b) recommendations for conducting life history research, as was detailed in the Method section of Chapter 5 for Study 2. Where the design of the present study departs from that of Study 2 is the inclusion of a case study within each life history. According to Denzin (1989a), personal histories, case histories, and case studies can be combined within life histories.

Both the warm-water-aerobic-training and weight-training programmes were conducted over 10-week periods. Studies on physical activity and HRQL, and meta-analyses on physical activity and psychosocial functioning, have shown that aerobic training (e.g., Petruzzello et al., 1991; Sutherland et al., 2001) over a period longer than 9 weeks (e.g., Craft & Landers, 1998; North et al., 1990;



Petruzzello et al., 1991) has the largest effects on HRQL and psychosocial functioning. A non-aerobic exercise protocol (i.e., weight training) was included as one of the types of exercise, because the small effect sizes found in the meta-analyses may be due to a comparatively low number of studies using non-aerobic exercise in the literature on physical activity and psychosocial functioning, and previous research on weight-training with people who have cerebral palsy has shown that it may enhance their psychological health (Darrah et al., 1999). Interviews about the participants' lives and their involvement in the programmes were conducted during weeks 1, 5, and 10. The measures of HRQL and psychosocial functioning were taken during weeks 1, 5, and 9. The final measures were taken at week 9, rather than after the programmes had finished (week 10), because Petajan et al. (1996) have shown that the removal of socialisation, which occurs at the completion of the programme, can have an adverse effect on psychological variables. Previous research with people who had another neurological condition (i.e., multiple sclerosis; Sutherland et al., 2001) demonstrated that measures of HRQL and psychosocial functioning, similar to the ones used in the present study, were sensitive to detecting chronic changes in these psychological variables, as a result of a 10-week exercise intervention. The HRQL and psychosocial functioning measures were administered prior to the participants exercising, to remove the possibility that any changes in these measures were as a result of their involvement in a single exercise session. For the participant in the warm-water-aerobic-training programme, I administered the measures on a separate day to the programme. The participant in the weight-training programme self-administered the measures on the day of the first exercise

sessions of Weeks 1, 5, and 9, and gave them to me prior to the sessions beginning. For the weight-training programme, measures of strength on three exercises (Smith machine bench press, lateral pulldown, 45° leg press) were taken at weeks 3 and 10. The first measure of strength was taken at Week 3, rather than during Week 1, so that the participant had time to become familiar with the exercises. Familiarisation sessions are recommended when changes in strength are being tracked over time, because familiarisation increases the likelihood that any changes will be due to physiological adaptations (American College of Sports Medicine, 2005), and not to learning effects. Through participating in the first two weeks of the programme, the participant learned, and had an opportunity to practice, each exercise used in the strength test.

#### *Measures*

Four instruments were used to measure HRQL and psychosocial functioning: the RAND 36-Item Health Survey 1.0 (Hays et al., 1993), the POMS-SF (Shacham, 1983), the PSES (Ryckman et al., 1982), and the MSPSS (Zimet et al., 1988). These instruments are described in the Method section of Study 1.

#### *Procedures*

The Victoria University Human Research Ethics Committee gave approval for this study to be conducted. The recruitment of participants is described in each life history. Informed consent from participants to be involved in the research was obtained before the studies began. Interviews were conducted at weeks 1, 5, and 10, using the same method as for Study 2. For the participant in the warm-water aerobic training programme, medical clearance was not necessary as he was already going to participate in a supervised programme, which would have

proceeded if the research had not occurred. During the programme, I observed the participant's behaviour, but was not involved in conducting the programme.

Qualified staff from a disability organisation, who managed a day programme that the participant attended, facilitated the programme. For the participant in the weight-training programme, medical clearance from the participant's medical practitioners was gained before the first training session. As detailed within the life history, the programme was conducted with qualified personnel, and followed exercise prescription guidelines for people with cerebral palsy (Blanchard & Darrah, 1999; Laskin, 2003). That is, the participant trained on two days per week, using free weights and weight machines, lifting resistance as tolerated. Consistent with Laskin's recommendations, the participant performed three sets of 8 to 12 repetitions for each exercise.

### *Analysis*

The analysis of life history material was consistent with that for Study 2. Further, the scores from the HRQL and psychosocial functioning measures from both participants, and strength data from the participant in the weight-training programme, are presented.

### *Results*

#### *David's Life History: A Messiah Looking for Love*

##### *Meeting David*

David found out about our research through a major disability organisation in Victoria. He completed a questionnaire that was given to him on my behalf (for Study 1) and indicated via the questionnaire that he was willing to participate in further research. Given the moderate severity of his disability (in his

questionnaire, David rated his level of gross motor function as three out of five on the GMFCS) and the proximity of his home to the university campus, he was an ideal candidate for this study. I sent him a letter inviting him to be involved further in the research through starting a weight-training programme and discussing his life. This letter was followed up by a phone call from me to discuss the research and to invite him to the campus to look around the facilities and to meet the gym staff who would be working with him throughout the programme. From the phone call, I could tell that David's cerebral palsy did not affect his speech. During the phone call, David indicated that he used a motorised scooter for mobility, and we discussed the problems that presented with accessing public transport. He indicated that he was able to access the train system, but I had reservations about whether he was able to use the busses from the train station to the campus. Although some buses on that route were designed to allow wheelchair and motorised scooter access, most of the buses were older and had steps to get on board. David indicated that this was not a problem, because he would ride his scooter from the station to the campus. I had doubts about whether a person would be committed to a programme in which travel to and from the programme would take a great deal of time and effort. Nevertheless, we arranged to meet at the campus, the following week.

David turned up late for his appointment with me, after mistakenly going to the wrong campus, which is located nearby. In a later interview, he indicated that he was anxious and confused coming to the campus, because he had been misdirected as to where to go by members of the public. Upon arriving, I

introduced myself and discussed the programme with him. We then entered the gym so I could show him the layout and introduce him to staff.

Because David indicated he could walk with assistance, I asked him to leave the scooter at the door, and we would walk around the gym. He walked with the aid of a stick in his left hand, and I provided him support by holding his right hand. Walking was a slow process, with little flexion of the knees and strong support needed from the stick and myself. It was evident from his movement that walking was extremely difficult for David, and in the gym sessions that followed he used the scooter to move between weight machines. Following the gym orientation, I walked beside him from the gym out to the street to direct him as to the best way to get back to the train station. During this time, he asked me, "Do you have a girlfriend?" This question came out of the blue, at least to me at the time, and embodied two important issues that manifested themselves during the interviews and the exercise sessions: his sadness over his lack of romantic intimate relationships with females throughout his life, and his identification with me, an adult male with cerebral palsy. As is common in psychotherapy, clients will, when they see time is running out, bring up the material that is really important to them. David's question was prophetic of our future discussions. These issues will be examined in due course.

David and I agreed to meet the following week to start the weight-training programme and to do the first interview. All three interviews were conducted in an office in the same building as the gym. The interviews were conducted on days when David took part in the weight-training programme, so that he did not have to make additional trips to the campus. On the first day of the programme, and of the

first interview, David seemed pleased to be involved in the research. David maintained his enthusiasm throughout the 10 weeks that I spent with him. After the first weight-training session he seemed happy with what he had been able to do in the gym. We then went upstairs to the office, where we began discussing his life.

### *Development of Competence to Walk*

David's difficulty with walking was in contrast to his achievements at primary school. When he was about 10 years old, David developed some ability to walk without assistance.

C: So you used to be walking?

D: Not walking constantly, but in one go. My physio used to say, she'd wind me up, and I started walking, 1, 2, 3, 4 (steps) [pause] unsupported. And when I was at primary school I walked often, so they had a ladder (that documented my progress with walking), [pause] you broke your record, everyone was supporting me, y'know, and when I did about 200 (steps) one of the teachers in grade six, he said, "if you do 200 steps I want to buy you your lunch," [pause] the same week I did about 250, it was like, "ah, you did it!"

David was able to show competence at walking through progressively increasing the number of steps he could take consecutively. Reflecting on these experiences, David gained a sense of achievement, which increased his self-esteem. David's self-esteem was also bolstered by the public recognition he received (e.g., from a teacher) for increasing his ability to walk. These experiences positively influenced David's decision to persist with walking.

### *Loss of Competence to Walk*

Unfortunately, David's development of his ability to walk did not progress unimpeded. At 12 years of age, he experienced severe pain in his lower back, which was being caused by tight hamstring muscles. The hamstrings were surgically lengthened to provide David with relief from pain. A negative consequence of this operation, however, was that he never regained the ability to walk to the same degree he had previously. The effect of this loss of walking ability on David's personality seemed profound.

Consistent with Freud's (1917/1991b) description of melancholia, David experienced a loss, but what he lost could not be clearly stated. Although the doctor's prognosis for David's walking was not favourable, it could not be as concrete as, say, a doctor's prognoses for people who have had their spinal nerves severed, and do not have any possibility of walking unaided again. David could not walk without assistance, but, given he still had an ability to move his legs, he could not discount the belief that he would, one day, walk again.

David's ego's object choice (i.e., walking) seemed to have a narcissistic basis, because the object cathexis lacked resistance to being withdrawn into the ego and the fixation to walking was strong. When the free libido was withdrawn into the ego, it established an identification of David's ego with walking. That is, David's ability to walk seems to have been replaced by a narcissistic identification with walking, so that even though his ability to walk was lost, his love of walking was not given up.

David seemed to have felt that the doctor who had performed the operation had let him down. Doctors in his childhood had been supportive of his walking,

but after the operation his doctor was direct in stating his prognosis that David would only have a limited ability to walk.

D: When I was young they would say, “Ooo,” after my hamstring release. The doctor, he used to say, “Oh, he’ll only be able to walk around on his crutches and that’s about it.” End of story and so, it’s like, [pause] they see what they’ve seen (i.e., the outcomes of hamstring-lengthening operations on other people with cerebral palsy) and I might be different. My frame of mind might be different, so give me a go.

With this experience, David’s perception of medical practitioners changed from regarding them as individuals who supported his progress to individuals who doubted his capacity to make further gains. David was unhappy with this situation, and wanted medical practitioners to perceive him to be a person who was unlike others in similar positions; he was special.

### *Early Adolescence and Social Isolation*

David’s adolescence was a tough period in his life, and included a father who David perceived did not want him (see *David’s Father, Going to the Gym, and Swimming*), a mother who was very devoted to him, but was, it seems, ineffective at advocating for him outside the home, and a lack of a strong peer group to support him. He also had back pain and was not achieving academically. These factors damaged his self-esteem and left him isolated and vulnerable.

C: What were you going through?

D: I was going through puberty, man, everyone’s going through puberty, all the emotions, things like that [pause] everything was closed up, y’know.

C: What do you mean by that?



- D: Just my emotions, y'know, I thought I was useless, a piece of shit, that's how I felt, a piece of shit.
- C: Why did you feel like a piece of shit?
- D: Everyone around me was putting too much judgement on me and just put me down, too down.

Puberty and adolescence are times when young people become primarily concerned with how they are viewed by others, rather than how they perceive themselves (Erikson, 1985). Young people often form groups, and, thereby, exclude those who are different. David, however, did not benefit from a tight-knit peer group; he was not part of the in-group. Although his report cards indicated that he was a “team player,” and got on with others, David did not connect with his classmates. He found it hard when his classmates were running around having fun, and wished that he could do the same. David also said that he was thinking about issues that were not generally discussed by people his age. He was concerned with the future, what he wanted to do beyond school, and how he could become independent. From his descriptions, he appeared to be indicating that he had rejected social involvement with his peers because they were immature, rather than his peers rejecting him because he was different. David's explanation seems flawed, however. Life in the future, possible career options, and independence are all issues that young people typically deal with in this psychosocial stage. This blaming others, putting down others, and thinking of himself as special and different, and, in some ways, superior, are narcissistic features that would appear again and again during the interviews.

*David's Father, Going to the Gym, and Swimming*

The feeling of being “put down” by teachers and medical practitioners was also present at home, where David did not feel that his father was supporting him. David spoke about his father on several occasions during the interviews, with his words and body language displaying a range of emotions, including, anger, sadness, and sarcasm. David indicated that his father did not try to understand him at a time when he was trying to come to terms with his disability and trying to be accepted by his peers. He said that his father could not work out why he was not happy.

- D: He used to say, “Why are you depressed, you’ve got everything, [pause] you get everything you want,” and I go, “But Dad, you don’t understand, you haven’t got that emotional attachment.” It’s like, he would take me to the local leisure centre, and we used to go swimming, and instead of looking at my swimming and to see if I’m drowning [pause] he would go into the spa or sauna and talk to people about politics [he said laughing]. Dad, c’mon man, stop it, y’know [pause], I just want him to have a better understanding of a person’s life with a disability, that sometimes you want to do things that you can’t, that able-bodied people take for granted, and that gets you pissed off [pause] you do get a bit cranked up about that.

David’s reference to drowning does not seem as though it was made in the restricted, physical sense of being underwater for a prolonged period of time. He was drowning in many major spheres of adolescent life (e.g., physically, socially, academically) and he desperately needed someone (e.g., his father) to rescue him.

David was limited in the physical activity he was able to perform, because he was socially excluded at school and had restricted options outside of school due to his impaired function. David seemed dependent on his father to assist his involvement in physical activity. When David was 15, his father began taking him

to the local leisure centre to swim and to exercise in the gym. Because of his cerebral palsy, David needed his father to help him to perform these activities. In the gym, he not only needed assistance to execute some of the exercises, David required somebody to help him to walk around the cramped gym, because his wheelchair was too large to be manoeuvred around the equipment. As captured in the previous quote, however, David's father typically left him on his own, which meant that he could perform few exercises. A similar situation occurred when David went swimming. David had limited confidence in the water and wanted someone to support him, so that he could feel safer and learn how to swim. His father, however, seemed to prefer to go to the leisure centre to socialise with his friends, rather than to help his son engage in physical activity. David persevered with swimming and exercising in the gym for about two years, at which time his father went overseas.

To gain a useful insight into David's relationship with his father, I shall momentarily depart from David as an adolescent to David when I met him. A poignant moment occurred during the interviews when David revealed one of his underlying feelings about his father. David was discussing how his father had gone back to see his family in Europe. His father had bipolar disorder, which appears to have contributed to him losing a substantial sum of money, presumably during manic periods, and to a number of trips home to Europe because he was not happy in Australia, presumably during depressive periods. David told of how his father would say that he was going home to Europe and not coming back, and that, after spending time in Europe, his father always returned to Australia, because he missed his family. On the latest occasion, his father had been

telephoning home, complaining of the state of affairs in his homeland, telling David's mother how much he misses his family in Australia, and promising to return soon. I asked David what he would like to say to his father; the following passage formed part of his response.

- D: If it wasn't for Ramadan, for fasting, (my father) would've been back (in the country) now. He said, "I'm never, I'm not going to come back," and now he wants to come back and, it's like, I'm just scared. I'm not scared, but it's like I will pop it. I will say to him, y'know, "I thought you weren't going to come back." Y'know, this, that, y'know. He booked his ticket for six months, and now he wants to come back earlier, and it's like, y'know, I'll say to him, y'know, "Why do you want to come back for? *I thought you didn't want me.* You were going to go away from us," this, that, this. I don't know, we'll see what happens.

The last passage encapsulates David's Oedipal ambivalence towards his father, which I speculated might have contributed to his first suicide attempt. David harboured hostile thoughts towards his father, and was clearly scared of the consequences of letting his anger show. Because of David's impairments, it was likely that any attempted physical aggression would be quite impotent. From the aggressive quotes, it seems that what David was afraid of was losing control of his emotions and berating his father. Part of the reason for David's suppression of anger towards his father may have been the internalisation of societal attitudes that prohibit anger from people with disabilities, and require them to be courageous and upbeat (Olkin, 1995).

In contrast to his speech throughout the interviews, David said the words I have italicised in a soft, slurred voice, with head bowed. It was clear that David's relationship with his father had caused David much emotional pain. The sentence reflects the feeling of abandonment, a feeling usually accompanied by a sense of

not being worthy of love and attention, which David seems to have felt several times in his life, with respect to his father. Situations where abandonment occurred included when he was at the leisure centre, when his father made a number of trips home to Europe, and when David wished to discuss various topics (e.g., disability, relationships) with his father. David's ambivalent feelings toward his father are further demonstrated in the following passage.

- C: You told me that you love your dad, what do you love about him?
- D: You have to love him, I guess, it's just that you have to love him [pause]. Sometimes he can get real funny [pause]. He just brings out silly jokes and things like that. You hear him talk about old times, and he used to be in the army [pause], the old stories [pause]. He can get happy when he wants to [pause]. He tries to (do) the best that he can, and I don't expect much of him because I know he's sick (with bipolar disorder). So, you've got to love him. You've got to show him that you love him. It's like, if you don't, he's going to get even more sick.

David seemed conflicted in saying that he loved his father. The choice of the words, "You have to," instead of, "I," suggests that he was attempting to conform to a societal expectation that children should love their parents, instead of revealing his true feelings for his father. The aspects of his father that he gave the impression that he loved (i.e., silly jokes, stories of old times) were rather superficial. The brevity of David's response to my question (i.e., only about half of the above response relates to what he loved about his father) also suggests that there was not a lot that he loved about his father. Tied in with his response were an accusation ("he can get happy when he wants to"), a belittling remark ("I don't expect much of him because I know he's sick"), and a sign of guilt ("if you don't [love him], he's going to get even more sick").

David sometimes seemed to be uneasy with his criticisms of his father. At times, David's hostility towards his father was masked by excuses for his father's limited parenting ability. These excuses included his father's mental illness, upbringing, culture, and age. In some of the criticisms, David would not refer to his father directly (i.e., using nouns), but would distance himself from the criticisms by using a collective pronoun (i.e., they) to suggest that the behaviours his father displayed were typical of fathers of his culture and age. David tried to give the impression that he cared for his father, but this caring often hid other emotions, such as resentment and blame. In the following passage, David appeared to find it as difficult to relate to his father with his illness, as it was for his father to relate to him with his cerebral palsy. In this way, David seemed to be like his father.

D: I just try to talk to him [pause]. I'm just trying to understand him a bit. Like, he's overseas now [pause]. I'm just trying to understand what he wants from life. I go, "You're not happy here and when you go over there you're like this (not happy). What do you want? Tell us what you want. We'll listen" [pause]. But, he was a chronic gambler, he started gambling when he was 12, and he let go of it when he was about 41. So [pause], he's probably wishing he didn't do that, but we don't throw it to his face. We say, "It happened, it happened, we forgive you. So what? Move on mate." Alright, he's lost 250 grand [pause], and he's lost a quarter of his life, so what?

Given David's hostility towards his father, it is doubtful that David wanted to understand his father. It seemed that this claim was a remnant of David's adolescent wish that his father would try to understand him. Once more, David made use of collective nouns, rather than referring to himself in the first person. Although his father may have been regretful of the consequences of his gambling,

it appears to be David's thoughts that are expressed in the above passage. David said that he had forgiven his father, but his use of language and, in particular, the last sentence of the passage suggests that he is still angry with his father.

David's Oedipal stories were infused with inferences to his own superiority over his father. David told me that what he had learned from his father was that he did not want to be like him. Because David's father had bipolar disorder, he conceived that he and his father were similar; they both had disabilities. David perceived himself to be better than his father, however, because he had not given up, he had overcome his depression, he embraced change and was willing to try new things, and he would be a better father.

### *First Suicidal Gesture*

David's inability to demonstrate competence in the social setting at school, as well as a lack of support from his father and teachers weighed heavily on him. He was not achieving in many aspects of his life, and at about 15-16 years of age, David made a suicidal gesture. He got to the point where he had a knife in his hand and was about to slit his wrists. The following quote illustrates the effect the memories of his mother had on preventing him going through with the act.

D: What stopped me? I guess when I did it, it was like, just things started flashing through my mind. My Mum, what happens if I did do it, what'll happen to her? She put all that effort in, she'll be a wreck, all the good things she did for me [pause]. It's a journey, mate, keep on going.

In understanding David's suicidal gesture, Freud's (1917/1991b) writings on melancholia are useful once again. It is conceivable that David's ego's object-cathexes were withdrawn from object-relationships, to which he was ambivalent;

namely from his peers, teachers, and father. David's hostility towards these people seems to have been derived from their unacceptance of him and his frustrated attempts to become socially connected with them. With the return of these object-cathexes, David's ego could have treated itself as an object, and directed those hostile impulses towards itself. In this case, however, the hostile impulses were not strong enough to overpower his ego's self-love.

Throughout adolescence, David's teachers were substantially different from the ones who supported him in his attempts to walk. At a time when young people are questioning how to connect the roles and skills they have accrued with the occupational choices available to them (Erikson, 1985), David was not achieving academically. Teachers recommended that he do easier subjects at the Year-11 level (young people typically turn 17 years of age during this year), which put him in a no-win situation. If he followed the teachers' recommendations, that put him in a position where he was admitting he could not achieve at the level he desired. By rejecting their recommendations, however, he set himself up for the failure that ultimately occurred. David's experiences with teachers matched those he had with medical practitioners. That is, David perceived that both teachers and medical practitioners supported him when he was a child, but now doubted his ability.

#### *Disappointment with Medical Practitioners*

In Year 11, David had been getting back pain for six years. A computed axial tomography scan revealed a small fracture, but it was inoperable. In the following extract, David explained his reaction.



D: I went off at my physio. I said, “For six years I’ve been telling you I’ve got pain, and you couldn’t even tell me, ‘Go get an x-ray,’ or, ‘Go get something done.’” It’s like, because she knew how much I could do. I was, like, walking from here to there holding my breath [pause] because of the pain.

This experience is a further example of medical practitioners failing to live up to David’s expectations. Even though nothing could be done for David’s pain, he was angry that the physiotherapist did not validate his pain. The anger displayed in this extract, however, was most likely suppressed when he was with the physiotherapist.

### *Second Suicidal Gesture*

Shortly after David received his Year-12 (young people typically turn 18 years of age during this year) final examination results, he made a second suicidal gesture. The second gesture was the same as the first in that he had a knife in his hand, with the intention of slitting his wrists. With the knife in his hands, David started crying. Like with the first suicidal gesture, David’s concern for how his mother would cope with his death was foremost in his mind. He contemplated the finality of what he was intending to do, and resolved that if he kept trying to achieve, his life may improve. David described what was happening in his life, at that time, in the follow way.

D: I said, “Mate, I’m never going to walk. I’m never going to get the girl I like. I’m going to be another nothing. Everyone’s thinking this, that, this, that. I’m going to end up a nothing. I may as well commit suicide.” It’s just all negative thoughts [pause]. All negative thoughts, negative, negative, negative [pause]. Studies not going well, health deteriorating, [pause] stress, fatigue, the whole lot.

Academically, teachers had suggested he do Year-12 over two years instead of one, which represented another lose-lose situation. Wanting to get the qualification over and done with, David did not take their advice and attempted Year-12 in one year. He performed well in the first half of Year-12, but during the second half he became depressed.

D: In the morning I couldn't wake up. You know that feeling when your bones don't want to get up. You feel so worn out that your bones don't even want to get up. It's like, it's finished [pause], don't push any more.

David's description of what he was experiencing suggested a failure of the self-system (Basch, 1988) to cope with the stress of academic study. The teachers had advised David well. Of all the Year-12 students that sat final examinations in the State, David's results ranked him in the twenty-third percentile (i.e., 77% of students had higher scores than David). David now had powerful evidence of his lack of competence at school.

### *Sexuality and Walking*

Like before his first suicide gesture, the feeling that everyone was putting him down was present. Two other issues were prominent in his mind also: thinking that he would never form a sexually intimate relationship with someone he loved, and thinking he may never be able to walk independently again, two issues that were closely connected.

Research has identified difficulties that adult males with cerebral palsy face in establishing romantic relationships (Joseph, 1991; Jureidini, 1988; Shuttleworth, 2000). As has already been mentioned, romantic involvement was a keen concern for David, as exemplified by him asking me if I currently had a

girlfriend when we first met. Although he had successfully negotiated brief sexual encounters on three occasions (see *Sexual Disappointment*), he had been unable to form a romantic relationship.

David's stories of his attempts to form romantic relationships with females highlighted a certain social immaturity in his actions and self-protective attributions for his lack of success. An example of his social immaturity was, in Year 12, when he wrote a 5-page letter to a girl that he liked and had one of his friends put it in her locker. He heard from another girl that she started laughing when she found the letter and read its contents. Although this experience must have been painful for David, he said he did not care that the girl reacted in this way. He had not succeeded in starting an intimate relationship, and, what is more, he had been embarrassed and, most assuredly, quite hurt in his attempt.

David had self-protective attributions for his lack of success in forming romantic relationships, primarily blaming the mothers of females with whom he has fallen in love, but more generally blaming society. In his stories of why he had been unsuccessful, he was never one of the factors why a romantic relationship was not formed, and the females themselves are hardly ever the cause of relationships not beginning. In a rare example of the latter, David said the following.

D: I go, "The way they're thinking isn't the way I'm thinking. The way I'm switched on, they're not switched on right."

But even in this example, David blamed the way the person was thinking on societal pressures. David suggested that the females who he liked, liked him as

well, and he seemed to believe that they would have gone out with him if they were not concerned with how other people might perceive them. As can be seen from the following dialogue, however, David had projected his perceptions of why one female would not go out with him onto her. By projecting these perceptions onto her, he was essentially blaming society for her decision.

D: It was just [pause], again [pause], just her friends, same culture, same thinking, “Oh, how would my friends perceive me if I went out with this person,” she’d say.

C: Did she say that to you?

D: You feel that [pause]. Because when I used to talk to her she’d be looking, looking, looking, y’know how women are, man, they like gasbagging.

His attributions may be due to a rich fantasy life in which he blended reality and his imaginary world. In the first interview, David said that he had asked two young women to marry him. I explored this subject again in the second interview, when it was revealed that he had not asked anyone to marry him, and had not had more than friendships with either of these young women. It appears as if these young women had been friendly towards him, and he had developed romantic relationship fantasies. The reasons for one of them not wanting to go out with him also seem to be based in fantasy. As can be seen in the last dialogue, David initially indicated that she had expressed concern over what her friends would think if she went out with him, but later said she had actually not expressed that concern.

The self-protective attributions continued when he later saw these people to whom he had been attracted. The last time he saw the first young woman that

he wanted to marry he appears to have projected his own emotions onto her when telling the story.

D: The last time I saw her, like, she would feel, try to run away from me, y'know what I mean, "I've done a mistake, don't rub it into my face, I'm feeling depressed, I'm not the same person you used to like, anymore" [pause]. Y'know, resentment, "Sorry I put you through all that."

Aside from his sexuality, walking was the other prominent issue that contributed to David's decision to attempt suicide for a second time. For David, sexuality and walking were conceptually intertwined. David perceived that if he could walk, he could attract females. The following passage illustrates the power that David attributed to the ability to walk. My question was about the first young woman who David had asked, in his fantasies, to marry him.

C: She was a beautiful girl, you said?

D: Yeah, she was [pause] kind hearted [pause] to herself [pause] and talkative [pause]. At that stage I thought (that she was the) right women for me, and just last year I started to sense that it was the mother that influenced her not to (go out with me) because I don't walk. *If I was walking, 200 girls (would be) knocking on my mother's door probably.* You know, I would have six mobile phones [pause], because I try to be good to everyone [pause]. I try to put that across, and that's the best thing to do, I don't want people hating me. If I've done something wrong with you, tell me by all means [pause]. And the second (young woman I wanted to marry), exactly the same thing (the mother objected).

In the first part of David's response, the blaming of other people for his lack of success in beginning a romantic relationship can be seen. He perceived that their major issue was that he did not walk. David seemed to have deduced that if he were able to walk, then he would be able to form romantic relationships. He had

an exaggerated impression of his potency, however, should he begin walking (italicised). Although his experiences of trying to find a romantic partner would probably have been different if he did not have cerebral palsy, the degree to which he would be successful at attracting a romantic partner, if he could walk independently, sounded like super-stud fantasies. In the following extract, David described what he was experiencing in this period of his life. Once again, reference is made to his potency, if he was walking.

- D: I was just a teenager going into adulthood. It's just the influence of the media. You get a bit like this. My culture's like this, because they don't help disabled people out that much or don't have the resources. They look down at you [pause] not down in a sense [pause], it's like, if I was walking I'd have 200 girls on my arm right now. I'd be married by now [pause], it's just the way the parents have brought (the women) up.

### *Tertiary Education*

Post-secondary school, David enrolled at a TAFE (Technical and Further Education) college, with the intention of pursuing a qualification in information technology. At TAFE, his conflicts with teachers resumed.

- C: What did you do at TAFE?
- D: I did Certificate Four in Information Technology [pause], and I wanted to do the programming side of it. I knew it was hard, and even then teachers straight away started, "You can't. Do designing (or) something first and then do this" [he said angrily]. Straight away, without even knowing my character, she's only known me for two months, so they're judging me.
- C: Would it have been normal to go straight into that course?
- D: Yeah, she probably just doubted my ability to do the programming side of it. That was my weak point, but still, I'd have given it a good go. At that time, I was feeling tired and things like that anyway.

This story resonates strongly with David's previous experiences with high school teachers. As in prior years, he appeared not to have the necessary skills to successfully complete the course. The teachers advised David of this issue, and he perceived the teachers to be judging him as a person. With this line of thinking, David seemed to view his mental strength and character as being superior to those of others, because other people would not have been enrolled in this course with similar academic records to David, and he expected others to view his mental strength and character as worthy substitutes for his lack of achievements. Rather than addressing the lack of competency in computer programming that his teacher had identified, David seemed to have rationalised his failure to get into the desired course through his teacher's failure to recognise his determination. That is, David saw his teacher as judgmental, rather than perceiving himself as being poorly equipped to handle the load.

At the end of the previous dialogue, David mentioned he was feeling tired. The next five years of his life (i.e., up until the age of 24) were characterised by starting, but never finishing, academic courses, and by periods of depression, the first of which seemed to have occurred during his first semester at TAFE. Although David was still confronting the issues that contributed to him making suicidal gestures on two occasions, physical issues came to the fore at this time. Because of the pain David was experiencing, doctors had suggested to him that they could operate on three parts of his body. David was confused about what to do, and given his psychological state, he opted not to go ahead with the operations because he felt that he was not capable of performing the post-operative rehabilitation that would have been prescribed.

Following secondary school, and the return of his father from overseas, David returned to the leisure centre and resumed swimming and performing exercises in the gym. Like when he undertook these activities previously (see *David's Father, Going to the Gym, and Swimming*), however, David struggled to demonstrate competence. David's father was involved in his own activities at the leisure centre and provided little support to his son.

### *Sexual Disappointment*

Depressed after six months of the TAFE course, David went to visit relatives in Europe for two months. During this time he visited a man, who David described as "sort of a naturopath," about the pain in his back. The treatment he was administered helped to ease the pain David was experiencing. On returning from Europe, however, David appears to have been still depressed. He did little for the next two to three months. At this time, however, David lost his virginity, which he perceived in a negative way, and probably contributed to his depression. In the following dialogue, David talked about his experience of having sex for the first time.

- D: We were out with mates, y'know, at a club or something like that [pause]. It was (the) curiosity of the woman, I guess. Y'know, she's tried able-bodied people and, I guess, she wanted to give me a go [pause]. I've got the power [he said excitedly]. I look at it this way, if God takes away one thing he gives you doubly in another thing.
- C: So what have you got double of?
- D: Warmth, respect [pause] I just know how to treat people right, I guess [pause] and when it happened it didn't feel right, y'know [pause] no warmth, no nothing.
- C: So was it a one-night stand?



- D: Yeah, it was like, is that all? ...
- C: What happened after you met her?
- D: The interaction after that [pause], she felt bad, I felt bad
- C: When did she feel bad?
- D: When everything was finished.
- C: The morning after?
- D: Yeah, it was like I was at the wrong place, she was at the wrong place, and, y'know, she goes, "You don't deserve, you didn't deserve this to happen" [pause]. It's like, I was searching for a connection, (the women with whom I had sex) were searching for, ah, what the hell, the fun of it [pause]. It's like, using.

In contrast to much of the interviews, David was slow to answer many of the questions relating to his sexual behaviour, and his responses were brief, which meant that I had to ask questions more frequently. When recalling his first, and two subsequent sexual experiences, David seemed sad and reflective.

Although his sexual encounters were beneficial to him, because he learned that it was physically possible for him to have sex with women, the memories of these experiences, which he attempted to suppress, were accompanied by feelings of shame, dissatisfaction, and feeling used. The feelings he had about these one-night-stands seem to have resulted from the betrayal of his religious convictions, the knowledge of the brevity of the relationship, and the regretful apologies expressed by his partners. David practiced the Muslim faith and regarded sex before marriage as a sinful act. He also expressed shame in that his mother would be disappointed in him if she had known what he had done, which was captured in his response to my questioning the reason why he chose a hotel room, in which to have sex for the first time.

D: I couldn't go home [pause]. If I took her to my house, my mother would be like, "Son, I didn't expect this from you, you're not this type of person." That's a private thing, you don't want your mum to find out, and I guess she [his sexual partner] was the same too ... but now I want to stay right away from them [women].

Uncharacteristically, David took a long time to answer this question, and spoke in a soft voice. Apart from having sex with someone to whom he had no emotional attachment, David felt he had let down his mother, the one woman who did love him. David would have preferred to have sex with someone who was his girlfriend, rather than having sex with someone with whom he did not have an emotional connection. He felt used in that he believed that the women had sex with him to find out what it was like to have sex with a person who had a disability. Although David claimed that neither he nor his partners were drinking alcohol, the expressions of remorse by the women the mornings after they had sex with him suggest that alcohol may have been involved. These experiences must have been painful for David, because, when I spoke with him, he wanted to avoid intimate relationships with women. David still seemed to want to have a long-lasting, sexual relationship with a woman, but given that his sexually intimate relationships with women were disappointing, one-night stands, he was not looking to forge new relationships with women.

### *Returning to Education*

David decided to continue to pursue education in information technology, and enrolled in an open learning course. He found it too difficult to study on his own, however, and gave up the course when he was aged 21. The next year, he returned to TAFE, this time studying tourism and hospitality. Although he

indicated that he was doing well in the course, he did not continue past the first semester. David's depression had either returned, or had got worse.

D: What was going on in your life at that stage?

C: Nothing [pause]. I was feeling happy, things like that, but my body just didn't want to respond to it, it just didn't feel right [pause]. All the stresses of past years had just probably built up [pause]. I was feeling tired first semester and the teachers were really nice. They were supportive and one of the teachers, she was real nice, and I said to her, "I can't go on like this [pause]. I've got to find myself. I can't go on being tired all the time, [pause] (and) having trouble getting up in the morning."

This passage contains a rare reference, since reflecting on his childhood, to a positive experience in an education setting. Despite the teachers' assistance, however, David was too fatigued to continue. He was also desperate to improve his condition, and said that he would have tried anything to improve. Two solutions he did try were self-prescribed bibliotherapy and vitamin tablets. David read books about hypnotherapy, meditation, and psychology. From these books he learned that it was necessary to evaluate his ability, and to aim for goals that were within his grasp. His exposure to this subject area may have also meant that he was more comfortable being involved in my research than somebody who had little knowledge of psychology. David indicated that when he started taking the vitamin tablets he began to feel like he had greater energy. At this point, he was taking 25 tablets per day, and it was costing him \$250 per month. After eighteen months he was feeling a lot stronger and cut down to eight tablets per day, which he still was taking when I met him. In the following extract, David describes the effect of these tablets on his health.

D: So then I found this multi-level marketing nutrition company. Started using their products (for) 3 (or) 4 months. (I) felt good (and had) energy [pause]. I never felt that way before and that helped me quite a bit. (I) started going to the gym again a little bit and then, I don't know what happened. My dad wasn't helping me out at the gym much (and) leaving me on my own at the pool.

At the end of this extract, the issue of his father's abandonment of him returns once more. David was attempting to perform exercise, but he was not getting support from his father. Without assistance, David was unable to swim in the pool and to perform exercises competently in the gym. Being dissatisfied with this situation, David stopped going to the leisure centre.

### *Back to the Gym*

Aged 24 years, David started seeing a new doctor, who thought it was imperative, for David's physical health, that he return to the gym. David told his doctor about his previous attempts at exercising in the gym and how his father gave him little support at the leisure centre. Knowing that David's father could not be relied upon to help him perform exercise, his doctor organised assistance for David to do a gym programme once a week. Aside from the physical benefits of doing this exercise, David reported that he had greater confidence and self-esteem. After one year of receiving assistance, David began going to the gym on his own, doing the exercises he could do by himself. He perceived himself to have greater competence at performing gym exercises, and his self-esteem was enhanced by positively reflecting on what he had achieved and by remarks from people who were impressed about what he could do.

It is here that David's belief that he was special manifested again. This belief was strengthened by favourable comparisons with people who were able-

bodied. Often these comparisons had no way of being countered. For example, he stated that if he were able-bodied he would be fitter than most people he knows. Such a statement is safe, because he will never be able-bodied and have to confront these claims in any objective manner.

In the gym, David's perceived achievement of better results than people who were able-bodied further contributed to his belief that he was special. The lifting of more weight than people who were able-bodied was a source of great satisfaction.

- C: When you are lifting more weight than able-bodied people, how does that make you feel?
- D: It makes me feel that I've done the impossible. Not impossible, but, [pause] y'know. When I first lifted up those big weights at my local gym everyone used to say, "Can you do that? Can you do that? Can you really do that? Are you sure?" It used to be reinforced every time, 100s, 1,000s of times. It was like, "Yeah, do you want to watch?"

### *More Disappointment with Medical Practitioners*

When David was 26 years old, his doctor prescribed a drug called Baclofen in an attempt to improve David's condition. Baclofen is an anti-spasticity medication that reduces muscle tone by acting as a  $\gamma$ -aminobutyric acid (GABA) agonist through binding to GABA<sub>B</sub> receptors (Krach, 2001). The side effects of Baclofen include ataxia, orthostatic hypotension, sedation, and weakness. David was on Baclofen for about two months. He described his experience as follows.

- D: I was gaining weight in just six weeks like no tomorrow and I was at the floor. I said, "That's it, this is going to wreck me, sideways" [pause]. And

I had researched it on the internet, (and saw) these side effects, and I was getting two, three, four of these side effects. He's (the doctor) like, "Maybe I gave you a bit too much, try three." *Are you sure? Are you positive this is really going to help me?* It was probably making me loose (i.e., decreased muscle tone). That was probably because I wasn't doing anything anyway. It was making my brain numb. Even though I was feeling down in the dumps. I was virtually watching TV everyday, man. Y'know, flicking the channels.

This extract captures a further example of David's hostility toward the medical profession. Although the medication helped relieve some of David's spasticity, he was angry with the doctor because he had experienced some of the known side effects. During the time he was on Baclofen, David did not go to the gym, because he lacked the energy to do so. In the previous extract, this anger manifested itself as sarcasm (see italics). The anger, like his previous anger with medical practitioners, seemed to result from David's medical treatment failing to deliver on his expectations. In the following dialogue, I tried to understand what he expected from medical practitioners. My first question reflected on his negative experiences of surgery and oral medication.

C: Because you've had bad experiences with both?

D: Yeah, bad experiences. I just want them (the doctors) to think outside their shell, y'know. They're scared to think outside (of) what they've seen. Y'know, think a bit different.

C: What do you expect them to come up with?

D: See me, see everyone differently, for their abilities and, y'know, give it a go.

C: Give what a go?

D: Y'know, anything.

David was unsure what he expected of medical practitioners, but it seemed, from his responses to other questions, that he expected them to find a cure for cerebral palsy. He had a limited understanding of cerebral palsy, which enabled him to retain his belief that scientists would, in his life, find a cure for cerebral palsy. Given his keen interest in the condition, I offered to provide him with readings about the neuropathology of cerebral palsy. David showed little interest in my offer, preferring to maintain his limited understanding of the condition, and preserve his hope that he will, one day, be cured of cerebral palsy.

During the six months prior to David and I meeting, he had gone back to exercising in the gym. David, however, did not seem to have the same energy levels that he had had before he began the Baclofen treatment. Although he often went to the gym three times per week, he frequently felt tired and did not perform exercises using weights and did not spend much time at the gym (typically about 25 minutes).

#### *David, as I Met Him*

I would now like to focus on David, as he presented himself during the interviews and weight-training programme. Up until this point, elements of narcissism could be seen in some of his stories (e.g., the belief that he was special). The extent of his narcissism, however, could be seen more clearly in his current state. The existence of narcissistic features in David's personality is consistent with writings that have associated the presence of physical disability with the development of narcissism (e.g., Freud, 1917/1991c; Niederland, 1965; Rousso, 1985). Although a *DSM-IV-TR* (American Psychiatric Association, 2000) diagnosis of Narcissistic Personality Disorder would have been too severe, David

did display some characteristics that were consistent with this diagnosis. In particular, he had a strong belief that he was special, he had a grandiose sense of self, and he, at times, lacked empathy towards others, especially those who were able-bodied.

David's belief that he was special recurred in several of the stories that he told. One previously-described example was when, at the age of 12, he was angry at the doctor's prognosis following the surgical lengthening of his hamstrings; the doctor had not accounted for David's "frame of mind" in making his prognosis. Another example is when he expected to be admitted into a TAFE course, without a strong background in the area, based on his character. David believed that his character was superior to those of other (read, able-bodied) people because of his cerebral palsy. David's feeling of superiority were seen when he talked about his first sexual experience (see first dialogue of *Sexual Disappointment*). David was excited when he said, "I've got the power," which caused me to suspect that his following sentence, that God had given him double of something, had sexual overtones. David quickly calmed himself, however, and appeared contemplative as he told me that he had more warmth and respect for others, and treated people better than others did. In this way, God was viewed as giving him compensation for having cerebral palsy through his enhanced character.

David's high moral values, when it came to the treatment of other people, were contrary to his behaviour in the three premarital sexual encounters, with women who may have been under the influence of alcohol at the time. The consequence of this divergence between his morals and his behaviour was deep remorse for his actions.



David believed that God tests everyone in a different manner, that God tests people to a level that He thinks is appropriate, and that if people can be happy with what God has given them, they will be rewarded in the afterlife. Because God has set David a substantial challenge (i.e., cerebral palsy), he felt that God believed that he was special, and had the resources to cope with this condition.

As well as believing he was special, David's grandiose impressions of himself were revealed through his stories. He had a somewhat messianic self-view, which manifested itself in the strong belief that he was able to help and motivate others towards success. The motivation for helping others, however, was self-centred. He felt that if he helped others to become motivated and successful, then that would make him motivated and successful, and validate his own specialness. The following dialogue occurred after David told me how God tests everyone differently. In David's response to my question, his image of himself is particularly revealed.

- C: So, if God is giving you a test, how do you think you're going?
- D: I don't really know. In the middle. I say in the middle, because I'm a sleeping giant still waking up.
- C: You're a sleeping giant? Can you explain that for me?
- D: I'm asleep. I'm just about waking up and say, "Hey, this is my purpose," and "Hey, I've got to do something about it," and "Hey, I'm not going to stress about it." Just keep on doing it. Y'know, what's your purpose in life? Everyone's got a purpose.

In David's responses, his messianic self-view was strong; David perceived himself as someone who would wake up (possibly "stand up and walk") and save

people. David stated that his purpose in life was to be happy and make others happy, in a world that he viewed as being corrupt (i.e., wars in progress, people trying to exploit others). His message was that anyone could be happy if they focus on being happy; a message that he seemed to be struggling to internalise.

Other people have acted in ways that have reinforced the grandiose image that David has of himself. This reinforcement is exemplified in the following two quotes, the second of which David recalled an osteopath had said to him.

D: People say to me I should become a motivational speaker [pause]. I've never thought of that before [pause], because I'd never thought I'd be that good at it. When I get out there I'll be shaking like hell.

D: [The osteopath said,] "People like you have more struggles in life, but at the end of the day they [people with disabilities] become more successful than able-bodied people [pause]. They have sort of a better outlook on life."

These experiences seemed to enhance David's perception that he was special and that he had the ability, because of this specialness, to motivate others. His concern was not that his message was worthy of people's attention, but rather that he did not know he could deliver it in a powerful form.

David lacked empathy towards others, especially people who were able-bodied, and was quite dismissive of personal issues that others may be facing. One example was that he could not understand why some of his friends were taking drugs (marijuana, heroin). In his view, he should be the one taking drugs, because only he had a good reason (i.e., he had cerebral palsy). In a broader sense, it seemed that, to David, the absence of physical impairment should equate

to the absence of personal issues. The following quote revealed some of his feelings toward people who were able-bodied.

D: Able-bodied people are complaining too much, [pause] they've got two arms, two legs, they can do (anything). If they put their mind to it, they can do it [pause]. Be thankful for what you have [pause] that's the thing, being thankful that I've got an arm and a leg that works [pause]. I'm happy, I've got an arm and a leg that works. It doesn't work quite as well as I want it (to), but still, I'm happy.

I did not believe David was happy. Many of the issues that he had struggled with throughout his life were still present. David's most recent coping strategy was to try to suppress his emotions. I will return to this issue later. For now, I will focus on the purpose served by David saying that he was happy. The quote seemed to add evidence for his feelings of superiority. That is, he seemed to be suggesting that, if he was happy, and had cerebral palsy, then he must be better than people who were able-bodied, and who were not happy.

David had ambivalent feelings towards people who were able-bodied. As well as feeling superior to some of them, he was resentful towards others, especially those whom he perceived as having achieved well in life. He questioned whether those people who had accumulated assets and were in good relationships were truly happy. David suggested that if he had these possessions and was in these relationships, he would be, somehow, different. In the following quote, David's messianic self-view comes through again, as a desire to help others achieve.

D: You look at people. People, y'know around you and they might look like, y'know, they've got everything in life, y'know. Got a nice car, a nice

house, nice wife, nice children, y'know, and they're up there, but are they really happy inside? Y'know what I mean? Are they the real winners? Y'know what I mean. Some people put (on) a good, a beautiful face, y'know what I mean. They know how to, y'know, play the field, y'know what I mean. But inside they're not really happy. So, if I do become successful, I want to be successful in a way where I'm happy for myself, and I don't lose the plot. Y'know what I mean? Get too caught up with it. I would be people-orientated. If I become successful I want to help other people achieve.

In this quote, David's resentment of, and superiority to, able-bodied people become united. He not only resented people who were able-bodied, because they had achieved, he resented them for not helping him to achieve. David felt superior to them because, if he had achieved those goals, he would help others achieve. David's guilt at feeling resentment toward others may have been projected onto the people who were able-bodied and successful, leading him to perceive them as being unhappy with their lives.

Another feature of the above quote is the number of times David used the expression, "y'know." Although this expression was a characteristic of David's speech, at times it seemed to have significance in a literal way. That is, he was saying, "you know what I mean because we're the same." The "y'know's" were not posed as questions, but rather as statements directed at me, "You know, just like I know." David's identification with me is an issue that is discussed towards the end of this case.

Part of David's psychological coping, when I met him, was an attempt to suppress his emotions. Memories, of what David referred to as "the slump" (i.e., the last period of his life when he was depressed), were powerful reminders to him to remain positive. He was determined not to be depressed again. Even though these memories provided motivation for him to think positively, David

tried to suppress these memories, because he did not want negativity in his life. During the interviews, David frequently tried to get back to talking about positive aspects of his current state when I was trying to understand his past, which was a sign that he was trying to leave the “negativity” behind him and focus on the positive present. David found that by regulating his stress levels, he was able to suppress his emotions.

D: Stress is the biggest thing for me. If I can control that, I can control all my emotions and everything [pause]. I intend not to get stressed out anymore.

To David, stress seemed to mean an inability to demonstrate competence. Examples of experiences when he felt stressed included when he was not doing his exercises properly, when he was tired, and when he was depressed. David’s desire to control his stress levels, and therefore his emotions, was partly derived from the reinforcement of others. This reinforcement is exemplified in the following quote, in which David’s messianic self-view comes through strongly as a perception of himself as a martyr.

D: I’ve learnt that people don’t want to see stressed out people [pause]. People want to see happy people. So I’m going to be as happy as I can, to bring that across, and make other people happy [pause]. We all have our ups and downs in life, so what comes, I’ll take it.

David used humour and positive self-talk as ways to stop himself feeling stressed and, thereby, to suppress his emotions. He tried to laugh at life when things did not go well. David had accepted that sometimes he felt good, whereas at other times he felt bad. For example, some days his muscles were tight, and

other days they were loose. He also used positive self-talk, an example of which is contained within the following quote. This quote is also a further example of his messianic self-view.

D: I try to get my energy level to really get myself up and going, “C’mon, you’re going to do it, you’re going to do it, today you’re going to put a smile on somebody’s face.”

Although I have suggested that the threads of David’s narcissistic features could be traced through some of his stories about himself as a child and young adult, I have not clarified why this narcissism may have developed. Niederland (1965) argued that narcissism could be traced back to the original narcissistic injury, which occurred when early physical experiences were unmastered or, perhaps, unmasterable. Knowledge of the characteristics and permanence of the physical defect shape the development of the ego and superego. It is likely that David would not recall these early mastery attempts, because of the amnesia of early childhood. These experiences may have contributed to, but do not fully explain, David’s narcissism.

The exclusion of others from one’s life is a further component in the development of narcissism (Adler, 1931/1979; Erikson, 1985). Erikson stated that the avoidance of experiences in young adulthood that require self-abandon (i.e., close affiliations, orgasms and sexual unions, close friendships and physical combat, experiences of inspiration from teachers, intuition from self), because of fear of ego loss, might result in isolation and self-absorption. David did not avoid these experiences, but was excluded by others from consistently having them. It is

tenable that the exclusion of a person by others from these experiences, rather than that person's avoidance of such activities, would also lead to self-absorption.

The reason for the absence of others from a person's life should not be solely attributed to exclusion on their part. The person's avoidance of others signifies a lack of social interest, which may have arisen due to diminished self-confidence to perform the tasks with which the person has been confronted (Adler, 1931/1979). Adler considered that a person who was narcissistic was weak. This weakness originated from a feeling of inferiority. In the major spheres of David's life, he was receiving messages that he was inferior.

### *The Weight-Training Programme*

The weight-training programme occurred at a time in David's life when he was involved in minimal physical activity (see *More Disappointment with Medical Practitioners*). In the two weeks prior to David and me meeting, however, he had been feeling tired and had stopped going to the gym. Although he was not engaged in physical activity, David was trying to improve his physical condition through visiting, on a weekly basis, an osteopath and a physiotherapist. David continued these appointments during the weight-training programme.

David participated in a weight-training programme for 10 weeks. Qualified personal fitness trainers facilitated the programme. During the programme, I collected data using instruments measuring HRQL and psychosocial functioning, interviews, measurements of physical strength, and my own observations while with David and the trainers.

*General health and psychosocial functioning: Week 1.* David described himself to be in good health at the start of the programme, with exceptions being

back pain “driving him nuts,” tiredness, and occasional gastrointestinal reflux.

Scores at Week 1 on measures of HRQL, mood, physical self-efficacy, and social support are shown in Table 7.1.

Table 7.1

*Measures of HRQL and Psychosocial Functioning During the Weight-Training Programme*

Measure of HRQL or psychosocial functioning	<i>Week 1</i>	<i>Week 5</i>	<i>Week 9</i>
<b>HRQL</b>			
Physical functioning	10.00	16.67	11.11
Role limitations – physical	100.00	100.00	100.00
Role limitations – emotional	100.00	100.00	100.00
Energy/fatigue	67.50	55.00	90.00
Emotional well-being	80.00	60.00	92.00
Social functioning	87.50	100.00	100.00
Pain	80.00	80.00	80.00
General health	85.00	80.00	80.00
<b>Mood</b>			
Tension-anxiety	0.17	0.17	0.17
Depression-dejection	0.00	0.00	0.13
Anger-hostility	0.14	0.00	0.43
Vigour-activity	2.50	3.00	3.00
Fatigue-inertia	0.80	1.00	0.80
Confusion-bewilderment	0.20	0.20	0.00
<b>Physical self-efficacy</b>			
Perceived physical ability	33.00	36.00	30.00
Physical self-presentation confidence	55.00	55.00	58.00
<b>Social support</b>			
Family	7.00	7.00	7.00
Friends	6.75	7.00	6.25
Significant others	6.75	6.25	6.25

With the exception of physical functioning, David’s HRQL scores were higher than those of adults with cerebral palsy (Study 1). A higher score represents a more favourable state of health (Hays et al., 1993). David’s mood scores seemed to be reflective of his suppression of his emotions. Compared to the adults with cerebral palsy (Study 1), David had experienced less tension-anxiety,



depression-dejection, anger-hostility, fatigue-inertia, and confusion bewilderment, and more vigour-activity. For the depression-dejection subscale, David's score was more than one standard deviation below that for the adults with cerebral palsy. David had greater physical self-efficacy than did the sample of adults with cerebral palsy (Study 1). He had higher levels of PPA and PSPC. David perceived that he had high levels of social support from family, friends, and significant others. Overall, then, David's scores tended to be more favourable (e.g., higher HRQL, physical self-efficacy, and social support) than those of adults in the comparative sample (Study 1). Even so, David's scores were typically within one standard deviation of the scores from adults with cerebral palsy. Some of the scores represented the extreme, or near extreme, ends of the subscales, creating ceiling and floor effects for the potential positive movement in scores. This situation meant that the interview and observational data were more valuable in evaluating the effectiveness of the programme. The measures of HRQL and psychosocial functioning remained useful, however, in identifying any possible deleterious effects of the programme on these variables.

The ceiling and floor effects on several of the measures' subscales are further evidence that David was trying to suppress his emotions. This suppression was also evident in the following quote.

D: I'm happy with myself, y'know what I mean? I'm happy with myself. I'm happy the way things are going, y'know. I've learnt not to be stressed. Things may not go the way you want to go straight away, but when it doesn't go straight away it's like, y'know, I keep on saying to myself, "If I just keep at it, keep at it slowly but surely, y'know, it'll get there, y'know."

As I indicated earlier, I was not convinced that David was happy in his current state. In the quote above, the incessant way in which he said he was happy provided further evidence to the contrary. David had achieved pseudo-happiness through the suppression of his emotions. For David, real happiness seemed contingent on him finding a woman to marry.

*Weight-training programme familiarisation: Weeks 1 to 3.* David trained two days per week: Tuesday and Thursday mornings. Each session was approximately 60 minutes long. Before the programme started three daily workout plans were devised, with the intention of rotating these workouts if David could do all the exercises. The programme was consistent with guidelines from the *American College of Sports Medicine* (Blanchard & Darrah, 1999; Laskin, 2003). Each workout contained three compound exercises, for the chest (barbell bench press, seated cable press, or Smith machine bench press), back (lateral pulldown or prone barbell row), and legs (45° leg press or seated leg curl). The seated leg curl was the only isolation exercise, and was included because it was noted that David appeared to have weak hamstrings. When lying prone, David could not raise either foot off the floor by flexing the knee joint. The leg curl, in combination with the stretching of the quadriceps muscles, was prescribed in an attempt to improve his voluntary range of motion at this joint.

During the first three sessions, it was found that David could do all exercises, albeit with assistance and slight modifications. For the barbell bench press, a bench was placed under David's feet, because his feet did not come into contact with the floor, due to the lack of range of motion at the knee joints. This modification was not required for the Smith machine bench press, because the

bench was long enough to fully support his legs. For the lateral pulldown, David sat on two 25kg weight plates, because the seat was too low for him to sit upright with the low range of motion in his knee joints. For the 45° leg press, a partially deflated indoor soccer ball was placed between David's knees to ensure correct alignment of the knees during the exercise. For the seated leg press, a weight belt, placed mid-shin, was used to strap David's legs onto the machine. David needed assistance to get into position for each exercise, and some help to execute the exercises.

During each session, David performed three sets for each of three exercises. The targeted repetition range was 8 to 12 repetitions. Following the performance of these exercises, David was stretched with the assistance of the trainer and me. The major stretches were for quadriceps, hamstrings, and adductors.

*First strength test: Week 3.* The strength test was conducted on the Smith machine bench press, lateral pulldown, and 45° leg press. The testing was designed to find David's three-repetition maximum on each exercise. Increases were found for all three exercises. In Week 3, the weight at which David could perform eight repetitions of the lateral pulldown, instead of three, was recorded, because he was too fatigued to perform a further set after his set of eight repetitions. The results of the test are shown in Table 7.2.

*General health and psychosocial functioning: Week 5.* The scores on measures of HRQL, mood, physical self-efficacy, and social support, for Week 5 are shown in Table 6.1. These scores changed minimally from Week 1 to Week 5. The increases in vigour-activity and fatigue may have resulted from involvement

in the programme. David was more active, but this increase in physical activity made him tired.

Table 7.2

*Results From the Strength Tests at Weeks 3 and 10*

	Week 3		Week 10	
	Weight (kg)	Repetitions	Weight (kg)	Repetitions
Smith machine bench press	70	3	95	3
Lateral pulldown	55	8	100	3
45° leg press	180	3	270	3

*Note.* Using Fleck and Kraemer’s (1987) guidelines for determining the intensity of dynamic weight training, David’s effort on the lateral pulldown at Week 3 was approximately equivalent to him performing 3 repetitions at 64kg. This value is only a rough estimate, because a range of training, physiological, and neural factors can influence the amount of weight lifted per repetition (Fleck & Kraemer, 2004).

The weight-training programme occurred at a time when David was changing the way he approached life. The following extract revealed some of David’s thoughts when he was invited to participate in the present study. He also mentions the effect of an event happening in a “split-second” causing his cerebral palsy and the necessity to “reprogramme” his brain to compensate for the loss.

D: I was reprogramming myself before the programme and I said right, it’s about CP right (David was speaking about the present study). They want to learn about CP and physical training. Now, [pause] I thought I could show them how I’ve changed psychologically by doing interviews or by saying, “C’mon,” at the gym. You’ve heard me screaming. I don’t mean to be offensive but, it’s like, c’mon, it’s all in the mind. If the mind says you can do it, everything after that, it might take time to happen, but it will happen. ‘Cos if you look at it, I’ve had this thing since birth, that’s 27 years. How can you repair 27 years of damage in two or three years? It’s impossible. It happened in a split second, [pause] but to reprogramme, it’s not going to happen in a split second. It might take me another 20 years. So what?

Although the neurological damage to David's brain probably happened very quickly, he stated he was trying to "repair 27 years of damage." It seems that rather than trying to compensate for the neurological damage, David was trying to "repair" 27 years worth of psychological damage. Taken in this sense, David seems to be reflecting on the losses he had suffered throughout his life. Ruth and Blotzer (1995) reflected that disability is not a loss at a single moment, but represents repeated losses associated with obstacles and suffering caused by an unaccommodating society.

David described himself as feeling happier and enthusiastic. Although he did not feel he had more energy, he said he was feeling good. Physically, David had noticed greater flexibility in his hamstrings and quadriceps. I enquired about this further, and some of the psychological changes that had occurred became evident. David stated that the weight-training programme had made him more confident.

C: Can you expand on that please?

D: Just showing people that I can do it, you, (the trainer). Like, it can be done. Like, I've had my off days. Some days I've felt strong, some days I've felt weak. The last two weeks I've felt a bit weak. Other than that, I've been right [pause]. It's good that you're doing the research, because at least it's a step [pause]. Someone's doing something at least [pause]. From where I see it, trying to do something and hopefully we get benefit from it. I will get a benefit, you will get a benefit, (the trainer) will get a benefit [pause]. That's how I operate, y'know. *It's not all about me. Throw it in the bin if it's all about me. Throw all this case study in the bin. Throw everything in the bin. Throw this interview in the bin.*

With the programme, the trainer and I entered Basch's (1988) developmental spiral at the behavioural stage. Through selecting and modifying exercises that

David could perform, and by assisting him in the execution of those exercises, we helped him to show competence in the gym environment. Reflecting on this experience, David gained a sense of satisfaction that he was able to exercise effectively. The knowledge that the weights he was lifting were increasing and the support and encouragement he received from us also contributed to his self-esteem.

The programme, however, seemed to serve other purposes; it increased David's sources of narcissistic supplies. David enjoyed having the full attention of the trainers and me. He seemed, also, to want to draw attention and admiration from others, through yelling, "C'mon," before some sets.

In the previous dialogue, I have italicised David's protest that it was not "all about him." His behaviour during the programme and his stories during the interviews consistently suggested otherwise. David's insistent way of saying that the programme was not all about him was much like when he said he was happy. To paraphrase from Shakespeare's *Hamlet*, David doth protest too much, methinks. On some level, David may have been aware of his egocentric tendencies, which went against his desire to help others, and this statement was an attempt to cover up these narcissistic behaviours. In the following dialogue, threads of David's narcissism can be seen again.

C: Can you tell me about any elements of the programme that you found beneficial?

D: (I've) always been into weight training, but it's at a different place, [pause] somewhere different to experience and different machines, different atmosphere, y'know. When a person trains at a particular place for a long time, if there's no change in the atmosphere, it gets sort of boring, you sort of don't get motivated. I think before I started the programme, I started

feeling a bit, y'know [pause]. I was doing my training but, it was like, same place again, and now, this place has motivated me again [pause]. I guess it's saying, this one's a study, just keep trying, just keep going, [pause] *it's not always going to be razors everywhere*, [pause] just keep going and going and going and never stop until the day you die.

David talked about receiving admiration for his efforts at his old gym. With time this admiration might have diminished, as other gym members became used to seeing David around the gym. The present programme was in a different gym, which meant that there were new people David could try to impress.

The phrase that has been highlighted with italics in the last extract may be explained by how David was treated by the trainers and me. I have previously reported stories of people questioning David's ability to achieve in certain domains (e.g., teachers warning against taking a full academic load and difficult courses, doctors stating he would never walk without crutches after his surgery). During the weight-training programme, however, the focus was placed on what David could do, how exercises could be modified to make them more effective, and how we could get the most out of the exercise sessions. David may have perceived our way of working with him (using David's words, "Thinking positive") to be different from those of other people with whom he has dealt. The trainers and I were in a position in which we could focus on helping David to achieve, rather than highlighting his limitations.

The words following the phrase highlighted in italics seemed to signify that David drew motivation from our research, and being involved with the study gave him hope that one day he would achieve his goals. This effect on David may have been powerful within the context of his life. In his life, there were two occasions when he made suicidal gestures, and other periods of prolonged

depression. David viewed the programme as a vehicle for improvement and a way to give knowledge to others. He seemed to be encouraged, through his involvement in the research, to persist with trying to achieve his goals.

*General health and psychosocial functioning: Week 9.* The scores on measures of HRQL, mood, physical self-efficacy, and social support are shown in Table 6.1. Over the three time periods that the measures were administered, David's scores changed very little. It seemed that David's suppression of his emotions was persistent during the length of the study. As I highlighted in my description of David's general health and psychosocial functioning at Week 5, he seemed to have increased self-esteem from participating in the programme. This increased self-esteem may have contributed to David's dedication to the programme. Throughout the time David was involved in the programme, he was a motivated individual. He attended all the exercise sessions except for one, which was due to a battery malfunction in his scooter that could not be remedied quickly. During the exercise sessions he was eager to do well and to lift as much weight as he could. His motivation came from the need to show competence, and from narcissistic reasons. The following dialogue revealed his underlying motivation for participation in the programme.

D: I come here. It is a good thing [pause].

C: You like coming here?

D: Yeah many new people, y'know, showing them what I could do and what I can't do and, y'know, helping them out, y'know.



*Second strength test: Week 10.* The results of David's strength test at Week 10 are shown in Table 6.2 Between Week 3 and Week 10, David became stronger at performing all three exercises. In particular, David's strength on the 45° leg press increased by 50%.

### *David's Identification with Me*

Although I have presented David's life history in the final study of this thesis, it was the first one that I did. On reflection, and in comparison to the other life histories, this one was perhaps the most challenging for me to undertake. On many levels, this life history was virginal ground for me. The study represented the first time I had had extensive involvement with another adult with cerebral palsy, the first time I had taken life history data, and the first time I had applied psychodynamic theory to interpret another person's stories. I shall discuss the first of these issues throughout this part of the life history. With regard to the latter two issues, I improved my ability to interview people and interpret their lives through supervision and extensive reading.

One prominent feature of this life history, to which I have only made scant reference thus far, and which made it more challenging for me, was David's identification with myself, an adult male with cerebral palsy. I was not aware that he was identifying with me until late in the 10-week programme. As I have alluded to, on reflection, this identification started on the first day we met, when he asked me whether I had a girlfriend. In supervision, I discussed many of David's comments during the interviews and training sessions, as well as my own feelings about David. Because I did not identify with David, I was possibly

resisting his identification with me. Although we both have cerebral palsy, I did not perceive us as being similar in other ways.

David's identification with me seemed evident during the interviews. He frequently used the term, "y'know," and phrase, "Y'know what I mean?" His repeated use of the words, "we," and, "us," seemed to indicate that he thought that he and I, he and other people with cerebral palsy, or he and other people with disabilities shared characteristics and experiences beyond that of the disability.

D: Oh well, I mean, me and you, we're still searching, we're like, we are both about the same age, y'know, so I mean, once we get married, I think we'll stop scratching our heads too, y'know.

The identification was also present in his response to my question regarding the rapport he had with the trainers.

D: It's good, y'know, like [pause] everyone is different. Y'know what I mean? So you, you play the field. Y'know what I mean? You gotta know how, what to say, and what not to say to a particular person, and after it's you and me. You know how to do that by now. 'Cos of our life experiences and stuff.

Although David knew from our first meeting that I did not have a girlfriend, I did not tell him anything more of my personal life in this regard. Therefore, he made the assumptions that I wanted to get married, like him, and was confused by the dating process. Because of his identification with me, it appears that he also assumed that I had similar experiences to him in my relationships with potential partners.

David's identification with me also occurred during the training sessions. He knew that I trained and frequently asked how my training was going. My responses were polite, but lacking in specific details. David often wished to know what exercises I did and what weights I lifted. For several reasons, the trainers and I did not disclose the details of my training. I did not want to create a situation where David may have tried to lift a weight that was too heavy for him, which was extremely unlikely given his constant supervision during training, or where he would lose self-esteem because someone with whom he identified was lifting greater weight. The trainers and I reinforced that it makes little sense to compare weights, when training, with somebody with a different body type and length of experience. Therefore, the focus of all training sessions, maintained by the trainers and me, was on the improvement in David's own performance.

I did finally recognise his identification with me, but continued my resistance. My missing of this aspect was due to me not seeing any likeness between David and myself, apart from having a similar medical condition. This absence of a likeness, in my mind, was probably due to my abhorrence of my own condition; my active de-identification with others who had cerebral palsy, coupled with my internalised ableism; my view that people with cerebral palsy, including myself, are inferior to those people who do not have the condition; and my detesting of my own perceived physical inferiority. It was not until a supervision session, late during the 10-week training programme, that I became aware of the transference between David and me. Because I failed to acknowledge and reinforce his identification with me, David persisted in pointing out how we were similar.

Despite being aware of David's identification with me late in the training programme, I could recollect times during the interviews where I felt frustrated with David, because he would not elaborate on information. The basis for his failure to expand appears to have been that he believed I knew what he had experienced, because I, too, had cerebral palsy. At times, I felt hesitant at probing further, because I felt that I was expected to know what he had experienced. At these stages in the interview, I explained to him that sometimes people could have a range of experiences, even given that they may have the same medical condition. This approach allowed me to avoid self-disclosure at points where it may have been harmful to David, and enabled David to discuss some of his experiences in greater depth. Although protecting David, my approach also protected me. It meant that I did not have to confront my own issues, and, more importantly, I did not have to confront them in front of another person with cerebral palsy. To do so, would have meant that I would have been identifying with David, a situation that I was keen to avoid.

Having become aware of David's identification with me before the final interview, I had the opportunity to ask David what it was like for him to be involved in a project where he was being researched and trained by a person with cerebral palsy. His response revealed, once again, his identification with me.

D: It's been good. It's been good because, um, y'know, [pause] we understand each other, y'know what I mean? We understand our limitations. It's like we help, y'know, it's been a helping curve for both of us, y'know like you've got your limitations and I've got my limitations, and we both accept it, y'know what I mean. Even though it might be small, still limitations um it's, it's good that someone, someone out there is doing something for CP, finally, y'know what I mean.

This extract is perhaps the most profound in the level of identification that David had with me. David's life was full of people who did not understand him. I represented one person in his life who could show that I understood. Despite being able to show I understood, my own issues limited my ability to demonstrate empathy.

Later in the interview, I had an opportunity to ask him what he had learned from me, if anything. David's response was interesting in that he did not identify anything, but reinforced what I should have learned from him. In the response, he also paid a compliment to me. Given the level of identification and the narcissistic features of his personality, however, he was probably paying himself the compliment.

C: If anything, what have you learned from me?

D: [Deep breath.] If anything [pause], y'know, we talk about, discussion about CP, y'know, and the limitations and that, this, that, this [pause]. I've learnt from you; you've learnt from me that nothing's impossible. That's the thing, y'know. I believe that you, you're going to do it, y'know. You're bloody strong mate. It's been good, y'know.

David also identified, but to a much lesser extent, with one of the trainers, who was older than David, and married. The identification was probably due to the trainer being at a point in life that David desired.

D: Like, y'know we mainly talked about his holiday and what he wants to do in the future and, y'know that, y'know, I'm thinking of doing the same sort of thing you know.

In speaking about his future ambitions, David's messianic self-view was evident in his descriptions of his personal and professional goals. On a personal level, he wished to get married and to have children. He dreamed of having two children of his own, but also wanted to adopt a further two children. His reasons for wanting to adopt children could be interpreted as his desire to heal his own past.

D: I always thought I want to give someone that hasn't had a good start in life, a good start. Y'know what I mean? Because I've been through it, y'know. I've been through quite a bit. Y'know what I mean? Like struggle, struggle, struggle. I don't know, I'm still struggling, but, y'know, I'm going to come to the point where, y'know, I'll get there.

On a professional level, David wanted to achieve in the information technology industry. The extent and manner in which he wishes to achieve, however, seemed ambitious given his poor academic performance generally, as well as specifically with technology-related subjects (i.e., his performance at TAFE). In the following quote, David's messianic self-view and his desire to heal his own past came through once more, this time as compensation fantasies (fantasies in which people compensate for their perceived inferiorities).

D: Be someone that's successful in there and giving, y'know, people with disabilities a go, y'know. Oh, one of my goals is to open up a company and hopefully, y'know, get people with different types of disabilities, not just CP, y'know, working as a team in a building, y'know. Giving them opportunities, y'know, because I believe that we can do it, y'know what I mean?

### *Summary and Reflections on David*

David's life has been characterised by an inability to demonstrate competence in a number of settings (e.g., education, physical, social) and by

significant others in his life (e.g., his father) emotionally abandoning him. This inability to show competence contributed to his development spiralling downwards into periods of depression, which included two suicidal gestures. When I met David, he seemed to be struggling with the nuclear conflict of intimacy versus isolation (Erikson, 1985). David had made numerous attempts throughout his adolescence and young adulthood to become connected with others, especially young women with whom he wished to form romantic relationships. Seemingly emanating from his lack of competence, generally, and his difficulties with developing close relationships with others, specifically, were the narcissistic features of David's personality. These features allowed David to cope with the disappointments he experienced throughout his life.

Central to this case was David's sexuality, and its connection to his cerebral palsy and, more specifically, his ability to walk. David felt that, if he were able to walk, then his prospects of having romantic relationships would dramatically improve. The importance of physical activity to David was closely associated with this relationship between sexuality and walking. By performing physical activity, David was able to maintain the hope that he may be able to walk again, and, through walking, he was confident in his ability to attract a potential life partner.

The weight-training programme seemed to serve at least two purposes in David's life: it was a vehicle for self-improvement towards his goal of attracting a life partner and it was a new source of narcissistic supplies. There was little movement in the scores on the measures of HRQL and psychosocial functioning, which probably could be attributed to David's attempts to suppress his emotions.

David seemed to benefit from the programme, however, through demonstrating competence physically and through being treated in a positive way by the trainers and me. These features of the programme were relatively absent from David's life.

A significant aspect of this life history was David's identification with me. He saw a narrow part of my life, but a part in which I could be perceived as successful. This identification began from our first meeting and continued throughout the interviews and training sessions. I was typically frustrated when he referred to "us," but did not recognise that he was identifying with me until this issue was explored during supervision late in the programme.

Through working with David's life history material, however, I have become more empathetic with him. David wished to form the intimate connections that are characteristic of the young adult stage of psychosocial development (Erikson, 1985), but was finding it difficult to do so in the face of issues connected with his cerebral palsy, the consequence of which was social isolation and self-absorption.

### *Tim's Life History: Turning Toward Disability*

#### *Meeting Tim*

Tim was recruited for Study 1 through a day service provided by a major disability organisation in Victoria. Tim indicated, through the Study 1 questionnaire, that he was willing to participate in further research.

The purpose of the day service, which Tim attended, was to assist people with disabilities to make the transition from school into adulthood. An indoor, warm-water aquatic programme was one of the activities that the day service staff



offered. The programme lasted approximately 10 weeks and was conducted four times per year. Because a one-to-one, staff-to-client ratio was required for safety and to assist the involvement of people with a range of intellectual and physical impairments in this programme, few clients were able to participate (typically only two to four clients participated per programme).

This aquatic programme afforded me the opportunity to conduct research with a person who had cerebral palsy in a naturally occurring exercise setting. I asked the manager of the day service if there was anyone who was to be included in the next programme who would be a suitable person for my research. Tim was to be involved in the next programme and, because he had had minimal involvement with physical activity through his life, I asked him to be involved in the research, to which he agreed.

Our first meeting was at the day service he attended. The severity of Tim's cerebral palsy meant that he used an electric wheelchair for mobility. We used a staff office to meet, to complete the questionnaires for this study, and to conduct the first, and subsequent, interviews. Tim had a cold that day, which seemed to have an adverse effect on his energy levels.

Although Tim said that he was able to read and write, he asked me to read the questions and to record his responses on the questionnaire. This act was significant, because Tim had a long history of requesting assistance from others for simple tasks. Just as he had with other people in his life, Tim asked me for help on activities that he could do himself. I shall discuss this topic during my presentation of Tim's life history (see *Extra Assistance*).

This life history was, perhaps, the most challenging for me in terms of obtaining rich stories upon which I could base my interpretations. Although a willing participant, Tim seemed guarded in the brief responses he gave to my questions. He frequently answered my questions with “I don’t know,” or “I can’t remember.” Tim’s apparent reluctance to expand on his stories possibly indicated that he had a relatively low level of self-reflection. He did not expand on stories that were positive experiences in his life, nor those that seemed to evoke negative emotions. In this life history, I relate and interpret the stories that Tim told me, and state the situations when I encountered reticence.

### *Learning to Walk*

Tim learnt to walk independently at the age of six. Tim’s father was instrumental in helping his son walk. Tim seemed to have a close relationship with his father, which I explore further later in the life history (see *Parents and Girlfriend: Understanding Tim’s Current State*). At home, Tim’s father regularly had him walk around the perimeter of their property. When Tim was speaking about gaining the ability to walk longer distances, he seemed proud of what he had accomplished. Over time, Tim increased the number of laps of the section he would walk, until he was performing 50 laps of the property, which was a total distance of about two kilometres.

### *Going to School*

Tim spent his school years attending both mainstream schools and schools for people with disabilities (special schools). His time at primary school corresponded with a time when Government policy promoted segregation of students with disabilities from their able-bodied peers. When Tim started school

he attended a mainstream primary school on two days a week, and a special school on the remaining three days a week. Given Tim's experiences of both mainstream and special schools, I asked him to contrast these two environments.

C: Can you tell me about the differences between the mainstream and the special schools?

T: Well, stuff that I used to do at the mainstream school was probably a little bit harder than the one I used to do at the special school.

Before commenting on the content of this interaction, I will discuss Tim's answer as an example of Tim's responses to my requests for stories and information. The brevity of this answer was typical of his responses during the three times I interviewed him. Although this style of responding could have been indicative that I had not developed adequate rapport, the consistency of the brevity, during the 10 weeks over which I met with Tim, may suggest an alternative explanation. Even when I spoke with him on topics that interested him (e.g., music), his answers remained brief. Tim's style of responding may have been a consequence of the environment in which he had developed. A substantial portion of Tim's time was spent with other people with disabilities. The majority of Tim's friends were people with whom he went to the special school, and with whom he was now at the day service. Many of these people had intellectual impairments as well as, or apart from, physical disabilities. The restricted intellectual capacities of some of these people may have reduced Tim's opportunities to develop conversational skills. Tim's acquisition of these skills may also have been restricted in his home environment. Although Tim was the third of four children, there were large age gaps between him and his older brother and sister (i.e., 10

and 7 years difference, respectively). This large age gap may have meant that Tim behaved like an older child, rather than the third child in the family (Adler, 1932), which may have resulted in Tim not competing with his older siblings. Tim's development may also have been restricted through associating more with his brother, who was three years younger and also had physical impairments, than with his older siblings.

The "stuff" that Tim perceived was harder at the mainstream school referred to the school work. Tim was ambivalent towards the extra challenge of the work at the mainstream school, and seemed to have preferred the work he was required to perform at the special school. The work at the special school was less intellectually demanding. Tim could be more industrious, and show competence far easier, at the special school. Whereas the work at the mainstream school was stressful for Tim, he experienced positive reinforcement at the special school. Tim's ability to perform the work at the special school seemed to lead to a sense of being able to be effective in the school environment, and to him persisting more with the work.

A further reason for Tim preferring the special school was that he had more friends at this school. Although Tim had friends at the mainstream school, he formed closer friendships with children at the special school. I was interested in the differences in Tim's social experiences at the two types of schools, but Tim was reticent in his responses to my questions.

C: Why do you think you had closer friendships at the special school?

T: I don't know, don't know. Like the friends that I had at the special school were easier to get along with, 'cos they've got like they had a disability like I've got.

C: So what made them easier to get along with?

T: Um, I don't really know. Um, don't know, yeah, I don't know, yeah.

Seemingly due to his cerebral palsy, Tim had different experiences with his classmates at the two types of schools. Tim seemed to identify more strongly with his classmates at the special school. Tim's reticence, however, meant that I was unable to ascertain more information about his experiences at these schools. His preference for associating with his classmates with disabilities may signal that Tim had difficulties relating to able-bodied children. As Erikson (1985) stated, the latency stage can be socially divisive, in that some children learn that factors other than their ability to be industrious may determine their worth. Tim was struggling to be industrious, and his cerebral palsy may have exacerbated his difficulties. Tim may have developed a sense of inferiority in his dealings with able-bodied children. This sense of inferiority may have increased his preference to associate with children with disabilities, in whose company he could develop a sense of competence, and, perhaps, even a sense of superiority. In comparison to the other children at the special school, Tim may have had greater physical function (he could walk, whereas many of his classmates may have used wheelchairs) and intellectual ability (many of his classmates had intellectual impairments).

### *Swimming at School*

While at the special school, Tim started to swim. Tim was able to demonstrate competence in the water, and found swimming fun. On two

occasions, Tim competed in school swimming carnivals, and was successful in winning ribbons in backstroke and breaststroke. Tim, however, could not expand his story on these experiences, and could not remember why he stopped swimming. It seems unusual that Tim stopped engaging in an activity that he loved and in which he was successful. Perhaps significant others in his life made the decision for him, because they did not have the resources or time to assist him to continue swimming.

Apart from swimming and walking, Tim did not participate in any other physical activities during his childhood. He did not give any reasons for his non-participation or tell any stories of failed attempts to be involved with physical activity.

### *Loss of Function*

At about 14 years of age, walking became increasingly difficult for Tim. Pressure had developed on his spine, which meant that walking became painful, and he lost his ability to walk. Tim needed surgery to release this pressure. Following the operation, the prognosis for walking was poor. The consequences of not having the operation, however, were undesirable. If he did not have operation he would lose his ability to walk again and would not be able to control his bowels. Given these alternatives, Tim had the operation.

Although Tim's competence at being mobile reduced with the loss of his ability to walk, his independence increased through the use of an electric wheelchair. Tim had previously been using a manual wheelchair for long distances, which required another person to push the chair. Through using an electric wheelchair, Tim was able to be mobile on his own. This gain in

independence, however, did not compensate for the lack of ability to walk. As I shall describe later in this life history, the ability to walk had meaning beyond the mobility that Tim gained through his use of an electric wheelchair (see *The Drive to Walk*).

### *When I Grow Up*

During his adolescence, Tim's growth was retarded. Tim's hydrocephalus when he was young, which he had in addition to cerebral palsy, may have contributed to his stunted growth. He needed growth hormone injections to continue growing.

T: I used to actually be a little shrimp, because, yeah, I wasn't growing on my own. That was one of the reasons that I wanted to have the growth hormone injections, because I wanted to be able to drive one day.

Tim's wish to get a car licence and to drive was the manifest reason why he wanted growth hormone injections, and also emerged as a primary motivator for him to regain his ability to walk. Driving a car and walking were two issues that were prominent in Tim's present functioning. Before discussing these issues, however, I shall continue with a chronological presentation of Tim's life.

### *Early High School*

Tim's recall of his experiences at high school was also quite limited. As with his primary education, Tim attended both a mainstream high school and a special school. Tim's descriptions of his experiences at these schools were similar to those of his time at the two types of primary schools. That is, he had more friends and the work was easier at the special school.

- T: So, when I finished year 10 (aged 16), I went to special school full time.
- C: Did you prefer going to the mainstream school or the special school?
- T: Yeah, (I liked) the special school, 'cos it was a bit easier and the workload wasn't as stressful.

From the limited amount of information that Tim provided, it seemed that he was struggling to perform academically at the mainstream high school. This challenge to Tim's demonstration of competence may have contributed to a restriction of Tim's development, and to an increased sense of inferiority. The stress that Tim spoke about in the last dialogue was alleviated through becoming a full-time student at the special school for his final two years of high school. This switch from being a part-time student to being a full-time student at the special school may have resulted in him reappraising his competence. Being a full-time student at this school meant that Tim could gain a sense of superiority through his completion of easier work, and through favourable comparisons with the academic ability of his peers, many of whom were intellectually impaired.

### *Relationships and Sex*

Tim had several girlfriends throughout his adolescence, whom he met at the special school and, later, the day service. When he was 15, Tim's girlfriend at the time, who was two years older than him, asked him for sexual contact.

- T: She asked me, (and) I just said, "No," 'cos, I mean at that stage, like when she did ask me, though, we were together, but I mean I was only bloody 15 years old then.

Tim attributed his unwillingness to engage in physical intimacy, with his girlfriend, to his young age. Although this explanation seems understandable, Tim



provided little further information that would allow for a more in-depth interpretation.

### *Extra Assistance*

Following Tim's last two years at the special school, he started going to TAFE, for two and a half days per week, and attended the day centre for a further two and a half days per week. Tim was enrolled in a course that focused on literacy. He was able to undertake the course with the assistance of a note-taker. Going into his third, and final, year of this course, Tim had the benefit of having the same noter-taker as he had worked with during the previous year. Tim's teachers, however, complained to the staff member who organised note-takers that the woman who helped Tim was providing him with more assistance than she should.

C: When you said that the teachers thought your note-taker was too verbal with you, what did you mean by that?

T: Like instead of, basically, me telling her what to write, which is what I should've been doing, and I was, but as far as some of my teachers were concerned, she was sort of telling me what she had to write, so yeah.

C: So your teachers thought that she was doing the work for you?

T: Yeah, basically, yeah.

This story reflected my experiences with Tim when we were completing the questionnaires. That is, Tim seemed to have got his note-taker to do tasks that he was required to perform, just like he had me assist him to complete the questionnaires by reading the questions and recording his responses. Tim

expressed fondness for this note-taker, which seemed to be partially based on her willingness to help him to do activities that he was meant to do for himself.

Tim seemed to experience difficulties during this final year of the course. His note-taker was removed from working with him, and was replaced by other note-takers. Tim found this situation disheartening, because the replacement note-takers regularly missed classes. Through not having the assistance of someone with whom he had developed rapport, he could not be as effective as he had previously been. An additional difficulty was that he increased his hours at TAFE with the addition of a drama class.

T: I ended up at TAFE four full days (a week) and that was getting a bit too much, as well I was getting a bit too tired. . . . Yeah, and I was starting to get a bit bored with (the course) towards the end too.

C: Why was that?

T: I don't know, just yeah, just did I s'pose, I don't know.

This extract is another example of Tim's reluctance to expand on his stories. It might also reflect a relatively low capacity for self-reflection. Tim provided sufficient information, however, to offer some interpretation of what happened during Tim's third year at TAFE. Without his favourite note-taker, it seems that Tim struggled to be as effective as he was when she was there helping him. Without the regular support of note-takers, Tim could not demonstrate competence, in the way he had done during the previous two years. The stress of the situation seemed to have manifested itself in depressed mood and fatigue. Tim

handled this situation through leaving TAFE before he had finished his course, and continuing his literacy studies at the day service he attended.

It was difficult to establish the significance of the drama course during Tim's third year at TAFE. Tim seemed to rationalise that his difficulties in the literacy course, and his tiredness, were due to the change in note-takers and to the extra time he was spending at TAFE. Some of this extra time was spent in drama class. In the class, Tim and his peers were rehearsing a play based on Shakespeare's *A Midsummer Night's Dream*. Talking about this experience was one of the few times when Tim expressed anger during my time with him.

T: But we never ever got to bloody do the play, because half the cast never turned up to the class [angrily].

C: How did that make you feel?

T: A bit pissed off, 'cos I was looking forward to it, and all the bloody hard work that I put in.

C: And then you didn't get to do the final production?

T: No.

C: So what character were you?

T: Um, I can't remember now.

Tim's last response was surprising to me. After telling me how important the production was to him, Tim could not recall what character he played. It seemed like Tim had exaggerated his input into the drama course to rationalise his tiredness and his lack of performance in the literacy course. Tim's reticence,

however, means that I cannot offer a richer interpretation of the meaning of the play in his life.

### *Lack of Physical Activity*

Tim's tiredness, during his third year at TAFE, could have been due, in part, to his lack of physical fitness. In his early 20s, Tim participated in few physical activities. Tim used his electric wheelchair for mobility and practiced walking infrequently. Other physical activities in which he was involved were bocce and swimming. Tim played bocce once a week, with other people who had disabilities. Bocce was a social activity for Tim, who participated with some of the other clients of the day service he attended. In physical terms, bocce was a relatively easy activity for Tim to perform. He was able to throw the bocce balls from sitting in his wheelchair. In terms of swimming, sometimes he would visit his best friend, who had a swimming pool in his backyard. At his friend's home, he was able to resume, albeit infrequently, a physical activity that he had enjoyed as a child.

T: I haven't been over there for a swim for a while, but sometimes if it's hot enough when I go over there, I take my bathers with me and we go for a swim.

C: So how did you get on in the water?

T: Well, they've got a life jacket that he used to use, but he doesn't need it anymore. So his Mum just lets me borrow it, and if I've got something like that then I'm usually pretty right in the water on my own.

I met with typical reticence when I tried to learn more about his best friend. They had met at school, and, at the time I met Tim, were going to different day services for people with disabilities. Tim had not seen this friend for a long while, but

occasionally spoke with him on the phone. When they did see each other, they frequently played video games. Apart from the occasional swim, Tim did not seem to participate in any other physical activities with his best friend.

### *The Drive to Walk*

When I met Tim, the challenge of walking was one of the main issues he was facing. During the interviews, Tim often spoke about his desire to walk again. Following his medical operation when he was 14, however, Tim's doctor gave him a slim chance of walking again, if he did not walk within two years of the surgery.

C: When I was born (the doctor said) that I wouldn't be able to walk, but I proved them wrong. I started walking when I was six-and-a-half years old. *So I could prove them wrong again.* I just don't know when.

The sentence I have italicised sounded somewhat vengeful and aggressive.

Possibly Tim saw his doctor as someone who was denying him the chance to fulfil his goal of walking. Instead of encouraging him in his attempts to walk, medical practitioners were pessimistic about his chances of regaining this function. Tim seemed to find it difficult, however, to articulate what regaining the ability to walk would mean to him. Tim displayed ambivalence toward walking. In one respect, he valued walking without needing physical support (e.g., from a walking frame). In another respect, however, Tim typically avoided opportunities to practice his walking.

C: At which times, in your life now, do you wish you could walk?

T: Well, I know it's still possible to get my (car) licence [pause]. Like, that was one of the things I wanted to do, like when I was walking, I wanted to get my licence, which I know I probably still can, and one day I'm going to go for it.

At a superficial level, walking independently (without physical support) would mean that Tim would be able to drive a car more easily. Although cars can be modified to meet the needs of drivers with disabilities, Tim wanted to drive regular cars to save on expense and to be able to drive his parents' cars. Tim seemed to be displaying the ambivalence that adolescents typically display in that he wanted independence from his parents, through driving a car, but still manifested dependence on them, through wanting to use their cars.

Possibly Tim was still trying to resolve the conflict of the locomotor-genital stage (Erikson, 1985), initiative versus guilt. Tim's initial attempts at walking were delayed, with Tim not being able to walk independently until he was six years old. His less than successful attempts at walking may have led to feelings of guilt that he could not control his body properly, and to unintended outcomes, such as tripping or falling. As an adult, Tim seemed to be trying to show initiative. Although other mobility options were available to him over long distances (e.g., having his Dad drive him, hiring a taxi), they involved dependence on other people. Using other people's assistance in transportation may have led to feelings of guilt that he was not able to do this task for himself. Tim, however, seems to have become reconciled to dependence on others and encouraged others to help him.

Tim seemed to view the solution to this conflict as being able to walk independently again. Tim, however, typically did not walk at home and avoided

practicing at the day service. In many ways he seemed like a typical adolescent stuck in ambivalence.

C: Tell me the sorts of things you are doing to try to walk independently.

T: Well, when I can, and when one of the staff are available to help me, like, I go for a walk, just up and down the corridor here on the walking frame, and also I've started doing a bit of walking in the swimming pool.

C: What about at home, do you do any walking at home?

T: No, no.

C: Would you like the opportunity to do more walking?

T: Well, I suppose it's really, when I want to go for a walk here (at the day service), really it is up to me. I've just got to get myself to find a staff member that is available and ask them, but I'm just a bit bloody too lazy. I keep forgetting.

Tim's "forgetting" to practice walking suggested that there may have been unconscious processes that prevented Tim from asking for assistance to walk, and from practicing on his own. Although Tim wished to walk, it seems that practicing was too challenging for him. Walking was difficult, because the muscles in Tim's legs were atrophied, and his cerebral palsy meant that he could not move his legs in a coordinated manner. The slowness of his progress with walking, and the discomfort Tim experienced while trying to move his legs and bear weight must have been frustrating for him. During the times when he was practicing, his goal of walking without the need for physical assistance must have seemed a far away dream.

T: Well, I would (do more walking), but the hard [Tim accentuated the word, “hard”] thing about it is [pause] every time I get the idea in my head to go for a walk, I go up to ask, like, ask one of guys (day centre staff members), but they just seem busy. So I don’t bother, and I don’t want to bother them if they’re busy.

C: Yeah. It’s really busy around here isn’t it?

T: Yeah

My observations, from my visits to the day service, were that the staff were constantly involved in dealing with the needs of clients. The staff seemed to have time for their clients, but they were constantly occupied with clients and their issues. I could see how Tim got the impression that they were regularly busy. If he had asked them for assistance, however, it seemed that the staff would have spent time helping Tim into a walking frame. The apparently, consistently busy staff gave Tim justification for avoiding the punishment associated with practicing walking.

#### *Parents and Girlfriend: Understanding Tim’s Current State*

When Tim told stories that involved his parents, it seemed as though they frequently treated him like a child, which frustrated him. A prominent concern was his relationship with Natasha, who had been his girlfriend, on and off, for six years. Natasha lived in a residential unit for people with disabilities, and, because she did so, she did not have much money to spend after paying rent. During the weeks when I was visiting Tim, Natasha ran out of credit on her mobile phone, and did not have sufficient money to purchase more. Tim purchased more credit for her phone, but told his father that it was for his phone. Unfortunately for Tim, the credit on his own phone ran out two days later, which required another



purchase of credit. When Tim's parents found out what Tim had done, they disapproved of his actions.

T: (When I ran out of credit on my phone, I thought,) "Oh shit, what am I going to do?" And then, yeah, my Mum and Dad had a go at me. So yeah.

C: What did they say to you?

T: They basically said that I shouldn't be doing that, which I know. *I know theoretically it is wrong*, but I like to help her when I can. And I know, because (she) lives in a (residential unit) she can't really afford (to buy credit for her phone), because she's gotta pay for the rent on her room and everything like that. And my mum said to me that if she can't afford it, she shouldn't have a phone, but I don't (think she should go without a phone). I think that seems a bit unfair saying something like that.

In this story, Tim's parents seemed to treat him like a child, and he responded in a fashion that was consistent with this infantilisation. Tim initially lied to his parents to deal with the anxiety of doing something that he thought his parents would dislike. His parents' reaction to Tim was to scold him for wasting his money on his girlfriend. As I will comment shortly, Tim's mother did not seem to like Natasha, which goes some way to explaining her criticism of his actions.

As I have italicised, Tim thought his actions were "theoretically wrong." I asked Tim what he meant by this statement, and he said that he did not know. In contrast to his "not knowing" elsewhere in the interviews, Tim seemed genuinely not to know what he had done wrong. After telling me that he did not know why his actions were theoretically wrong, Tim proceeded to tell me that he thought his behaviour was acceptable. Tim seemed to have accepted his parents' standards at a vague "theoretical level," but did not know the reasons why those standards existed.

- C: How does that make you feel when your parents talk to you like that?
- T: I'm a bit pissed off and upset. . . . I basically was in tears the other day when they had a go at me.
- C: Tell me what was going through your head.
- T: *I thought to myself, "Not this crap again."* Like, basically the reason why I told that little white lie (was) so I wouldn't get in trouble. But I mean I tell a lie (and) I get in trouble. I tell the truth (and) I still get in trouble. I can't bloody win.

Tim's frustration with being treated as though he was much younger than his 24 years came through clearly. The words in italics suggested to me that this parental behaviour was the norm, rather than the exception. I pursued this idea further in my questioning, and Tim said that he sometimes felt like his parents treated him like a two-year-old, and were overprotective of him. Questioning Tim about other occasions when his parents had been overprotective, however, met with reticence. Although there had been other times when Tim felt his parents had been overprotective, he was reluctant to speak about them.

Being frequently treated like a child by his parents, Tim sometimes behaved in a way that was consistent with how they perceived him. Evidence of this behaviour came from him speaking about his parents and girlfriend. Tim provided a rather deflective response when I asked him to speak about his mother.

- C: Could you tell me a bit more about your mother?
- T: Well, I suppose she works two days (per week) in a school canteen, and sometimes she brings home food and that. So that gets me out of making my lunch sometimes. So I enjoy that. 'Cos (it) depends (on) what she brings home. If she brings home something nice I'll pack it in my lunch instead of making my sandwich, 'cos I actually have to make my own

lunch now. Yeah, which I don't mind doing, but sometimes I get sick of it.

Although Tim may have desired to be independent, relying on others was often an easier path for him to take. In the previous extract, Tim described a situation where he tried to avoid taking responsibility for himself. Tim seemed to prefer other people doing tasks for him, and, in this sense, avoided chores and physical activity. When his mother did not bring food home for him, he often bought his lunch instead of making it himself. Tim told me little more about his mother, which was a further example of his reticence. After Tim's initial response to my request for information about his mother, he did not seem to have anything to add. Tim seemed to be avoiding speaking about emotional material. I asked Tim whether he loved his mother, and received an ambivalent response.

C: Do you love your Mum?

T: Yeah, sort of yes, sort of no, if you know what I mean.

C: Can you explain what you mean by that, please?

T: *Yeah, as I said, I do, because I know you're supposed to love your mother, but I don't love her, because of the way she treats (Natasha) sometimes.*

C: How does she treat (Natasha)?

T: She's just like, as I said, when she rings me (Natasha) said, "Is (Tim) there please," and as far as my Mum's concerned she doesn't say please, when I know for a fact (that) she would say please.

C: What else is it about (Natasha)? Is it only the fact that she doesn't say please?

T: Yeah, I think so, yeah.

Tim's mother's disapproval of his girlfriend was hard for him, and may be interpreted as an Oedipal story. Tim's mother did not seem to like Natasha, ostensibly because she thought that Natasha did not use manners, and expressed this dissatisfaction to her son. In essence, Tim's mother may have perceived that no woman was good enough for her son except for her. Because his mother did not seem to like Natasha, Tim, in return, appeared to have withheld some of his love for his mother (*italicised*). For Tim, this one aspect of the mother-child relationship appears to have overshadowed other aspects of their relationship. This narrow view of his mother is further seen, in this dialogue, where Tim provided no examples of when he loved his mother, and one example of when he did not love her.

Tim seemed to enjoy the relationship he had with his father. Tim's father rarely spoke about Natasha in negative terms and, most importantly, did a lot for him.

C: Tell me about Dad.

T: Yeah, my Dad looks after me pretty good.

C: You're pretty close to your Dad, aren't you?

T: Yeah, fairly close, yeah.

C: Do you love your Dad?

T: Yes [he answered this question quickly].

C: What do you love about your dad?

T: I don't know, he just spoils me [he said enthusiastically].

C: How does he do that?

T: He just does, say, for example, in the mornings, I can dress myself, but I can't put my shoes on. So he does that for me, and yeah he does other stuff as well. He does so many things to spoil me that I can't remember them all.

Being "looked after" and "spoilt," although sometimes existing between two mature adults, typically feature more often in relationships between adults and children. There was a sense in this dialogue, and the stories that Tim told about his mother, that he enjoyed other people doing things for him.

The pattern of behaviour between Tim and his father was probably developed from infancy and childhood. Such pampering of children can lead them to have more intensified feelings of inferiority (Adler, 1932/1979). In Tim's case, his feelings of inferiority may also have been intensified through having cerebral palsy. Tim's behaviour suggested that he had been pampered in infancy and childhood, as well as in adulthood to date. That is, he tended to depend on others to develop solutions to his problems, or to do tasks that would have a determining influence on him. Examples of this dependency include getting his note-taker at TAFE to provide him with answers and having his mother bring home his lunch. A further example is his reaction towards his father buying a new van that would accommodate his wheelchair. Tim said that before his father bought the van, he was considering leaving home in the following two years. Tim rationalised that if he did leave home, his father would have wasted his money buying a new van. He, therefore, decided to remain living with his parents. Given his pattern of being dependent on other people, Tim may have had no real plans to move out of home in the first place. Once Tim's father bought the van he may have retroactively believed that he had plans to be independent, but now could not go through with

them and have his father waste his money. This retroactive construction of a plan for independence served at least two purposes: Tim could believe that he was thinking about, and planning for, the future; and he could believe that he was noble for considering his father, and how much money he had spent.

C: Where does your Dad take you in the van?

T: Well, he takes me to bocce, and basically he takes me wherever I need to go when I want to take this wheelchair, 'cos otherwise, if he doesn't, I'll have to pay for bloody taxi fares, and that can be a bit expensive.

This story encapsulated Tim's dependency on his parents for expenses and transportation. Although Tim received an income from the Government for people with disabilities, he preferred to rely on his parents to pay his transportation costs. Tim's apparent comfort with his dependency on other people seemed to be greater than his need for independence (e.g., hiring a taxi to go places).

Tim and Natasha's relationship resembled a childhood romance. They rarely saw each other away from the day service, spent their time together talking, and engaged in little physical intimacy (nothing more than holding hands or Tim kissing Natasha on the hand). This situation was comparable to children romantically involved at primary school, who see each other only during playtimes, chat with each other, and may hold hands and, if unseen by others, kiss. On this basis, however, Tim had decided that he would like to marry Natasha one day.

C: What is it about (Natasha) that you like?

T: Oh, I don't know, she's basically, I don't know. I just like her because she's nice (and) she'll do anything for me that she can, which is something that I love about her. I s'pose I'm the same with her.

Tim did things for Natasha (e.g., purchasing phone credit for her), and this support was reciprocated. I tried to find out more about this loving relationship, but was met with either reticence or an actual inability to elaborate on what he had said.

### *The Day Service*

During this research programme, I visited Tim's day service on numerous occasions. I initially went there to recruit participants for Study 1, and later returned to interview Tim and to assist him in completing questionnaires. In contrast to many of the service's clients, who had intellectual impairments and were demanding on staff members' time, Tim was quiet and did not need constant supervision. Each day he was involved in programmes, including literacy, woodwork, going out into the community, and the warm-water aerobic programme. Tim seemed to be popular at the service. From what I observed, Tim seemed to get along well with staff and the other clients. Many of the clients were people with whom Tim had gone to school, and who had been his friends for many years. When I asked Tim about receiving emotional support from his friends, however, he mentioned two staff members at the day service.

C: Are there any of your friends in whom you can confide?

T: Probably, well I haven't really (needed to confide in anyone) yet, but there's probably at least two here that I can think of, and they're actually staff members.

- C: So that must be really great for you to have people around who you can talk to.
- T: Yeah, yeah, yeah.
- C: What makes them special to you?
- T: I don't know. (I) just feel close to them both, and feel comfortable talking to them if I have to.

Tim's last response is a further example of his limited responding to some of my questions. This response, however, did not seem reticent like many of his replies to my questions. Tim seemed cut off from both his emotions and his thinking, which may suggest that there was substantial repression. A further explanation is that Tim could be slightly intellectually impaired.

There may be many reasons why Tim would have chosen to speak with the staff members, rather than his peers. One reason is that many of his friends seemed to be operating at a lower intellectual level than Tim. Perhaps Tim perceived that they could not understand the issues he was confronting and give advice.

### *Live on Air*

Tim wanted to be a commercial disc jockey. He had made a foray into the industry through undertaking a radio course at a local station, and had a small weekly show, in which he played his own compact discs and took requests.

- C: So, tell me about the show.
- T: Well, I just like, basically, play music, take requests, and stuff, so yeah. If people want to either ring me or send me an SMS they can, and as long as I've got the song that they want I'll put it on. 'Cos, like, I use my own CDs. I don't use the CDs that the radio station's got. I'm allowed to take my own CDs, so yeah.



C: How do you feel about having your own show?

T Yeah, I love it.

C: What do you love about it?

T: I don't know, just like maybe, I don't know, just like getting on air playing music (and) taking requests.

As is illustrated in Tim's last comment, he appeared to have low levels of insight into why he engaged in various activities and displayed certain behaviours. A further example of Tim's limited self-reflection was that he could name his favourite singer, but did not know what it was about her music that he liked. Although I have interpreted many of Tim's brief, and often superficial, responses to be reticence, his replies in the previous dialogue suggest that there may be additional explanations for this way of answering questions. Tim seemed to have limited conscious access to both affect and cognition. As I have previously indicated, repression and intellectual impairment could have affected Tim's responses. Repression may explain his limited ability to recall negative events, and slight intellectual impairment could account for some of his difficulties in recalling both positive and negative material.

Through the course and working on radio, Tim developed competence in this area, and was motivated to persist with the radio work. Tim wished to keep practicing his skills, and proposed to approach a commercial station for work in about three years.

### *The Warm-Water Aerobic Programme*

The 10-week, warm-water aerobic programme was located at another day service for people with disabilities. The pool was specifically designed to cater for

people with mobility impairments, and had features, such as steps into the pool, a hoist, and water that was heated to a higher temperature than that of a regular heated pool to limit heat loss from people with restricted movement.

Prior to the start of the programme, Tim had been involved in minimal physical activity. Tim participated in bocce during one evening per week, and had been involved with another warm-water aerobic programme, facilitated by the day service he attended, six months prior to this current programme beginning. One session in the water was scheduled each week, with Tim spending about one hour in the water each session. Tim was not involved in the first two weeks of the programme, because he had a cold during the first week and the pool was closed for repairs during the second week. In the 10 weeks, I collected data using measures of HRQL and psychosocial functioning, interviews, and my own observations of Tim in the pool.

*General health and psychosocial functioning: Week 1.* During part of the first interview, I questioned Tim broadly on the concepts contained within the questionnaire. Apart from having a cold, Tim did not divulge any physical, emotional, or functional difficulties he had been having in the previous four weeks. The scores on measures of HRQL, mood states, physical self-efficacy, and social support are shown in Table 7.2.

Tim's scores on the measures seemed to reflect my impressions from the interview data that he lacked conscious access to his emotions and thoughts. Apart from Tim's score on the physical functioning subscale, his scores on the HRQL subscales represented a more favourable state of health (Hays et al., 1993) than many other adults with cerebral palsy (Study 1). All of these scores, however,

were within one standard deviation of the scores of the Study 1 participants. On four of the subscales, Tim scored the maximum values possible. These scores seemed to paint a picture that was removed from the sick and unenergetic person who I interviewed. Compared to the Study 1 participants, Tim experienced greater vigour-activity and less tension-anxiety, depression-dejection, and fatigue-inertia. Tim's scores on these subscales were over one standard deviation from the means of the Study 1 participants' scores. Tim's scores, however, did not fit with his presentation during the interview. For example, Tim's tiredness did not seem to be reflected in the mood scores. Tim also had more perceived physical ability than the adults from Study 1. This score also seemed inconsistent with Tim's appearance. For example, Tim perceived that, because of his agility, he could do things that many others could not do. Either Tim was comparing himself to people with less physical function than himself, or he had a distorted perception of his physical capabilities. His scores on the social support measure indicated that he received greater support from friends and significant others than from his family. The comparatively low score on the family sub-scale on the social support measure suggests that Tim may have been experiencing difficulties with his parents before the issues with Natasha arose. Tim was either unwilling or unable to discuss these possible difficulties.

Through being involved with the warm-water sessions, Tim stated that he wanted to achieve independence in the water. He described how he needed flotation devices to keep himself buoyant, and the assistance of Grant, a staff member at the day service, to ensure that he remained safe in the water. For Tim,

independence meant being able to swim without floatation devices and without having to be closely supervised.

Table 7.3

*Measures of HRQL, and Psychosocial Functioning During the Warm-Water Aerobic Programme*

Measure of HRQL or psychosocial functioning	<i>Week 1</i>	<i>Week 5</i>	<i>Week 9</i>
<b>HRQL</b>			
Physical functioning	20.00	20.00	45.00
Role limitations – physical	75.00	100.00	100.00
Role limitations – emotional	100.00	100.00	100.00
Bodily pain	100.00	100.00	100.00
General mental health	100.00	92.00	96.00
Social functioning	100.00	100.00	87.50
Vitality	80.00	85.00	80.00
General health	80.00	85.00	80.00
<b>Mood</b>			
Tension-anxiety	0.00	0.00	0.00
Depression-dejection	0.00	0.00	0.38
Anger-hostility	0.29	0.29	0.43
Vigour-activity	3.33	3.50	3.17
Fatigue-inertia	0.40	0.40	0.60
Confusion-bewilderment	0.20	0.00	0.00
<b>Physical self-efficacy</b>			
Perceived physical ability	47.00	44.00	40.00
Physical self-presentation confidence	52.00	69.00	62.00
<b>Social support</b>			
Family	3.25	4.00	1.00
Friends	7.00	7.00	7.00
Significant others	7.00	7.00	7.00

C: What do you hope to get out of the programme?

T: I want to learn to swim independently, without having that floating device on or someone holding me in the water.

C: What would it mean to you if you achieved that?

T: I suppose if I achieve that, I'd be able to get into the water without any assistance.

C: How would that make you feel?

T: I suppose, good.

Tim seemed to be quite literal with his reasons for wanting independence, such as the surface physical meaning of not needing assistance. The deeper meaning of swimming independently, like the meaning of walking independently, seemed to be inaccessible. Tim's motivation for independence may be reflective of childhood strivings toward industry in the latency stage (Erikson, 1985).

Difficulties with achieving in swimming, and in other areas of his life may have resulted in Tim still facing the challenges of earlier stages of psychosocial development. Not meeting the challenges of the latency stage may have contributed to Tim's feelings of inferiority and to his seemingly limited persistence with trying to achieve independence.

*The programme: Weeks 1 to 5.* During the first five weeks, Tim participated in three sessions (Weeks 3 to 5). Tim did similar activities in each of those sessions. At the start of each session, Tim would hang onto the rail in the pool, and would work his way around the perimeter of the pool. Tim did this activity slowly, and appeared to be using his arms, rather than his legs, to do the work. Grant then equipped Tim with floatation devices, around his neck, upper body, and waist. These devices allowed Tim to float on his back. Tim spent about half of each session floating on his back, with Grant slowly towing him around the pool. During this time, Tim and Grant would engage in conversation, which was sometimes interrupted by splashing others, being splashed, and joking and laughing as they went by other clients and staff in the pool. To stretch Tim's abductors, the physiotherapist often would place a foam block between Tim's knees, to keep them apart. Tim spent approximately the last 15 minutes of each

session without the flotation devices, and practiced standing and walking in the pool. After he had walked out of the pool, with assistance, following the first session, I heard Tim comment to Grant that he was proud of himself. I followed up this comment in the second interview.

C: When you got out of the pool, after the first time I saw you in the water, I heard you say to Grant that you felt proud of yourself. Can you tell me about why you felt proud?

T: Because I was walking in the water, unassisted. . . .

C: That's one of the things that I picked up from our last interview, that walking is important to you.

T: Yeah, yeah.

C: What would it mean to you to be able to walk unassisted again?

T: Well, I'd probably be able to do a bit more. . . . I'm not saying that, like, I can't drive (a car if I use) a wheelchair, 'cos I can. I will be able to (drive), and I want to get my license one day. But if I was walking independently, it'd probably make things a bit easier.

Doing physical activity in the water contributed to Tim's desire for independence on the land (through walking), as well as in water (swimming). Given that Tim had shown competence at walking in the water, and had reflected positively on this experience (e.g., his feeling of pride), I expected to observe Tim doing more activities in the pool that were directed towards walking, or to hear stories from him about practicing more often on dry land. I shall report my observations from the remainder of the programme shortly. For now, I will discuss Tim's walking on land.

C: The physio does a bit of work with you in the water as well, doesn't she?

T: Yeah, yeah

C: Can you tell me about that?

T: That's just, I s'pose, so I get some physio, 'cos I don't really get some unless I'm in the water, although, occasionally, I get to go for a walk around here (at the day service), on the walking frame.

C: Would you like to get more physio than you're getting at the moment?

T: Yeah, yeah probably, yeah [unconvincingly].

The pride and self-esteem that Tim gained from walking in the pool did not translate into walking more regularly on dry land. In the previous dialogue, Tim seemed ambivalent towards the idea of wanting more physiotherapy, which may be attributable to the increased difficulty, for Tim, of walking on land. When Tim climbed the steps to get out of the pool, the necessity of having to carry his own body weight, as he emerged from the water, made Tim's legs buckle under the strain. This experience, as well as those of his other attempts at walking on land, seemed to have adversely affected Tim's sense of competence, reduced his self-esteem, and inhibited his willingness to practice walking on land more often.

*General health and psychosocial functioning: Week 5.* The scores on the HRQL and psychosocial functioning measures, for Week 5, are shown in Table 7.2. These scores changed minimally from Week 1. The minor changes in the HRQL scores seemed to reflect that the cold that Tim had at Week 1 was gone by Week 5. Tim's general health subscale score was marginally higher (5 points on a 100-point scale), because he was now not limited in the activities he could perform, and he was full of energy more often. The changes in the PSPC score seemed to reflect an inconsistent understanding of the items that were negatively

worded. For example, item 3 was, “I am rarely embarrassed by my voice.” In completing the measures in Weeks 1 and 9, Tim seemed to have interpreted the item without the word *rarely* and, therefore, responded differently.

*The Programme: Weeks 6 to 10.* Consistent with the predictions of Basch’s (1988) developmental spiral, I observed Tim walking in the water more often than he had done in earlier sessions of the programme. Tim spent less time floating on his back, being fully supported by floatation devices, and more time walking independently in the water or doing exercises prescribed to help his walking. These exercises included pushing off from the wall with his feet, while his upper body was supported by floatation devices; walking with a noodle (a thin, long, cylindrical floatation device made of foam); walking with assistance from staff members; walking up and down the lower steps of the pool with the physiotherapist; and lying on his back, using floatation devices, and kicking his legs.

In these sessions, I overheard two comments from staff members, which may have had a positive effect on Tim’s self-esteem. During the session in Week 6, the physiotherapist said to Grant, “Look at this, (Grant)!” This exclamation occurred when Tim was climbing and descending the lower steps of the pool, with the assistance of the physiotherapist. During the following session, Tim was walking with a noodle, and a staff member, who had not previously been assisting with the aquatic sessions, observed that, “He’s come a long way with his walking.” Any increases in self-esteem, derived from these comments, may have contributed to Tim’s decision to keep practicing walking in the water.



Tim's development in the water, during the final weeks of the programme, did not translate into a decision to practice walking more often on land. In the final session, when Tim was practicing walking in the pool with the physiotherapist, she suggested that they should practice more on land. Tim, however, was unenthusiastic about her suggestion. This event is consistent with previous stories and interpretations. Although Tim valued the ability to walk, he seemed to have limited motivation for undertaking the practice that would give him a chance of walking independently again.

*General health and psychosocial functioning: Week 9.* In Table 7.2, scores for HRQL, mood states, physical self-efficacy, and social support, for Week 9, are shown. Minimal changes occurred between the scores in Weeks 5 and 9. There were, however, a substantial increase in the score for physical functioning and a rather large decrease in the score for social support from family. The increase in physical functioning may represent the greater self-esteem for walking that Tim appeared to have gained during the aquatic programme. Tim perceived he was more able to engage in activities of a moderate intensity, in climbing stairs, and in bending, kneeling, and stooping. He may have had an exaggerated perception of his ability to walk, however, because he indicated that he would not be limited in walking moderate distances (i.e., walking more than one mile, walking one block).

The change in scores on the social support from family subscale seemed to reflect the issue that Tim was having with his parents, with regard to Natasha. The pain and anger that Tim experienced, because of his parents' apparent disapproval of his relationship with Natasha, and their scolding of him for behaving in a

generous way towards her, seemed to have been reflected in the family subscale score.

### *Tim and Me*

The story of Tim and me is perhaps one of misunderstandings on my behalf. Being a neophyte interviewer, I was eager to use my skills in working with Tim to help him relate his stories and to learn valuable insights from him into why he thought his experiences developed the way they did. During the interviews, I became frustrated at times with his short and somewhat limited responses and his lack of insight, both of which I interpreted as a failure on my behalf to ask the right questions and to develop rapport. At other times, I felt lost when Tim responded to open-ended questions with only a few words.

I did not make an emotional connection with Tim. Even when, during one interview, we digressed onto the topic of music, for which we shared a mutual interest, Tim continued to be brief and unreflective in his responses. Outside of the time I spent interviewing Tim and assisting him to complete the questionnaires, our time together was brief. On the turning off of the tape recorder or the completion of the questionnaires, Tim was eager to leave the room and return to his other activities at the day service. Although Tim was a willing participant, his abruptness made me feel like I was an intrusion in his life. This lack of connection also occurred during the aquatic programme, when he would sometimes ignore my presence when he arrived for a session.

On reflection, Tim may have perceived me in the same way that he may have viewed health practitioners. That is, going to see them was not a social occasion, but a time to exchange information and to perform certain activities.

The work of our sessions, possibly like his sessions with medical practitioners, was bookended with the barest of pleasantries. Tim may also have sensed my frustration with him and have been reluctant to speak more widely on the topics about which I was enquiring.

### *Summary and Reflections on Tim*

In my first draft of this life history, I was, at times, dismissive of Tim and more willing to label his behaviour as infantile. Such a portrayal was unfair to Tim and was a manifestation of my frustration with the lack of data he provided. I had limited empathy towards the challenges that he faced, and far too readily held Tim responsible for his behaviour, rather than accounting for the context in which he was living. If he had had the benefits of the supportive environments that I have enjoyed throughout my life, he perhaps would have been a far different person. My infantilisation of Tim followed in the footsteps of others in his life (e.g., his parents), who seemed to treat him like a child.

A significant part of this life history was the limited amount of data I could collect about Tim's life. I suggested various reasons why Tim did not tell more detailed stories, including his repression, reticence, slight possible intellectual impairment, and limited insight and reflection. Tim may have also recognised my frustration during the interview, which could have impaired our relationship. The superficial content of many of the stories that Tim told meant that it was often difficult for me to make rich psychodynamic interpretations as I have done in the other life histories.

In Tim's early life, he experienced mainstream schools and special schools. This time period seems to have been crucial in Tim's development,

because he had two routes that he could take for the remainder of his schooling. Although he struggled to perform in the mainstream schools, he may have been able to succeed in this environment, if he had received greater support. By the middle of his adolescence, however, Tim seemed to turn away from being involved in mainstream society. Mainstream schools meant less competence with work and fewer friends. Tim could avoid this environment through identifying, and associating, with people with disabilities. Being in an environment with people who had disabilities, however, seemed to impair his psychosocial development. Many of his friends had varying degrees of intellectual impairment, which limited Tim's opportunity to achieve greater maturity through communicating with them. In the family environment, Tim's development was also inhibited through his parents treating him like a child, which fostered his dependence on them.

Although Tim wanted to walk again, his involvement in practising walking, and in other physical activities, was limited to organised programmes, such as the warm-water aerobic programme and bocce. Tim was able to show competence in the water, which led to greater self-esteem and to more frequent involvement in water activities directed towards walking. The progress in the pool, however, was difficult for Tim to translate into walking on land. The infrequency of the sessions (once a week) and the brevity of the programme (10 weeks) seemed to have made it difficult for Tim to experience sufficient progress for him to resume practice of walking on land. Physical activity seemed to have a positive impact on Tim's life, but this influence was tempered by infrequency of participation.

### Summary of the Life Histories

In some respects, David and Tim had similar life histories in their early years, but ones that differed remarkably from adolescence to young adulthood. Both men had delayed development of their ability to walk, but were able to obtain this ability through persevering through early childhood. They seemingly received support from one of their parents, and received strong reinforcement from other people for their walking. For David, it was his mother who assisted him in his walking, whereas for Tim, his father supported him. David and Tim both experienced severe back pain during early adolescence, which contributed to their loss of ability to walk. Both had surgical procedures that, although easing the pain, did not have optimistic prognoses for regaining the ability to walk.

During adolescence, however, the courses of David and Tim's lives seemed to sharply diverge. The type of schooling David and Tim received during this time seemed to be crucial in their psychosocial development and their assessment of the value of physical activity. David went to a mainstream school. He could not show competence in this environment in many important areas of adolescent life (academically, physically, socially). These experiences contributed to a loss of self-esteem and to two suicidal gestures. David deeply wished to connect with his classmates and to perform at the same level they were, but was not able to do so. The stress associated with trying to meet the standards of able-bodied classmates was also evident in Tim's life history. Tim, however, seemed to have a safety net, in that, when being at a mainstream school became too stressful, he converted to being a full time student at a special school. Although going to this school may have acted as an impediment to Tim's psychosocial development,

it allowed him to demonstrate competence, and sometimes superiority over others, at a range of tasks.

For both men, physical activity (walking, in particular) seemed to be connected with psychosocial growth. Although David seemed more urgent in his desire to walk, this impression may have been a manifestation of his stronger articulation of what walking would have meant for him. The importance of walking to David was firmly linked with finding a life partner. David believed that, if he was able to walk, he would be more attractive to women. For Tim, however, walking was associated with the ability to drive a car, and, more broadly, with independence from his parents.

One of the features of these two life histories was the apparent lack of support from one parent of each of these men. Although David's father appeared to be supporting him in the best way he knew how, he did not provide David with the emotional and physical assistance that he required. This lack of support meant that David did not engage in physical activity as often as he may have wished, and was not effective as he might have been with assistance when he was involved in such activities. Tim's mother seemed to foster dependence, rather than independence. Tim did not tell me any stories incorporating her attitudes towards him being physically active, however, and his portrayal of his mother may have been strongly influenced by the issues he was having with her, in respect to his girlfriend, at the time I interviewed him.

David's and Tim's experiences in environments of predominantly able-bodied people and people with disabilities, respectively, during adolescence and young adulthood seemed to have significantly influenced their current states of

psychological health. In the face of seemingly insurmountable challenges in his life, David's personality had developed narcissistic features, which helped him to cope with the continual disappointments of trying to succeed alongside able-bodied people. Although Tim may have avoided some of the stresses that David met, through turning towards environments (the special school and day centre) in which he could display greater competence, the possible negative consequence of this choice was that many of the people with whom he was associating were not operating at the same emotional or cognitive levels as him. This environment and Tim's parents' infantilisation of him seemed to inhibit his psychosocial development. Although Tim wished to gain greater independence, he was not receiving sufficient support to do so.

Although David and Tim's scores on the measures of HRQL and psychosocial functioning changed minimally over their respective 10-week programmes, ceiling and floor effects on many of the subscales meant that possible changes could not be detected. Through the qualitative data, the significance of these programmes for David and Tim was revealed. David's programme gave him another avenue for self-improvement towards his goal of attracting a life partner and a new source of narcissistic supplies. The programme also provided David with the opportunity to demonstrate competence physically, and to be treated with positive regard by the trainers and me. Tim's programme provided him with the opportunity to develop independence at swimming and at walking. Throughout the programme, Tim seemed to develop greater self-esteem for these activities, as illustrated by his expressions of satisfaction with his

progress and by his increasing involvement in practising walking when he was in the water.

In summary, the meaning and experiences of physical activity for the two men with cerebral palsy were associated with their psychosocial development. Both men seemed to perceive physical activity favourably, and spoke of positive experiences during their lives. During their adolescence and young adulthood, David and Tim had made several attempts to regain the ability to walk, which they had lost in early adolescence. David perceived walking to be important in facing the psychosocial challenges of young adulthood (intimacy versus isolation; Erikson, 1985), whereas walking seemed important for Tim in addressing the nuclear conflict of the locomotor-genital stage (initiative versus guilt; Erikson, 1985). Although the programmes did not produce changes on the measures of HRQL and psychosocial functioning, interview data showed that these programmes assisted David and Tim in facing their respective psychosocial challenges, and increasing their self-esteem to perform physical activities.



## CHAPTER 8

### GENERAL DISCUSSION

Two main findings from the descriptive study (Study 1) that laid the foundations for much of this thesis were that adults with cerebral palsy typically do not engage in enough physical activity to meet recommended levels for significant health benefits (Rimmer, 2001; USDHHS, 1996), and that involvement in such activity was typically weakly correlated with aspects of HRQL and psychological functioning. The first of these main findings is consistent with previous research with young people with cerebral palsy (Bandini, Schoeller, Fukagawa, Wykes, & Dietz, 1991; Blum, Resnick, Nelson, & St. Germaine, 1991; Longmuir & Bar-Or, 2000; van den Berg-Emons et al., 1995) and adults with the condition (Heller et al., 2002; Turk et al., 1997) and suggests that physical inactivity may be lifelong patterns for many with cerebral palsy. The second of these main findings, however, contrasted with the limited previous research on physical activity and people with chronic neurological conditions (Sutherland, 2001), which found much stronger relationships between physical activity and HRQL, daily hassles, mood, and social support. Issues that contributed to physical inactivity, and its relationship with HRQL and psychological functioning, in adults with cerebral palsy were elucidated through examinations of the lives of adults with cerebral palsy in Studies' 2, 3, and 4.

#### *Childhood Experiences with Physical Activity*

Common findings from the early lives of people with cerebral palsy were that their involvement in physical activity often represented difficult, painful, and socially divisive experiences. Because of their cerebral palsy, the six life history

participants found it difficult to display competence at physical tasks. Although they all learnt to walk, and they perceived walking positively, this developmental milestone was delayed. The physical self-esteem that the life history participants gained from their successful attempts to walk, however, seems to have been eroded during the first school years, particularly for Alana, Amy, Ben, and Judy. The physical abilities of these four participants (and probably the other life history participants as well) did not compare favourably with those of their able-bodied classmates. The limited physical ability of the people with cerebral palsy meant that they often avoided physical activity or that other people (e.g., classmates, teachers) excluded them from participation. The participants seemed to have gained a sense of inferiority from these experiences, and were reluctant to participate in further physical activity. For Alana and Judy, these experiences contributed to lifetime patterns of minimal participation in physical activity.

As reported by some of the life history participants, perceptions of having limited physical ability and being excluded from participating in physical activity with others are evident in the literature. In an example of the former, the 14-year-old female in Peganoff's (1984) study, initially made disparaging comments about her swimming ability. In reference to the latter, both children (Vogler et al., 2000) and adults (Cousminer, 2003) with cerebral palsy have been excluded from participating in physical activity. Although some of these situations have been resolved through increasing competence at physical activity (Peganoff, 1984) or through the intervention of another to allow inclusion in physical activity (Cousminer, 2003), many people with cerebral palsy may not have the motivation, or support from others, to engage in, and persist with, such activity.

Most of the life history participants perceived physiotherapy as a negative experience. Physiotherapy was often associated with pain (Alana, Ben, David), and some participants (Ben, Judy) did not know why they had to perform the exercises that they were prescribed. These life history participants' experiences of physiotherapy were similar to those of women with disabilities (such as amputation, cerebral palsy, congenital limb deficiency, multiple sclerosis, rheumatoid arthritis, and spinal cord injury; Guthrie, 1999; Guthrie & Castelnovo, 2001; Henderson & Bedini, 1995), who perceived participating in physical activity (mainly physiotherapy) to be an unpleasant experience. In Guthrie's studies, some of the women participated in physical activity for fear of the negative consequences of being physically inactive (e.g., functional decline).

In contrast to these negative perceptions of physiotherapy, Amy reported positive experiences from working with physiotherapists. Physiotherapy gave Amy an opportunity to practice standing, a position in which she may have felt less inferior than she did when she was sitting in her wheelchair. Amy also liked the physiotherapist stretching her muscles, which seemed to reduce tension, rather than causing her pain.

Physical activity was a socially divisive experience for many of the life history participants (Alana, Ben, and Judy, in particular) when they were young. Because of their cerebral palsy, these participants did not have the ability to join in the games their classmates were playing, which often involved physical activity. For Ben and Judy, this exclusion from the social milieu of primary school seemed to be an origin of lifetime patterns of difficulties with social relationships. Both Ben and Judy wished to be close to others, but seemed cautious about

becoming so, for fear of revisiting the hurt that accompanied being socially excluded in childhood. Although Alana also experienced social isolation during primary school, her relationships with others outside of school (e.g., her older sister), and her effectiveness in making friends when she went to high school, seemed to have compensated for these difficult earlier experiences.

Alana, Ben, and Judy's wishes to have greater involvement with their childhood classmates reflected the results of research by Hutzler et al. (2002), in which the children with physical disabilities strongly identified with their able-bodied peers. Not being involved in physical activity accentuated the differences between these life history participants and their classmates, just as it had for the children in the Hutzler et al. study. For the life history participants, these experiences contributed to low physical self-esteem and greater feelings of inferiority, which endured, in various forms, into adulthood.

### *Difficulties During Adolescence*

Adolescence presents the psychosocial nuclear conflict of identity versus role confusion, with its emphases on settling on an initial career path and on forming associations with other like-minded individuals, to the exclusion of those who are "different" (Erikson, 1985). In Victoria, Australia, adolescents face the specific challenges of State-wide academic assessment during their last two years of high school and of finding employment or beginning tertiary education. Although these experiences are challenging for many able-bodied adolescents, they may be more difficult for people with cerebral palsy. Their cerebral palsy may mean that other adolescents often socially exclude them, because their condition means that they look different, and their physical impairments may

make doing school work more difficult and time consuming. Previous case studies of psychotherapy and adolescents with cerebral palsy have illustrated how such difficulties can lead to anger (Olkin, 1995), depression (Jureidini, 1988), and suicidal ideations (Olkin, 1995) or attempts (Jureidini, 1988). These issues were particularly prevalent in the life histories of Ben and David, who, during adolescence, were struggling to perform the tasks of that psychosocial stage.

### *Lack of Physical Activity and Functional Decline*

Evidence from this thesis suggests that functional decline may be slowed through participation in physical activity. In the descriptive study, a large association was found between the time involved in household activity and physical functioning. Although this finding could mean that the performance of household activity for longer periods of time may reduce the rate of functional decline, it could also mean that those who performed more household activity could do so because they were not as physically impaired as the other participants. Both interpretations of this association probably have explanatory power.

Stronger evidence that physical activity may slow functional decline comes from the life history data. With the exception of Ben, all life history participants experienced functional decline during their lives. Such adverse changes in physical functioning are common among people with cerebral palsy (Ando & Ueda, 2000; Bottos et al., 2001; Jahnsen et al., 2004; Strauss et al., 2004). The functional decline of four of the participants (Alana, Amy, David, Tim) led to the loss of ability to walk without physical assistance in early adolescence. These participants' difficulties in remembering their childhood experiences with physical activity, particularly the extent of their involvement,

made it difficult to determine if a lack of physical activity in their lives contributed to functional decline. Both Amy and Tim, however, used wheelchairs during their childhood, which means that they were not doing as much walking as they could have been. Using a wheelchair instead of walking may have resulted in less physical fitness, loss of flexibility, and, possibly, loss of coordination. These factors would make walking more difficult and wheelchair use a more favourable mobility option.

In three life histories (Alana, Ben, Judy), the pattern of physical activity and functional decline (or lack thereof) is much clearer than in the data from the other participants. Following functional decline in early adolescence, Alana regained her ability to walk. During her 20s, Alana stopped performing physiotherapy, and was involved in minimal physical activity. Once again, Alana experienced functional decline. Similar to Alana, Judy participated in minimal physical activity throughout her life. Judy's decline in function, however, did not occur until much later in life (Judy experienced functional decline in her late 50s). The late onset of Judy's functional decline may have been due to the mildness of Judy's cerebral palsy and to her not using a wheelchair. These women's lack of involvement in physical activity may have exacerbated the extent of functional decline they reported. In contrast, Ben, who had performed a large amount of physical activity, had not experienced functional decline. Although this absence of functional decline may have been due to the mildness of his cerebral palsy, Ben contended that his physical condition would have been poorer if he had not been physically active.

### *Physical Activity and Enhanced Psychosocial Functioning*

Although most of the six life history participants had negative experiences with physical activity during childhood, some (particularly Amy and Ben) increased their involvement in such activity as adults. Participation in physical activity allowed the demonstration of competence and increased social connectedness. Whereas, in childhood, Amy and Ben seemed to have compared their physical abilities to those of their able-bodied classmates, as adults they referenced their ability against their past achievements. Ben also judged his swimming ability with respect to other athletes with cerebral palsy and with similar degrees of impairment. These more favourable comparisons allowed both Amy and Ben to positively reflect on what they had achieved and meant that they were more motivated to continue engaging in physical activity.

For some of the participants (Amy, Ben, David), engagement in physical activity served social purposes. Amy's motivations for performing physical activity strongly reflected the social reasons for involvement from the participants in a study by Stahi et al. (2002). That is, through maintaining her physical function, Amy was able to remain involved in daily family life and to stay connected with people outside her family home (e.g., people at her church). In doing so, Amy was enjoying intimate relationships with others and, thereby, meeting challenges of the young adult stage of psychosocial development (Erikson, 1985). David's motivations to be involved in physical activity were also representations of strivings to achieve intimacy in this psychosocial stage. As do many people with cerebral palsy (Joseph, 1991; Jureidini, 1988; Shuttleworth, 2000; Turk et al., 1995), David had experienced sociocultural barriers in his

attempts to obtain romantic intimacy. David perceived that he would have opportunities to have such a relationship if he could walk. Performing physical activity was the vehicle that provided him with an opportunity to develop his walking ability. Although Ben's motives for performing physical activity were also socially-related, they were directed towards trying to satisfy his substantial need for social approval, rather than towards goals of intimacy. Sport was a platform on which Ben saw other people (successful, high profile sport people) receiving public accolades, and he perceived that, if he shared that stage, then he, too, would receive praise and acceptance.

### *The Effectiveness of Physical Activity Interventions*

The weight-training programme was effective at increasing David's strength. Although the single-subject design of this programme means that other factors apart from the programme may have influenced these changes in strength, the minimal presence of other physical activities in David's life suggests that a large proportion of the increases in strength may be attributable to the weight training he performed. This finding adds to the growing body of literature (e.g., Blundell et al., 2003; Dodd et al., 2002; Taylor et al., 2004) proposing that weight training can increase the strength of people with cerebral palsy.

The effects of the warm-water aerobic and weight-training programmes on the HRQL and psychosocial functioning of David and Tim, however, were difficult to judge, because there were ceiling and floor effects on many of the variables that were measured. For Study 4, it would have been desirable to have selected participants who had scores on each of the measures that represented poor HRQL and psychosocial functioning. Conducting research with such



participants would have enabled an evaluation of the effectiveness of these programmes to increase HRQL and psychosocial functioning. This opportunity was not available, however, due to the scarcity of volunteers to take part in the physical activity programmes.

Through the interviews, however, David and Tim identified benefits of the programmes that the psychometric instruments did not directly measure. Although a psychodynamic definition of self-esteem from Basch (1988) was used in interpreting the life history data, the findings from Studies 2, 3, and 4 are consistent with previous cognitive-behavioural research, in which it has been reported that participation in physical activity is positively associated with self-esteem (e.g., Calfas & Taylor, 1994; Gruber, 1986). David and Tim seemed to increase their self-esteem through reflecting on their increases in competence at the various exercises they performed. Tim's increase in self-esteem, for example, could be interpreted from his expressions of satisfaction with his progress with swimming and walking, and from his increasing involvement in practicing walking in the water. The programmes also seemed to assist David and Tim in their attempts to perform tasks relating to their psychosocial development. This reason for participation in physical activity seems to be absent from the literature on the meaning and experiences of physical activity. For David, the importance of walking seemed to be associated with the challenges of young adulthood (intimacy versus isolation; Erikson, 1985), whereas for Tim, walking seemed to have been connected with the locomotor-genital stage (initiative versus guilt; Erikson, 1985). The programme also seemed to benefit David through the support he received from the trainers and me. A common theme that appeared regularly

through David's stories about his life was that significant others in his life (e.g., his father, medical practitioners, teachers) did not support him. In the programme, however, the trainers and I expressed belief in his ability to achieve at weight training and we designed his programme in such a way that he could display competence. Our positive approach to David and his weight training also seemed to reinforce features of his personality through providing him with a new source of narcissistic satisfaction.

### *Narcissism and Inhibited Psychosocial Development*

One noteworthy aspect of two of the life histories (Amy and David) was the presence of narcissism. Like Niederland's (1965) patients, Amy and David's narcissism may have resulted from an unresolved narcissistic injury. That is, their early experiences with cerebral palsy may have led to failures at performing various physical tasks and losses of love from significant others. Attributing Amy and David's narcissism solely to their cerebral palsy may be unsatisfactory, however, because the other life history participants probably also had unresolved narcissistic injuries, but did not seem to have narcissistic features in their personalities. A further commonality in the lives of Amy and David was an intense desire to undertake tasks of particular psychosocial stages, and subsequent failures to successfully perform these tasks. In both lives, the failure was specific to the young adult stage of psychosocial development (Erikson, 1985). For Amy, being denied the opportunity to get married and to have children seemed to have contributed to narcissistic fantasies of rebirth, which were accompanied by the disappearance of her disability, and of immortality. David's difficulties with the challenges of the young adult stage of psychosocial development (Erikson, 1985)

were much more pervasive, particularly with regard to romantic intimacy. He had developed stronger narcissistic features, including a strong belief that he was special, a grandiose sense of self, and a lack of empathy towards others, especially those who were able-bodied.

#### Method Issues from the Present Research

Because the participant inclusion criteria were consistent between studies, the weakness of the first study (i.e., the restriction of the inclusion criteria to those with higher cognitive functioning) applies equally to the other studies. Many people with cerebral palsy, however, have intellectual impairments (Stanley et al., 2000; SCPE, 2002). Further research is warranted on determining whether the physical activity experiences of people with cerebral palsy and intellectual impairments are similar to those of the participants in the present studies.

A weakness of the life history studies was the narrow distribution of ages of the six participants. Five of the participants had ages ranging from 24 to 30, and one participant (Judy) was aged 60. Although this allowed a detailed examination of how these people met some of the earlier psychosocial challenges (up to, and including, young adulthood), issues that may arise for people with cerebral palsy during their 30s, 40s, 50s, and beyond remain relatively unexplored (with the exception of Judy's life history). Investigators in the future may wish to investigate the physical activity experiences of people older than most of the participants in the present study.

The data that were collected from David and Tim showed how people's psychological make-ups could affect their perceptions of their HRQL and psychosocial functioning. Both men tended to respond to the items of the HRQL

and psychosocial functioning measures in sharply positive fashions, which belied the stories they told during the interviews. David's quantitative data seemed to have been affected by his suppression of emotions, whereas Tim's data may have been adversely influenced by his seemingly limited access to his emotions and thoughts. Researchers using self-report HRQL and psychosocial functioning measures in further investigations should keep in mind that psychological characteristics of participants could sometimes distort their responses.

An interesting aspect of this research was that, like the participants, I have cerebral palsy. For the life history participants, my cerebral palsy may have helped me develop rapport with them. Two of these participants (David, Judy) identified with me during parts of the interviews. This identification may have made it easier for them to disclose sensitive information. That is, their beliefs that we had common experiences throughout our lives may have made them more comfortable with sharing their stories. For me, the research has been professionally enjoyable and personally uncomfortable. On a professional level, I have enjoyed the challenge of having to bring together disparate areas of knowledge, of interviewing, of learning research methods and ways of interpreting data that were new to me, of applying the knowledge I have learnt to the analysis of the data, and of forming the research into a cohesive document. On a personal level, I have disliked being involved in the research. Due to the confessional aspect of this research, I have often felt that I have had to include details about myself that I have only rarely spoken about with close friends and family members. I have not told these people some of the issues I am facing, because I associate the stories with feelings of embarrassment and shame.

Although the participants in this research have anonymity as a right, I, as the researcher, do not enjoy the same luxury. Conducting this research has also affected me in other ways. In *My Life Experiences* (Study 2), I spoke about my internalised ableism and disparaging attitudes towards people with disabilities. Through conducting this research, my internalised ableism has become conscious to me. Although I still identify with people who are able-bodied, this conscious awareness of my internalised ableism has made me confront the truth that I do have cerebral palsy and the existence of my condition is plainly obvious to anyone who meets me. After hearing numerous stories from the life history participants about their difficulties when trying to meet various psychosocial challenges, against the backdrop of an unaccommodating society, however, I do not wish to be like them and have similar experiences as they have had. My disparaging attitudes towards people with disabilities, however, have substantially reduced. During the course of conducting the life history interviews and working with the data, I have become more empathic to the immense challenges that people with cerebral palsy often face.

### Implications for Practice

The findings of this thesis may have implications for those who typically make important contributions to the lives of people with cerebral palsy, such as parents, teachers, and physiotherapists. The thesis also provides valuable information for psychologists and fitness professionals, who may occasionally see clients with cerebral palsy.

### *Parents and Teachers*

To assist in the social development of children with cerebral palsy during childhood, their inclusion in physical activity may need to be supported by significant others in their lives. At home, parental guidance may be necessary in choosing activities in which their children with cerebral palsy can develop competence. Parents may also help their children perform physical activities with other children at home through modifying the activities, so that they can successfully participate.

Parents may also assist their children through accessing organisations that provide modified physical activity for people with disabilities and those that hold competitions for people who are similarly impaired. For example, Amy sailed a boat that had been designed for people with physical impairments. She also performed gym exercises with a personal trainer, and Ben competed in swimming events against others with a similar level of physical function as he had. As with Amy, even people with severe cerebral palsy can display competence at physical activity.

At school, the responsibility for facilitating the inclusion of children with cerebral palsy in physical activity may fall on teachers. Like parents, teachers may be able to assist children with cerebral palsy through modifying physical activities, so that they can display competence. In helping children with cerebral palsy play more effectively with others, teachers may help their students to adapt games in the schoolyard, so that children with cerebral palsy can be involved. For example, if the children were playing tag, the game could be modified, so that

when the child with cerebral palsy was “it” the other children would walk and not run.

### *Physiotherapists*

The life history participants’ experiences of physiotherapy in the early stages of development have implications for the administration of such treatments. Two issues that physiotherapists may need to address are the pain and the perceived relevancy of treatments. There has been little research on how pain during physiotherapy could be reduced for people with cerebral palsy. Steele et al. (2003) recently demonstrated how virtual reality could be used to reduce the perception of pain during physiotherapy treatment. Other non-pharmacologic, analgesic techniques that have been effective in the treatment of burn patients, and that may be useful during painful physiotherapy with people who have cerebral palsy, include hypnosis (Patterson, Everett, Burns, & Marvin, 1992), mental imagery (Fernandez & Turk, 1989), relaxation and biofeedback (Knudson-Cooper, 1981), and watching videos that incorporate beautiful scenes and that are accompanied by music (Miller, Hickman, & Lemasters, 1992).

The perceived relevancy of physiotherapy exercises may be addressed in two ways. First, children and adolescents may benefit from explanations of why they have been prescribed exercises to perform. As people develop through childhood and adolescence, these explanations need to be repeated using language that relates to their developmental levels. By receiving messages periodically about why physiotherapy is important, young people may be more motivated to persist with the exercises. Second, rather than focusing on developing function using abstract exercises, physiotherapy patients may be more motivated to comply

with the treatment if they are asked to perform tasks that are similar to those they would perform in their day-to-day lives. Developing balance, for example, may be more effective if activities were formed into games, in which the patients catch, chase, kick, or throw balls, rather than if they are asked to stand in one place for a period of time. By using such activities in treatment, children may be able to transfer this learning into the schoolyard and play with others more effectively.

### *Psychologists*

The life histories in this thesis supplement the information available on psychotherapy and people with cerebral palsy (Acquarone, 1995; Blotzer, 1995; Donovan, 1995; Feuerstein, 1995; Jureidini, 1988; Lantican et al., 1994; Olkin, 1995; Sullivan, 1953). Through the life histories several issues emerged that were common among many of the participants (e.g., difficulties with schoolwork, lack of competence with physical activity, social isolation). How each participant dealt with these issues, however, tended to be unique to the individuals, their histories, and their social environments. Familiarity with these issues and some of the possible psychosocial consequences of their manifestations may help psychologists in their provision of therapy to people with cerebral palsy.

A prominent issue that appeared in the life history data was the difficulties participants faced in fitting into the social milieu of primary school. For some of the participants, these difficulties extended into adolescence and adulthood. A consequence of this social exclusion was that some of the participants did not have the confidence and skills necessary to negotiate successfully the adult social world. Psychologists may provide assistance to clients with cerebral palsy to help them develop the ability to successfully engage and interact with others.



The life histories provide rich information on some of the possible outcomes of limited success in meeting psychosocial challenges. The life history of David was perhaps the most extreme example of a participant's inability to meet psychosocial challenges. David's life included repeated failures to show competence in academic and social spheres. When I met David, he seemed to be coping with his inability to be a productive member of society and his social exclusion through the development of the narcissistic features of his personality and through the suppression of his emotions. Other examples of the consequences of difficulties in meeting psychosocial challenges include desires to be more socially connected (Judy), narcissistic fantasies (Amy), attempts to compensate for deep sense of perceived inferiority (Ben), and narrowing of the social sphere to near-exclusive involvement with people who have disabilities (Tim).

### *Fitness Professionals*

Complementing Cousminer's (2003) account of how difficult it was for him to join a fitness centre, the life histories provide further evidence of the difficulties that people with cerebral palsy face when trying to begin an exercise programme at a fitness centre. These difficulties can be because of the concerns of people with cerebral palsy about their ability to exercise in a fitness centre (Ben) or because they are denied access to such facilities (Alana). Although literature exists to guide fitness professionals in their prescription of exercise for people with chronic health conditions (American College of Sports Medicine, 2003), many fitness professionals may not have received formal education on this topic, and may not be aware of, or have immediate access to, material that can help them in their roles as fitness professionals. Instruction in assessing the fitness of, and

providing exercise programmes for, people with chronic health conditions should become part of the curriculum for fitness industry students. To improve the knowledge of the present fitness industry workforce, information about this topic could be presented at conferences for fitness professionals.

### Implications for Future Research

There are many areas for potential research on physical activity, psychological functioning, and people with cerebral palsy. I have already highlighted two of these areas (research on people with cerebral palsy and intellectual impairment, research with middle-aged and older adults) as fertile grounds for research.

Study is also warranted on interventions to assist adults with cerebral palsy into physical activity. The performance of physical activity has the potential to improve their aerobic capacity (e.g., Emons & Van Baak, 1993; Fernandez & Pitetti, 1993; van den Berg-Emons et al., 1998), strength (Allen et al., 2004; Blundell et al., 2003; Dodd et al., 2002; Taylor et al., 2004; see also Study 4 this thesis), and physical functioning (Damiano & Abel, 1998; Darrah et al., 1999; MacPhail & Kramer, 1995; O'Connell & Barnhart, 1995), and also appears to benefit their psychosocial functioning (Study's 3 and 4). The results from Study 1, however, showed that many adults with cerebral palsy are involved in minimal physical activity. Investigations are needed to examine the effectiveness of various interventions to produce changes in physical activity participation. Part of this research may include a study of the perceptions of adults toward physical activity. The life history studies provide some examples of negative views of

physical activity (e.g., it is punishing), but it would be useful to establish how widespread these perceptions are among people with cerebral palsy.

Another question, in relation to which may elucidate the perceptions of physical activity of people with cerebral palsy, is why so few people with the condition volunteered to participate in the research that incorporated exercise programmes. Although most participants who volunteered for Study 1 indicated that they were willing to be involved with further research, only one person (David) volunteered for the weight-training programme. For many of the potential volunteers, the long distances from their homes to the University campus, where the research was conducted, may have been a factor that discouraged or prohibited them from being involved. For those who were closer to the campus, however, it may benefit researchers designing further studies to know other factors that inhibit people with cerebral palsy from being involved in physical activity research.

Research is still needed on one of the original questions of this thesis. That is, what are the effects of exercise interventions (e.g., warm-water aerobic exercise, weight-training) on the HRQL and psychological functioning of adults with cerebral palsy? This research could not be conducted because of the scarcity of willing participants. Recruiting participants for research of this kind may be more successful in states of Australia (e.g., Western Australia) and in countries where registers of people with cerebral palsy have been established for many years. Researchers must reflect carefully on the content and manner of the invitations to participate that they present to people with cerebral palsy.

Investigations are also needed into children with cerebral palsy and the experiences of primary school. Many of the life history participants reported

negative experiences at primary school, which had psychosocial reverberations throughout their lives. Most of the participants, however, were attending primary school in the 1970s and early 1980s, when many schools may not have been equipped to include children with cerebral palsy. Research is warranted to establish whether children with cerebral palsy who are currently at primary school are having negative experiences such as those of the life history participants.

### Concluding Comment

The present research was designed to investigate physical activity and psychosocial functioning in the lives of adults with cerebral palsy. Although many of the participants (Study 1) indicated that they performed physical activity, it seems unlikely that the intensities of these activities were sufficient to produce significant health benefits. Even so, these participants typically reported high levels of HRQL, mood states, and social support. The two areas in which the participants' scores were lower than those of data from able-bodied samples were the physical functioning subscale of the HRQL measure and two subscales of the physical self-efficacy measure. When asked to respond to questions about their physical selves (e.g., functional capabilities), the participants' scores were typically lower than those of able-bodied populations. The participants reported other aspects of themselves (e.g., general health, mood, social support) in a similar fashion to able-bodied samples. A reason for this limited connection between physical activity and psychosocial functioning may be that many of the Study 1 participants may have had adverse experiences with such activity as children, similar to those of the life history participants (Study's 2, 3, and 4), and had since avoided much involvement in physical activity. Many of these people

may not have experienced high levels of physical activity during their lives, and as such, have limited points of comparison (i.e., times when they were highly active) for their levels of HRQL, mood, physical self-efficacy, and social support in their relatively physically inactive lives. These findings do not suggest, however, that physical activity does not, and cannot, have a positive influence in the lives of adults with cerebral palsy. A strong theme throughout most of the life histories was the importance of physical functioning in the meeting of psychosocial challenges. If people with cerebral palsy are able to maintain or improve physical functioning through participation in physical activity, they may be in a better position to face the challenges of each psychosocial stage. I hope that the knowledge gleaned in the present research will stimulate further study of psychological factors associated with physical activity in the lives of people with cerebral palsy and other physical disabilities.

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## APPENDIX A

### CEREBRAL PALSY

I describe cerebral palsy in detail in the following sections. Specifically, I examine the incidence and prevalence, aetiology, comorbidity, mortality, classification systems, and pathophysiology of cerebral palsy. I then describe the physical health of adults with cerebral palsy and the role of exercise in the management of the condition. First, however, I provide a brief introduction to cerebral palsy.

Cerebral palsy has traditionally been defined in clinical terms, because aetiology and pathology were unknown. The most recent consensus definition of the condition described cerebral palsy as “not a single entity but covers neurological impairments characterised by abnormal control of movement or posture resulting from abnormalities in brain development or an acquired non-progressive cerebral lesion” (The Australian and New Zealand Perinatal Societies, 1995, p. 85). This definition incorporates several important aspects of the condition.

As described in the definition, cerebral palsy is not a single condition, but covers a range of similar conditions that have separate clinical manifestations, aetiologies, and pathologies. The heterogeneity of the conditions within cerebral palsy was recognised by people who were involved in discussions on the classification and terminology of cerebral palsy, and who first conceived the term (Mac Keith & Polani, 1958). The contributors to that discussion envisaged that the names of the individual diseases would be used once more was known about them. Although cerebral palsy classification systems have been suggested, researchers continue to try to develop a greater understanding of aetiology and pathology of the various manifestations of the condition.

Although the definition of cerebral palsy focuses on motor impairment syndromes of neurological origin, significant levels of comorbidity exist within the population of people with this condition (Pharoah, Cooke, Johnson, King, & Mutch, 1998; Stanley et al., 2000). The isolation of motor impairments from other conditions (e.g., mental retardation), however, allows service providers to better cater for clients’ needs.

The requirement that the brain lesion be cerebral in location and non-progressive allows for the exclusion of other conditions, including neurodegenerative conditions, neuromuscular disorders, neural-tube defects of the spine, and tumours (Badawi et al., 1998). The determination of whether or not a brain lesion is static is not always straightforward, because lesions cannot often be observed (Stanley et al., 2000). Adding to the confusion, for some conditions (e.g., metabolic abnormalities; Morton, Bennett, Seargeant, Nichter, & Kelley, 1991) cerebral insult can be halted through treatment, and in some conditions (e.g., the ischaemic cerebrovascular disease, moyamoya; Soriani, Scarpa, Voghenzi, De Carlo, & Cilio, 1993) there may be repetitive, but singularly non-progressive, insults. Diagnosis of a static lesion is, therefore, inferred from the clinical manifestations, which remain consistent with changes in a person’s age, fatigue, health, and mood (Stanley et al., 2000).

In summary, the term cerebral palsy encompasses several conditions, characterised by non-progressive cerebral lesions, which cause motor impairment. These conditions may differ from each other, and have separate clinical

manifestations, aetiologies, and pathologies. The various clinical manifestations, and their accompanying aetiologies and pathologies, have yet to be fully understood. One factor that hampers researchers in their attempts to understand cerebral palsy is its low prevalence.

#### Incidence and Prevalence of Cerebral Palsy

To gain an impression of the extent to which cerebral palsy is present in the population, it is useful to understand how rates of a disease can be measured. An important distinction, when considering the epidemiological literature on cerebral palsy, is between incidence and prevalence. Incidence refers to “the number of new onsets [of a disease] or in a population within a specified period of time” (Silman & Macfarlane, 2002, p. 13). Incidence is described in terms of a given rate per year. Prevalence refers to “the number of individuals in a population with a disease or personal attribute” (p. 16). Prevalence relates to a single point in time and is usually expressed as a proportion. If the mortality and migration rates of people with the disease under investigation are the same as for the general population, then the rates of incidence and prevalence of the disease will be identical. The occurrence of cerebral palsy in the population has been measured using both incidence and prevalence rates, as well as with hybrids of these methods.

The occurrence of cerebral palsy is normally cited as a prevalence at a certain age per 1000 live born children (Stanley et al., 2000). This method of measuring prevalence has several advantages. The use of this denominator acknowledges that some children, who die in early childhood, may have had complications, such as cerebral palsy. Because the prevalence of cerebral palsy cannot be determined for those children who die in early life, they are necessarily excluded from statistics. A greater proportion of preterm than term children are excluded in this way; a population with a higher risk of both infant mortality and cerebral palsy. The nomination of a certain age for determining prevalence rates allows for more accurate statistics to be calculated. Children of the same birth cohort are assessed. Except for the most severe cases, cerebral palsy is difficult to diagnose in the early years of life, leading to a possible underestimation of the prevalence rate. In addition, some motor impairments resolve or change in later childhood, making the initial diagnoses of cerebral palsy sometimes inaccurate. Using the prevalence rates cited by Taft (1995), for example, the rate of diagnosed cerebral palsy at 12 months of age was over two and a half times greater than at seven years of age.

Producing accurate rates of cerebral palsy is particularly challenging for the epidemiologist. Establishing rates of prevalence can be problematic, because of the large samples needed to calculate stable figures (Stanley et al., 2000). Although cerebral palsy is the most common childhood motor disability, its occurrence is relatively rare.

The prevalence of cerebral palsy has been reported to be approximately 2 to 2.5 of every 1,000 children in the Western world (Missiuna et al., 2001). This rate was stable across the 14 studies in the Missiuna et al. review, with the highest prevalence rate of 3.87 being reported in the United Kingdom (Sinha et al., 1997), and the lowest prevalence rate of 1.19 being reported in Germany and Sweden (Krägeloh-Mann et al., 1994).

The recent study from the Surveillance of Cerebral Palsy in Europe (SCPE; 2002) integrated data from 13 centres based in eight European countries. Data on 6,502 children with cerebral palsy was collected and a prevalence rate of 2.08 per 1000 live births was calculated. This study proved difficult for the SCPE, because of between-centre differences in the definition and classification criteria, the assignment of milder cases of cerebral palsy, the upkeep of cerebral palsy registers, and the neo-natal care provided, and thus the prevalence rate may be underestimated.

In summary, approximately 2 to 2.5 of every 1,000 children born in the Western world have cerebral palsy. Issues, such as the need to keep accurate records and to decide on an age at which cerebral palsy should be diagnosed, make epidemiological studies into cerebral palsy difficult. To generate more reliable statistics in the future, accurate records need to be maintained and the inclusion criteria for these records need to be standardised across centres.

#### Aetiology of Cerebral Palsy

In this section, I describe the Stanley et al. (2000) causal pathways model of the aetiology of cerebral palsy. I then review the epidemiological literature pertaining to cerebral palsy in respect to the Stanley et al. model.

Stanley et al. (2000) argued that traditional models of causation may be problematic, when applied to cerebral palsy, because they focus on the contribution of exposures as independent causal agents to the manifestation of the condition. Using this traditional approach, measures of association, such as multivariate analyses, are used to examine the strength of independent factors. The strongest exposures are retained in the causal model and weaker factors are eliminated. This strategy leads to erroneous conclusions, however, if the exposures to causal agents are not independent, as is the case with cerebral palsy. Stanley et al. pointed out that, with this type of analysis, important information, which may have highlighted a preventable cause, may be lost.

Stanley et al. (2000) outlined four alternative aetiological models that may be used for cerebral palsy:

- (a) causal pathways where factors are caused or influenced by earlier factors;
- (b) a pathway in which a factor requires additional, independent exposures in order to constitute a cause;
- (c) the outcome has several distinct causes; or
- (d) several different adverse outcomes are possible following the exposure (p. 43).

The recognition of causality is further complicated if factors that are considered to represent a single exposure are heterogeneous, and some of these factors are on causal pathways, whereas other factors do not contribute to the condition. Stanley et al. (2000) cited preterm birth and intrauterine growth restriction as examples of such factors. Both factors have several distinct antecedents, not all of which contribute to the causation of cerebral palsy.

#### *Known Causal Pathways to Cerebral Palsy*

Stanley et al. (2000) illustrated the causal pathway to choreoathetoid cerebral palsy in an infant whose mother and father are Rh incompatible. A pregnancy in a Rh- mother with a Rh+ foetus causes transplacental haemorrhage and, consequently, a maternal immune response, the production of antibodies to

foetal blood. If a subsequent pregnancy occurs with a Rh+ foetus, neurotoxic bilirubin is produced by the destruction of foetal blood. The bilirubin is able to cross the blood-brain barrier, a condition known as kernicterus. It is kernicterus that causes cerebral damage leading to choreoathetoid cerebral palsy.

Understanding of this causal pathway has made it possible to develop strategies to prevent this form of cerebral palsy (Stanley et al., 2000). Strategies for the prevention of birth of an infant with choreoathetoid cerebral palsy, when a woman and her partner are Rh incompatible, include having no children, anti-D administration to prevent the maternal immune response, having no further children after the first Rh+ child, terminating a subsequent Rh+ foetus, and, in response to the production of bilirubin, foetal/neonatal exchange transfusion or phototherapy.

#### *Suggested Causal Pathways to Cerebral Palsy*

In the Stanley et al. (2000) comprehensive review of the epidemiological literature several casual pathways to cerebral palsy are suggested, which involve pathways initiated periconceptionally or in early pregnancy, premature birth, intrauterine growth restriction, birth asphyxia, and multiple pregnancy. I briefly review these pathways, and include recent research to highlight the effect of certain exposures on the risk of cerebral palsy.

##### *Periconception and Early Pregnancy*

Stanley et al. (2000) listed six periconceptional and early antenatal factors that have been associated with higher risks of cerebral palsy. First, maternal factors, including genetics and infertility, have been identified as risk factors. Although cerebral palsy has recurred in some families, this occurrence has been rare and without clear patterns. Genetics seem to be a greater risk factor when consanguineous families are common, accounting for approximately 2% of cerebral palsy cases (McHale et al., 1999, 2000). Autosomal recessive genes have been linked to the occurrence of symmetrical spastic cerebral palsy (McHale et al., 1999) and ataxic cerebral palsy (McHale et al., 2000). Approximately half of the 5 to 10% of cases of ataxic cerebral palsy may be attributable to the recessive gene on chromosome 9p12-q12.

With regard to fertility, Strömberg et al. (2002) compared the neurological sequelae of children who were born after in-vitro fertilisation (IVF;  $n = 5,680$ ) with population-based matched controls ( $n = 11,360$ ). Cerebral palsy was the most commonly diagnosed neurological sequelae in those born after IVF. The risk of cerebral palsy was higher for children born after IVF than for children who were the controls (odds ratio [OR], 3.7, 95% CI, 2.0-6.6). The independent risk of cerebral palsy after IVF remained significant in the logistic regression analysis (after controlling for low birth weight, maternal age  $< 30$  or  $> 35$ , and male sex) for all children (OR, 2.1, 95% CI, 1.0-4.5), but was not significant for singletons (OR, 2.1, 95% CI, 0.8-5.4).

Second, foetal malformation syndromes may cause cerebral palsy (Stanley et al., 2000). Nelson and Ellenberg (1985) found that major malformations, outside of the central nervous system (CNS), occurred in triple the number of children with cerebral palsy than in children without the condition. The relative risk (RR) of major non-CNS malformations was slightly higher in children with a birth weight over 2,500g (RR = 3.9) than in children with a birth weight less than, or equal to, 2,500g (RR = 3.1).



Third, infections may be on a causal pathway to cerebral palsy (Stanley et al., 2000). Vertically transmitted viral infections that are known to cause damage to the foetal central nervous system include toxoplasmosis, rubella, cytomegalovirus, and herpes simplex virus. Although a recent study indicated that intrauterine exposure to infection was not a risk factor for spastic cerebral palsy among children who were very prematurely born (gestational age < 32 weeks) with birth weights less than 1,999g (Grether, Nelson, Walsh, Willoughby, & Redline, 2003), prior research showed that maternal infection was associated with unexplained cerebral palsy in singleton children of normal birth weight (Grether & Nelson, 1997). In Grether and Nelson's study of 46 children with spastic cerebral palsy and 378 control children, several types of maternal infection were associated with cerebral palsy, including: maternal fever exceeding 38°C during labour (OR, 9.3, 95% CI, 2.7-31), clinical diagnosis of chorioamnionitis (OR, 9.3, 95% CI, 2.7-31), histological evidence of placental infection (OR, 8.9, 95% CI, 1.9-40), and the presence of one or more indicators of maternal infection (OR, 9.3, 95% CI, 3.7-23). Compared with children who were the control, maternal infection was more common in the deliveries of children with spastic quadriplegia (OR, 19, 95% CI, 6.5-56) than in children with spastic diplegia (OR, 6.7, 95% CI, 1.7-34). Placental infection was particularly greater for children with spastic quadriplegia (OR, 31, 95% CI, 7.9-109) than for the control children.

Fourth, deficiencies may cause cerebral palsy (Stanley et al., 2000). Studies conducted by Pharoah and his colleagues (Pharoah, Butfield, & Hetzel, 1971, 1972; Pharoah, Connolly, Hetzel, & Ekins, 1981; Pharoah, Ellis, Ekins, & Williams, 1976; Pharoah & Hornabrook, 1974) have illustrated the importance of iodine to foetal neurodevelopment. The studies were conducted with participants from the Jimi river valley, an isolated area situated in the Western Highlands Province of Papua New Guinea. A sharp rise in the prevalence of endemic cretinism, a feature of which is spastic diplegia, occurred in the late 1950s (Pharoah & Hornabrook, 1974). The increase in prevalence was alongside sociological change in the valley, brought about by the first European contact in 1953, and the later establishment of missionary stations and government. The Europeans used rock salt, which had substantially inferior iodine content, for trading purposes, and traditional methods of salt manufacture quickly ceased.

Pharoah et al. (1971, 1972) found that intramuscular injection of iodised oil was effective in preventing endemic cretinism. Of the 688 children born to mothers who did not have iodised oil injected, 31 were endemic cretins, the mothers of 5 of whom were pregnant at the start of the trial (Pharoah et al., 1972). In contrast, of the 687 mothers who had iodised oil injected, there were 6 children born with endemic cretinism, the mothers of 5 of whom were pregnant when the trial began.

Low neonatal (Reuss, Paneth, Pinto-Martin, Lorenz, & Susser, 1996) and maternal (Pharoah et al., 1981; Pharoah et al., 1976) thyroxine levels have also been associated with cerebral palsy. Low serum total and serum-free thyroxine can be caused by severe iodine deficiency, and although the contribution of these factors could not be established in the Pharoah et al. studies, Reuss et al. found that severe hypothyroxinemia was associated with disabling cerebral palsy (OR 17.6, 95% CI, 5.0-61.7). This association remained after adjusting for gestational

age and a large number of prenatal, perinatal, and early and late neonatal variables (OR 4.4, 95% CI, 1.0-18.6).

Fifth, toxicities may be a cause of cerebral palsy (Stanley et al., 2000). Methylmercury is neurotoxic and can cause widespread and diffuse damage to the immature nervous system (Castoldi, Coccini, Ceccatelli, & Manzo, 2001). Even if the mother shows no signs of poisoning, concentrations of methylmercury may be high enough to have adverse effects on the foetus. These adverse consequences may include cerebral palsy, severe mental retardation, blindness, and deafness.

Discontinuation of the use of benzyl alcohol as a preservative to flush intravascular catheters resulted in a decrease in neurologic handicaps in surviving infants of very low birth weight (VLBW, < 1,250g; Benda, Hiller, & Reynolds, 1986), and a decrease in grade III/IV intraventricular haemorrhage and mortality of infants with birth weights of less than 1,000g (Hiller et al., 1986). Benda et al. found that the incidence of cerebral palsy among surviving VLBW infants, during the 12 months prior to the discontinuation of benzyl alcohol use, was 50%, whereas the incidence in the 12 months post discontinuation of benzyl alcohol use was 2.4%. Comparing the 13 months pre- and post-discontinuation of benzyl alcohol usage, Hiller et al. found that the incidence of grade III/IV intraventricular haemorrhage decreased from 46% to 19%, and the mortality rate decreased from 80.7% to 45.7%.

Adverse foetal outcome has been associated with severe accidental maternal carbon monoxide exposure, but not with mild accidental maternal carbon monoxide exposure (Koren et al., 1991). Severe carbon monoxide exposure was defined as grades 3 (not alert) to 5 (comatose) on a 5-grade system, and mild exposure were grade 1 (alert and orientated) and 2 (alert, but with an altered mental state). Of the two cases of grade 5 poisoning, one foetus was a stillbirth at 29 weeks gestation and the other foetus died at term, which was followed by maternal demise. Of the three cases of grade 4 poisoning, one infant was diagnosed with cerebral palsy at 8 months, and the other two infants had normal outcomes.

There is evidence that in utero exposure to cocaine may cause cerebral palsy. Wilson-Costello et al. (1998) found that a significantly higher percentage of mothers gave birth to infants of VLBW (< 1,500g) and who screened positive for cocaine at delivery had children with neurological impairments (10 of 16, 63%) or children with cerebral palsy (7 of 11, 64%) than their matched controls, who had normal children (3 of 13, 23%, and 1 of 8, 13%, respectively). In a study that focused on the neurological correlates of foetal cocaine exposure, Chiriboga et al. (1995) found that hypertonia was present in twice as many cocaine-positive infants, at six months of age, than cocaine-negative infants (OR 2.1, 95% CI, 1.0-4.6). Hypertonic tetraparesis, a form of hypertonia, was four times more common in cocaine-positive infants than cocaine-negative infants (OR 4.0, 95% CI, 1.5-10.8). The hypertonic tetraparesis resembled rigidity, rather than spasticity, and the hypertonia in 97% of infants was resolved by 24 months of age.

Sixth, vascular factors may contribute to the occurrence of cerebral palsy (Stanley et al., 2000). Recent research has shown vascular factors to be an important cause of cerebral palsy (Shevell, Majnemer, & Morin, 2003). In their study of 217 cases of cerebral palsy, Shevell et al. found that vascular factors were in the top five aetiologic factors, occurring in 9.7% of cases. The other four

aetiologic factors were periventricular leukomalacia (PVL, 24.9%), intrapartum asphyxia (21.7%), cerebral dysgenesis (17.1%), and intracranial haemorrhage (12.9%). In almost all cases in which vascular factors were evident (18 of 21), spastic hemiplegia was the diagnosed type of cerebral palsy.

### *Premature Birth*

Low birth weight has often been used in the epidemiological literature as a robust surrogate for premature birth (Stanley et al., 2000). An association between birth weight and incidence of cerebral palsy has been clearly demonstrated. In a recent European study, which included 3,434 children with cerebral palsy, the prevalence of cerebral palsy in children of birth weight less than 1,500g, 1,500-2,499g, and 2,500g or greater was 72.6 (95% CI, 67.4-77.8), 11.1 (95% CI, 10.4-11.8), and 1.2 (CI, 1.13-1.24) per 1000 live births, respectively (Surveillance of Cerebral Palsy in Europe, 2002).

Studies in Ohio (Hack et al., 2000) and Victoria, Australia (Doyle & Casalaz, 2001; The Victorian Infant Collaborative Study Group, 1997) have shown that cerebral palsy is particularly prevalent in children of extremely low birth weight (ELBW; < 1,000g). Of the 221 ELBW children without major congenital malformations included in the Hack et al. study, 44 (20%) had a major neurologic abnormality, of which 33 (15%) had cerebral palsy. In the stepwise logistic regression, two neonatal risk factors were significant predictors of neurologic abnormality: abnormal ultrasound finding (i.e., grade III to IV bleed, PVL, and ventricular dilation at time of discharge home) and chronic lung disease (i.e., oxygen dependence at 36 weeks).

Doyle and Casalaz (2001) determined the neurosensory outcome of a cohort of 79 ELBW and 42 normal birth weight (NBW) children at 14 years of age. Eight cases of cerebral palsy were found in ELBW children (10.1%), whereas only one case was found in NBW children (2.4%). The prevalence of cerebral palsy was greater amongst ELBW children, when the cohort was two years of age, which suggests that cerebral palsy is difficult to diagnose, apart from the most severe cases, when children are under the age of five. Cerebral palsy can be commonly over diagnosed for this age group (Taft, 1995).

### *Intrauterine Growth Restriction*

There is a higher prevalence of cerebral palsy in infants born small for their gestational age (Stanley et al., 2000). Low birth weight and gestational age are used as surrogate variables for intrauterine growth restriction. In a recent study, Gray, Jones, and O'Callaghan (2001) matched 30 children with cerebral palsy and 120 children, who were the controls, and compared the occurrence of a range of maternal factors in each group. Intrauterine growth restriction had occurred more often in the antenatal periods of children with cerebral palsy ( $n = 5$ ) than in the children who were the control ( $n = 3$ ; OR, 6.6, 1.8-25.2).

In their summary of the research, Stanley et al. (2000) stated that the risk of cerebral palsy in moderately preterm infants increased with lower birth weights. The underlying mechanism of the association between intrauterine growth restriction and cerebral palsy is not yet understood.

### *Birth Asphyxia*

Birth asphyxia was once hypothesised as being the cause of brain damage in the majority of cerebral palsy cases; Stanley et al. (2000) estimated, however, that birth asphyxia is associated with cerebral palsy in only 10% of cases. Blair

and Stanley (1988) estimated that intrapartum asphyxia had caused brain damage in 8% of cases of spastic cerebral palsy. Using a smaller sample ( $n = 41$ ), Torfs, van den Berg, Oechsli, and Cummins (1990) found that 22% of children with cerebral palsy had birth asphyxia. Other risk factors were present in the births of these children, however, which may have contributed to the brain damage.

Asphyxia has been experimentally defined as “impaired respiratory gas exchange accompanied by the development of metabolic acidosis” (MacLennan, 1999, p. 1055). Operationalising asphyxia in the clinical setting is problematic, however, because many clinical indicators of asphyxia have, either individually or collectively, been shown to be poor markers of asphyxia (Dilenge, Majnemer, & Shevell, 2001).

The American College of Obstetricians and Gynecologists (ACOG, 2003) updated the International Cerebral Palsy Task Force’s criteria (MacLennan, 1999) for determining whether an acute intrapartum hypoxic event is sufficient to cause cerebral palsy. ACOG presented four essential criteria that are necessary to consider an acute intrapartum hypoxic event as the cause of cerebral palsy, and five criteria that suggest intrapartum event timing. The four essential criteria for acute intrapartum hypoxia to be considered as the cause of cerebral palsy were:

1. Evidence of a metabolic acidosis in intrapartum fetal umbilical cord arterial blood obtained at delivery ( $\text{pH} < 7$  and base deficit  $\geq 12\text{mmol/L}$ );
2. Early onset of severe or moderate neonatal encephalopathy in infants born at 34 or more weeks gestation;
3. Cerebral palsy of the spastic quadriplegic or dyskinetic type;
4. Exclusion of other identifiable etiologies, such as trauma, coagulation disorders, infectious conditions, or genetic disorders (ACOG, 2003, p. 74).

Five criteria were suggestive of the intrapartum event timing. With the exception of the first criterion, they are, individually, weakly associated with a neurologically damaging acute intrapartum event.

1. A sentinel (signal) hypoxic event occurring immediately before or during labor;
2. A sudden and sustained fetal bradycardia or the absence of fetal heart rate variability in the presence of persistent, late, or variable decelerations, usually after a hypoxic sentinel event when the pattern was previously normal;
3. Apgar scores of 0-3 beyond 5 minutes;
4. Onset of multisystem involvement within 72 hours of birth;
5. Early imaging study showing evidence of acute nonfocal cerebral abnormality (ACOG, 2003, p. 74).

ACOG (2003) stated that if one of the four essential criteria is not met, it strongly suggests that acute intrapartum hypoxia was not the cause of cerebral palsy. The five criteria for determining intrapartum timing do not have to be met for a relationship to be established between the acute intrapartum hypoxic event and cerebral palsy.

#### *Multiple Pregnancy*

Blickstein (2002) has outlined six accepted views on the association between multifoetal pregnancies and the occurrence of cerebral palsy. First, the

risk of cerebral palsy increases with plurality of fetuses. In a study conducted in Western Australia (Pettersson, Nelson, Watson, & Stanley, 1993), the prevalence rate of cerebral palsy amongst triplets was 26.7 (CI, 11-60) per 1000 live births, which was greater than the rates for twins (7.4, CI, 5.3-10) and singletons (1.6, CI, 1.4-1.8). Amongst multiple births, however, twins accounted for 86% of the cases of cerebral palsy, because triplet and higher-order gestations were uncommon.

Second, the risk of cerebral palsy is invariably higher in children of lower birth weight (Blickstein, 2002). This trend was demonstrated in the Pharoah, Price, and Plomin (2002) study, where the prevalence of cerebral palsy in infant survivors of two maternities was lower for those whose birth weight was greater than or equal to 2,500g (1.9 per 1,000) than for those whose birth weight was 2,000-2,499g (3.2 per 1,000), 1,500-1,999g (9.6 per 1,000), 1,000-1,499g (29.8 per 1,000), or less than 1,000g (87.5 per 1,000). The prevalence of cerebral palsy was higher at each birth weight category for twin infant survivors, when the co-twin died as a foetus or as an infant, than when both twins survived infancy.

Third, children of multiple births, with birth weights greater than 2,500g, have greater risk of cerebral palsy than singletons (Blickstein, 2002). In a study conducted with data from 205,895 pregnancies in the Jiangsu Province of China, Liu et al. (2000) found that the prevalence rate of cerebral palsy was similar for singletons and children from multiple births with birth weights of less than 2,500g, but for children with birth weights greater than or equal to 2,500g the rate was higher amongst children from multiple births (4.0, 95% CI, 1.5-8.6) than for singletons (1.2, 95% CI, 1.1-1.3). In the 2500-2749g birth weight category, the prevalence rate for singletons and multiples were 3.7 (95% CI, 2.9-4.6) and 6.8 (95% CI, 2.2-15.9), respectively.

Fourth, the risk of cerebral palsy is invariably higher among preterm children (Blickstein, 2002). This trend was clearly evident in the Liu et al. (2000) study, where the prevalence rate of cerebral palsy in multiple births born after 28 weeks but before 31 weeks gestation (250.0 per 1,000 children, 95% CI, 31.9-650.8) was higher than for those born at, or after, 39 weeks (2.2, 95% CI, 0.3-7.8). No difference was found in the prevalence of cerebral palsy between singletons and multiples born before 37 weeks.

Fifth, children born after 37 weeks gestation have a higher risk of cerebral palsy than singletons (Blickstein, 2002). Continuing with the findings of Liu et al. (2000), for children born after a period of between 37 and 41 weeks gestation, the prevalence rate was higher in multiples (3.2 per 1000 children, 95% CI, 1.2-7.0) than in singletons (1.2 per 1000 children, 95% CI, 1.1-1.4). Blickstein explained these findings by suggesting that the term of pregnancy may occur earlier in multiple pregnancies than in single pregnancies.

Sixth, the demise of one foetus invariably increases the risk of cerebral palsy in the remaining foetus(es) (Blickstein, 2002). This increased risk is especially prevalent in monochorionic twins (i.e., twins sharing the same chorion). Glinianaia, Pharoah, Wright, and Rankin (2002) examined the neurodevelopmental morbidity of the surviving twin, when the co-twin died as a foetus or as an infant within the first 365 days of life. For the surviving twins, whose co-twin died as a foetus and who the researchers could trace ( $n = 97$ ), nine children had cerebral palsy, a prevalence of 93 (95% CI, 43-169) per 1000 infant survivors. Prevalence of cerebral palsy was higher amongst like-sex pairs (8 out

of 70) than unlike-sex pairs (1 out of 22), which equate to prevalence rates per 1000 infant survivors of 114 (95% CI, 51-214) and 45 (95% CI, 1-228), respectively.

For the surviving twins, whose co-twin died as an infant and who the researchers could trace ( $n = 130$ ), 18 children had cerebral palsy, a prevalence of 138 (95% CI, 79-198) per 1000 infant survivors (Glinianaia et al., 2002). Prevalence of cerebral palsy was higher amongst like-sex pairs (16 out of 104) than unlike-sex pairs (2 out of 26), which equate to prevalence rates per 1000 infant survivors of 154 (95% CI, 84-223) and 77 (95% CI, 9-251), respectively. Gliniannaia et al. explained the differences in prevalence rates between like-sex and unlike-sex twins to be a consequence of twin-twin transfusion syndrome, which only occurs in monozygotic twins.

### *Summary*

In summary, various exposures have been associated with higher prevalence of cerebral palsy. Stanley et al. (2000) have argued that these exposures may not be independent causal agents of cerebral palsy, but may lie on causal pathways to the condition. One known causal pathway to cerebral palsy is when an infant's parents are Rh incompatible. This knowledge allows medical practitioners to put strategies in place to prevent this form of cerebral palsy. On reviewing the epidemiological literature, Stanley et al. proposed that other pathways involve those that are initiated periconceptually or in early pregnancy, premature birth, intrauterine growth restriction, birth asphyxia, and multiple pregnancy. Further understanding of these causal pathways may lead to the development of strategies to reduce the prevalence of cerebral palsy.

### *Comorbidity and Cerebral Palsy*

The likelihood and severity of comorbidity in people with cerebral palsy increases with the extent and severity of the motor disorder (Stanley et al., 2000). The most common types of comorbidity are mental retardation and seizures (SCPE, 2002). From the cohort born between 1975 and 1990, recorded on the Western Australian Cerebral Palsy register, Stanley et al. demonstrated that, of those people with severe motor impairment, 52% had severe or profound intellectual impairment ( $IQ < 35$ ), whereas, of those people with mild motor impairment, 4.4% had severe or profound intellectual impairment. Seizures had occurred in 60% of those people with severe motor impairment and 20% of those people with mild motor impairment. Sensory impairments were also found, but were less prevalent, in the same cohort. Of those with severe motor impairment, 24% were blind and 3.7% were deaf, whereas of those people with mild motor impairment, 3% were blind and 0.3% were deaf.

Arpino, Curatolo, Stazi, Pellegri, and Vlahov (1999) found a similar pattern of impairment likelihood and severity in their study of the risk factors for cerebral palsy, when mental retardation and epilepsy are present. Arpino et al. compared children with cerebral palsy, mental retardation ( $IQ < 70$ ), and partial symptomatic epilepsy ( $n = 51$ ); children with cerebral palsy and mental retardation ( $n = 31$ ); and children with cerebral palsy alone ( $n = 48$ ). Quadriplegia was more prevalent in children with triple (48%) or dual (48%) diagnoses than single (25%) diagnoses, whereas diplegia and hemiplegia was slightly more common in children with single (46% and 29%, respectively) diagnoses than

children with dual (29% and 19%, respectively) or triple (32% and 23%, respectively) diagnoses.

With regard to the risk factors for cerebral palsy, Arpino et al. (1999) concluded that different aetiological pathways may culminate in the various manifestations of cerebral palsy. Demographic characteristics differed between the three conditions for parental education and family size. A higher percentage of mothers (90.3%) and fathers (80.6%) of children with dual diagnoses had 8 or fewer years of education, in comparison to mothers and fathers of children with triple (64.7% and 60.8%, respectively) and single diagnoses (62.5% and 56.2%, respectively). Children with triple diagnoses had more siblings ( $M = 1.0$ ) than children with dual ( $M = 0.7$ ) or single ( $M = 0.5$ ) diagnoses.

Differences between children of single, dual, or triple diagnoses were found for neonatal and maternal familial factors (Arpino et al., 1999). Children with triple diagnoses differed from children with single and dual diagnoses on neonatal convulsions, birth weight, and gestational age. Children with triple diagnoses were more likely to have neonatal convulsions (48.8%) than those children with dual (9.7%) or single (8.5%) diagnoses. For the children with triple diagnoses, 4 of 156 first degree relatives (one mother and three siblings) reported a history of epilepsy, whereas none on the 206 first degree relatives of children with single or dual diagnoses reported a history of epilepsy.

A lower percentage of children with triple diagnoses had a birth weight of 1,500 or less (2.0%) than children with single (22.9%) and dual (19.4%) diagnoses, and a lower percentage had a gestational period of less than 32 weeks (7.8%) than children with single (27.1%) or dual (32.3%) diagnoses (Arpino et al., 1999). A lower percentage of mothers of children with triple diagnoses (6.0%) were aged 33 years or greater at delivery than mothers of children with single (21.3%) or dual (25.8%) diagnoses.

In summary, comorbidities with cerebral palsy, particularly mental retardation and seizures, are common, especially for those people with severe motor impairment. Cerebral palsy with comorbidities, however, may not be a more intense manifestation of exposures associated with cerebral palsy, but may be the result of different exposures.

#### Mortality and Cerebral Palsy

Cerebral palsy is not a fatal condition, but the impairments manifested in the condition predispose people to shorter lives. Even so, most people diagnosed with cerebral palsy survive into adulthood (Blair et al., 2001; Hutton et al., 2000; Hutton & Pharoah, 2002). Blair et al. found that of the 2,014 people with cerebral palsy identified from the Western Australian Cerebral Palsy Register and born between 1958 and 1994, 225 had died by 1 June 1997. In comparison to the Australian population, the rate of mortality in people with cerebral palsy was higher in every 5-year age bracket up to 40 years of age. Specifically, the mortality of people aged from 1 to less than 15 years was over 25 times higher than that of the population. The ratio was substantially lower for those people with cerebral palsy, who were aged from 15 to less than 40 years, but was still 3 to 6 times higher than that of the population. Survival rates beyond 40 years of age could not be calculated, because recording of data by cerebral palsy registers only began in the 1950s. Blair et al. found that cerebral palsy was considered to be the underlying cause of death in 78.8% of the 151 cases where the causes of death



were available. In 89 cases, death was attributed to respiratory causes, with aspiration pneumonia ( $n = 25$ ) and other or non-specified types of pneumonia ( $n = 56$ ) being the most common.

The presence of an intellectual impairment was the strongest predictor of mortality in people with cerebral palsy (Blair et al., 2001). The mortality risk doubled between each of the six categories of intellectual impairment (i.e.,  $IQ > 85$ , 70-85, 50-69, 35-49, 20-34,  $< 20$ ), with the risk increasing as the extent of intellectual impairment rose (mortality risk ratio = 2.14, 95% CI, 1.88-2.44). The risk of mortality increased by 39% between each of the four categories of motor impairment (i.e., minimal, mild, moderate, severe), with higher risk related to greater motor impairment (mortality risk ratio = 1.39, 95% CI, 1.14-1.71). Although these methods of categorising intellectual and motor impairments are somewhat crude, the results strongly associate increased impairment with higher rates of mortality. Because severity of intellectual impairment and motor impairment are positively related, and the intellectual impairment data was more precise, the intellectual impairment variable may be a proxy for overall impairment. The close association between disability score (computed with ratings of category of movement disorder, severity of movement disorder, severity of intellectual impairments, and other impairments including blindness, deafness, and epilepsy) and the rates of demise supports this conclusion.

In summary, manifestations associated with cerebral palsy may predispose people with this condition to shorter lives. Longevity seems to be diminished with the presence of more severe forms of physical and intellectual impairment.

#### Classification Systems of Cerebral Palsy

Different systems for the classification of cerebral palsy have been developed, based on the types of motor disorder, topography, and motor function. The most common type of motor disorder is spasticity, which was evident, in a pure form, in about 76.2% of cerebral palsy cases on the Western Australian Cerebral Palsy Register 1975 to 1990 (Stanley et al., 2000). The clinical presentation of spasticity involves persistent and predictable hypertonia; a clasp-knife effect (i.e., an exaggerated stretch reflex, where there is resistance of the extensors, which suddenly gives way with further pressure) when passively stretching muscles in the extremities; clonic rigidity (i.e., involuntary, alternating relaxation and contraction) of muscles in the extremities, which fix in typical patterns; co-contraction of involved body parts, especially in joints that are proximal, such as the hips and shoulders; deep tendon reflexes that are exaggerated; and primitive reflexes that are persistent, and which a person is unable to free themselves from without assistance (Dzienkowski, Smith, Dillow, & Yucha, 1996). Dyskinesia, another type of cerebral palsy, is often found in conjunction with spasticity, but has occurred, in a pure form, in 5.8% of cases in Western Australia (Stanley et al., 2000). The clinical manifestation of dyskinesia involves inconsistent and unpredictable tone; extreme difficulty in producing purposeful and fine movements; intermittent tonic spasms and exaggerated, rhythmical postures of total extension or flexion; mobile spasms, represented by alternating limb motions of extension, flexion, pronation, and supination; facial grimacing, hand and fingers in writing motions; lead-pipe rigidity; and motor tremors (Dzienkowski et al., 1996). Ataxia occurs rarely in its pure form, representing 5.0% of cerebral palsy in Western Australia (Stanley et al., 2000).



This type of cerebral palsy is characterised by marked hypotonia occurring in early infancy; the gradual increase in stiffness and tone of the trunk by late infancy; truncal titubation, represented as a staggering, stumbling gait and shaking of the head and trunk; poor control of gravity and movement over a sustained period; eye movement with head movement and the fixation of eyes on stationary objects to maintain balance; and “bottom-shuffling” (Dzienkowski et al., 1996).

Topographical classification refers to the limbs affected by cerebral palsy. The four commonly occurring distributions of impairment are quadriplegia, diplegia, left hemiplegia, and right hemiplegia (Stanley et al., 2000). In Western Australia, cases of spastic cerebral palsy have been classified by topography (Stanley et al., 2000). Of the cases of spastic cerebral palsy, the topographical classifications are hemiplegia (43%), diplegia (24%), quadriplegia (12%), and non-classical forms (21%).

Functional classification depends on a person’s ability to perform specific tasks. Systems for grading the level of function in people with cerebral palsy have been developed for sport (Cerebral Palsy International Sports and Recreation Association, 2001) and clinical practice (Palisano et al., 2000; Palisano et al., 1997). For international sport, an 8-part classification system is used to ensure athletes compete with others who are similarly impaired. For example, class 3 athletes are either moderately quadriplegic or triplegic, or are severely hemiplegic.

In clinical practice, the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997) was developed to measure the level of motor function in children with cerebral palsy, and has recently been validated for adults with the condition (Sandström et al., 2004). The GMFCS has five levels that are analogous to the grading systems used in medicine (see Table 2). Each level has a description of specific self-initiated movement and is differentiated from the other four levels by functional limitations. A particular emphasis is placed on sitting and walking. These levels have different descriptions for each of four age bands: less than two years of age, two to four years of age, four to six years of age, and six to twelve years of age. To enable the quantitative measurement of gross motor function, the Gross Motor Function Measure (GMFM; Palisano et al., 2000) has been developed, based on the GMFCS. The predicted maximum GMFM scores were clearly different for each of the five GMFCS levels, and there was a strong association between GMFM scores and GMFCS levels ( $r = -.91$ ).

Table A.1

*Levels of the Gross Motor Function Classification System*

Level	Description
1	Walks without restriction; limitations in more advanced motor skills
2	Walks without assistive devices; limitations walking outdoors and in the community
3	Walks with assistive mobility devices; limitations walking outdoors and in the community
4	Self-mobility with limitations; children are transported or use power mobility outdoors and in the community
5	Self-mobility is severely limited even with the use of assistive technology

Scores on the GMFM have been found to be strongly associated with leg anaerobic power, but only moderately related to arm anaerobic and arm aerobic

power (Parker, Carriere, Hebestreit, Salsberg, & Bar-Or, 1993). Specifically, the *standing* and *walking, running, and jumping* subsections of the GMFM were strongly related to anaerobic leg peak power ( $r_s = .75$  and  $.83$ , respectively) and anaerobic leg mean power ( $r_s = .72$  and  $.80$ , respectively). The associations between both the GMFM total scores and GMFM subsection scores, and both arm anaerobic and arm aerobic power varied in magnitude between  $.28$  and  $.55$ . These relatively low associations can be attributed to the purpose of the GMFM being to assess whether children with cerebral palsy are capable of performing certain activities, rather than how well they perform them.

In summary, several forms of classification of cerebral palsy have been developed for different purposes (i.e., motor disorder, topography, motor function). Spasticity has been reported as the most common form of cerebral palsy, manifesting itself in several topographical distributions (i.e., quadriplegia, diplegia, left hemiplegia, right hemiplegia). Measures of motor function have been developed to allow classification for clinical and sport purposes.

#### Pathophysiology of Cerebral Palsy

Neuropathology and myopathy are both present in people with cerebral palsy. In this section, I discuss how neuropathology and myopathy are manifested in people with this condition.

#### *Neuropathology*

In this subsection, I review the research on the neuropathology of cerebral palsy. Before the research is reviewed, however, the roles of different structures of the brain contributing to motor production are briefly discussed to provide a background for the research findings.

#### *Brain Structures Contributing to Voluntary Movement*

Brain structures involved in the production of movement include the basal ganglia, cerebellum, cerebral cortex, pons, and thalamus. In this section, I briefly describe the roles of these structures in motor control, and highlight certain areas of these structures that are implicated in the following section in which I discuss brain structures that researchers have found to be damaged in people with cerebral palsy. Finally, the periventricular area of the developing foetus brain will be described.

The basal ganglia contributes to the production of movement, but the extent of this role is unclear (Kalat, 2001). The structure appears to be involved with motor learning, sequencing of movement, and movement itself (Ring & Serra-Mestres, 2002). Output from the basal ganglia is sent to the motor and premotor areas of the cerebral cortex (Nolte, 2002). Researchers have included various structures in the basal ganglia, with the nucleus lentiformis being one such structure (Nolte, 2002). The nucleus lentiformis is itself composed of two physically apposed structures: the putamen and globus pallidus. The putamen has a large role in the motor functions of the basal ganglia, receiving input from the cerebral cortex and substantia nigra and sending output to the globus pallidus, which itself is efferent to the thalamus.

Although the exact role of the cerebellum in the production of movement is uncertain, this structure has been associated with the performance of several different functions, including aspects of attention, habit formation, and timing (Kalat, 2001). Townsend et al. (1999) found that people with cerebellar damage required 800 to 1200ms to shift their visual attention, whereas unimpaired people

are able to do this task within 100ms. Barlow (2002) maintained that the cerebellum was involved in the production of movement, the improvement of motor performance through the updating of internal models, the adaptation of a learned movement for present conditions, and the control of limb velocity. Ivry and Diener (1991) found people with cerebellum lesions had impaired judgement of the velocity at which stimuli were moving. Like the basal ganglia, output from the cerebellum is sent to the motor and premotor cortex, rather than to the spinal cord (Nolte, 2002). One area of the cerebellum, the vermis, is involved in postural adjustments.

The structures within the cerebral cortex that are associated with movement production include the primary motor cortex, supplementary motor areas, premotor cortex, prefrontal cortex, primary somatosensory cortex, and posterior parietal cortex (Geyer, Matelli, Luppino, & Zilles, 2000; Kalat, 2001). The primary motor cortex is involved with the control of kinematic and dynamic parameters of voluntary movements, and the non-primary motor cortex areas (premotor cortex, supplementary motor areas) are involved in the planning of voluntary movement in response to various internal and external cues (Geyer et al., 2000). The prefrontal cortex is activated by sensory information that leads to movement; the premotor cortex is involved with the preparation for movement and is less active during the execution of movement; and the supplementary motor cortex is involved in preparation for the execution of sequences of movements. The results of the Tanji and Shima (1994) study supported the hypotheses that the supplementary motor cortex is involved in the temporal sequencing of multiple movements and in the coding of the time sequence between movements. The primary somatosensory cortex receives sensory information from touch sensations, muscle-stretch receptors, and joint receptors, and provides sensory information to the primary motor cortex (Kalat, 2001). The posterior parietal cortex integrates sensory information to produce a decision that is appropriate for guiding movement (Shadlen & Newsome, 1996). The cortex appears to have cells specialised for body-referenced information, and world-referenced information (Snyder, Grieve, Brotchie, & Andersen, 1998). There are proportionately fewer cells that process both body- and world-referenced information than specialised cells.

The thalamus receives input from most of the sensory systems, processes this information, and then sends output to the cerebral cortex. One such relay involves inputs from the basal ganglia and cerebellum to the ventral anterior and ventral lateral areas of the thalamus, which are sent to motor areas of the cerebral cortex (Nolte, 2002).

The pons contains the reticular formation, the descending portion of which is involved with motor control (Kalat, 2001). This portion of the reticular formation is one of many areas of the brain that controls the spinal cord's motor areas.

In the developing brain, damage to the germinal matrix, periventricular white matter, and ventricular system can lead to motor impairment (Volpe, 2001). The germinal matrix is located immediately ventrolateral to the lateral ventricles. Periventricular white matter is lateral and dorsal to the external angles of the lateral ventricles. The ventricular system consists of four fluid-filled ventricles and a central canal in the spinal cord. Between 10 and 20 weeks gestation, the

germinal matrix provides cerebral neuronal precursors, and in the third trimester it is the source of glial precursors that become cerebral astrocytes and oligodendroglia. The germinal matrix decreases in size as the foetal brain develops, and is involuted after approximately 32 to 34 weeks gestation (Norman, 1992). Motor corticospinal tracts descend past and through the periventricular region (Volpe, 2001). Damage to periventricular white matter would be expected to cause motor impairment, particularly in the lower extremities.

In summary, various parts of the brain are involved in the production of movement. Given that cerebral palsy is characterised by disorders of movement of neurological origin, it would be expected that signs of damage to these brain areas responsible for movement would be visible upon investigation. It is to this research on the association between neurological injury and motor disorder that I now turn.

#### *Neuropathology in People with Cerebral Palsy*

Studies using magnetic resonance imaging (MRI) have enabled the precise identification of the damaged areas of the brains of people with cerebral palsy (Johnsen, Tarby, Stuart Lewis, Bird, & Prenger, 2002; Krägeloh-Mann et al., 2002). Krägeloh-Mann et al. found that patterns of bilateral lesions of the thalamus and basal ganglia were associated with different types of cerebral palsy and the severity of the motor and cognitive impairments. MRI examinations ( $n = 27$ ) were performed with 10 males and 7 females, who ranged in ages from 8 days to 15 years at the time the MRI examinations occurred. All children had cerebral palsy, in which the brain lesions were attributed to birth asphyxia ( $n = 9$ ), neonatal shock ( $n = 4$ ), or could not be identified, but were assumed to be late prenatal compromise ( $n = 4$ ). Type of cerebral palsy was classified as purely dyskinetic, dyskinetic-spastic, or bilateral spastic. Motor impairment was classified as mild (i.e., learned to walk between 18 months and 5 years of age, or to sit between 10 months and 2 years of age) or severe (i.e., cannot walk at 5 years of age, cannot sit at 2 years of age, or cannot control head at 1 year of age). Cognitive impairment was determined by each child's ability to follow with the eyes and establish visual contact, developmental milestones (including language milestones), and school results, depending on the age of the child. MRI lesion patterns were classified as mild (involving the nucleus lentiformis and ventro-lateral thalamus only), moderate (involving the nucleus lentiformis, ventro-lateral thalamus, and pre- and post-central gyrus), or severe (involving the nucleus lentiformis, entire thalamus, pre- and post-central gyrus, and hippocampus).

Strong relationships existed between the severity of the lesion found by MRI and both motor ( $r_s = .71$ ) and cognitive development ( $r_s = .89$ ). A strong association emerged between the type of cerebral palsy and the severity of the lesion. Spastic cerebral palsy occurred in children with moderate ( $n = 1$ ) or severe ( $n = 5$ ) lesion patterns. Dyskinetic-spastic cerebral palsy occurred in children with mild ( $n = 3$ ), moderate ( $n = 3$ ), and severe lesion patterns ( $n = 2$ ). Dyskinetic cerebral palsy occurred in children with mild lesion patterns ( $n = 3$ ).

In their study of 10 cases of severe athetoid cerebral palsy, Hayashi, Satoh, Sakamoto, and Morimatsu (1991) associated two patterns of thalamus-basal ganglia damage to aetiology and clinical outcomes. For the globo-Luysian (GL) group the major sites of lesion were the globus pallidus and subthalamic nucleus, whereas for the thalamo-putaminal (TP) group the major sites of injury were the

thalamus and putamen. Severe jaundice was part of the aetiology of almost all (5 of 6) cases in the GL group, but was absent from the TP group cases. Perinatal asphyxia featured in the aetiology of all TP group cases, and was, partially or wholly, present in the GL group cases. Seizures were either frequent or intractable for the TP group cases, but absent, or only occurring once, for the GL group cases. The cases in the TP group had greater intellectual impairment (all IQs < 10) than the GL group cases, in which half the cases had IQs less than 10 points, and the other half of cases had IQs ranging from 40 to 70 points.

Johnsen et al. (2002) studied 13 children with cerebral palsy, who had injuries to the inferior cerebellum hemispheres. Most children ( $n = 11$ ) had severe damage to the cerebellum, and in all but one case this damage was symmetrical. In most cases, the damage could be detected on the MRI as the virtual absence of the cerebellum hemispheres, consistent with what would be viewed in an infarction. The remaining two children had mild cerebellar damage. Inferior vermis abnormalities were seen in six children.

In regard to other parts of the brain, injury to the pons (i.e., hypoplasia) was prominent in three children, mild in eight children, and minimal in two children (Johnsen et al., 2002). Damage to the cerebrum was varied, with periventricular leukomalacia (PVL) found in five children, enlarged ventricles noted in two children, microcephaly in one child, and no damage in the remaining five children. The severity of motor impairment was inconsistent amongst the 13 children, with some being able to walk and talk. Johnsen et al. stated that poor associations between clinical features and the MRI pictures are common in cases of cerebral palsy, and the timing of the infarction may be a key factor in determining the MRI and clinical outcomes. A slightly more consistent association was found between other clinical features and the MRI pictures. Johnsen et al. reported that all children in their study were microcephalic and mentally retarded. All of the children were visually impaired, with six children having severe visual impairments. Seven children experienced seizures.

PVL, periventricular hemorrhagic infarction, and germinal matrix-intraventricular haemorrhage (IVH) are common types of foetal neurological infarction, particularly in the premature infant (Norman, 1992; Volpe, 2001). In 802 very preterm infants (24 to 32 weeks gestation), 69 of whom developed cystic PVL, Zupan et al. (1996) found that the incidence of cystic PVL peaked at 28 weeks gestation (15.7%). The lower incidence of PVL before 28 weeks gestation may be an underestimation, because of the higher mortality rate and lack of post-mortem studies on the brains of preterm infants.

Yin, Reddiough, Ditchfield, and Collins (2000) found patterns of brain lesions to be closely related to the gestational ages of children at birth. In their sample of 42 children, 12 were born preterm (< 37 weeks gestation) and 30 were born at term (37 to 42 weeks gestation). Of those born preterm, PVL was found in 8 cases. For the three earliest born children (30 to 33 weeks gestation) PVL was the only diagnosis. Three children born at 36 weeks gestation had PVL and subcortical lesions (SCL) only. One child had PVL, SCL, and lesions consistent with neurofibromatosis, and another child with PVL and SCL also had a large left temporo-occipital porencephalic cyst. Three of the four remaining children had abnormal MRI scans, and the scan of the fourth child was normal. Three main patterns of brain lesions were found for children born at term: hypoxic-ischaemic

lesions ( $n = 13$ ), cortical migrational malformations ( $n = 5$ ), and white matter development disorders ( $n = 3$ ). Hypoxic-ischaemic lesions were characterised by PVL and SCL in nine cases and cerebral artery infarction in four cases. Cortical malformations took the form of neuronal migration abnormalities, which were clinically manifested as spastic quadriplegia and severe intellectual impairment in all five cases. Lissencephaly was found in three of the five cases, and, in two of the three children, there was also an abnormal signal in the white matter and dysgenesis of the corpus callosum. Polymicrogyria was found in the other two cases of cortical malformations. Disorders of white matter development were clinically characterised in two of the three cases by spastic quadriplegia with athetosis, severe intellectual impairment, and vision and speech impairments. Seven of the nine remaining children had abnormal scans that did not categorise into the aforementioned three patterns. Three of these seven children had unilateral lesions and two had lesions not involving cerebral hemisphere white matter. Two children had normal scans.

Comparing 50 VLBW children who had cerebral palsy and 50 VLBW matched normal children, Wilson-Costello et al. (1998) found that a higher proportion of infants with cerebral palsy (64%) had periventricular haemorrhages than the controls (19%,  $p < .01$ ). More children with cerebral palsy had grade 3 or 4 periventricular haemorrhage (40%) than normal children (8%).

Okumura, Hayakawa, Kato, Kuno, & Watanabe (2002) found that the type of chronic-stage electroencephalograph (EEG) abnormalities was associated with neurodevelopmental outcomes in 183 preterm infants ( $M_{\text{gestational age}} = 29.2$  wks;  $M_{\text{weight}} = 1,275$ g). Chronic-stage abnormalities were classified as one of two EEG patterns: dysmature or disorganised (Hayakawa, Okumura, Kato, Kuno, & Watanabe, 1997a, 1997b). The former pattern has been associated with cognitive impairments (Hayakawa et al., 1997b), and the latter pattern has been closely associated with deep white-matter damage and with cerebral palsy (Hayakawa et al., 1997a).

In the Okumura et al. (2002) research, cerebral palsy was more closely related to disorganised patterns in children than to dysmature patterns. Of the children with disorganised patterns ( $n = 52$ ), the majority had cerebral palsy ( $n = 39$ ). All children with disorganised patterns and PVL, observed using ultrasound assessment had either mild ( $n = 9$ ), moderate ( $n = 10$ ), or severe ( $n = 12$ ) spastic diplegia. Children diagnosed as having intraventricular haemorrhage (IVH) with parenchymal haemorrhage (PH) were also diagnosed with spastic hemiplegia ( $n = 2$ ), whereas those children diagnosed as having IVH without PH ( $n = 5$ ) did not have cerebral palsy. For those children who had normal ultrasound assessments, cerebral palsy was diagnosed in 6 of 14 cases, which took the form of mild ( $n = 4$ ), moderate ( $n = 1$ ), or severe ( $n = 1$ ) spastic diplegia. Of the children with dysmature patterns ( $n = 28$ ), cerebral palsy was not as commonly diagnosed ( $n = 5$ ). Moderate spastic diplegia was diagnosed in the one child with PVL. Hemiplegia ( $n = 2$ ) and mild spastic diplegia ( $n = 2$ ) were diagnosed in four of seven children who had IVH without PH. Cerebral palsy was not diagnosed for any children with dysmature patterns and normal ultrasound assessments.

In summary, researchers have shown that areas of the brain responsible for the production of movement have been the sites of neurological damage in people with cerebral palsy. Although some researchers have found strong correlations

between the severity of neurological lesion and both motor and cognitive development (Krägeloh-Mann et al., 2002), other researchers (Johnsen et al., 2002) have argued that this association is less clear. Other factors may influence the relationship between the manifested motor disorder and its neurological correlate, such as the timing of the infarction, gestational age at birth, and birth weight.

### *Myopathy*

Muscle from people with cerebral palsy is different to muscle from people in the general population (Fridén & Lieber, 2003; Rose et al., 1994; Tardieu, Huet da la Tour, Bret, & Tardieu, 1982). Tardieu et al. inferred, from the joint angle at which minimal torque was noted, that the triceps surae muscles of 21 children with cerebral palsy were abnormally shorter and the tendons were abnormally long, in comparison to the muscles of 12 children without physical impairment. Although full plantar flexion was produced by maximal contraction in the children without physical impairment, contraction of the muscle when in full plantar flexion did not produce any force in some children with cerebral palsy.

Rose et al. (1994) found that the variation in size and distribution of spastic muscle fibres from children with cerebral palsy differed in comparison to children's muscle fibres that had been interpreted as being normal. To determine the size variation of muscle fibres a coefficient of variation ( $SD/M$ ) was calculated. For type-I and type-II muscle fibres, the average coefficient of variation for area was higher in the spastic muscle from participants with cerebral palsy (33.3% and 32.7%, respectively) than in the normal muscle from control participants (17.3% and 17.2%, respectively). The combined coefficient of variation, having been weighted for the proportions of each fibre type, was higher in the muscle from participants with cerebral palsy (35.8%) than in the muscle from control participants (16.7%). A coefficient of variation for size within a fibre type of less than 30% is considered normal (Blomstrand, Celsing, Fridén, & Ekblom, 1984; Brook & Engel, 1969). The variation in mean fibre area between type-1 and type-2 fibres was also larger in the muscle of participants with cerebral palsy ( $M = 26.7\%$ ,  $SD = 18.9\%$ ) than from the muscle of control participants ( $M = 4.2\%$ ,  $SD = 2.4\%$ ). The predominance of one fibre type was stronger in the spastic muscle from children with cerebral palsy ( $M = 67.1\%$ ,  $SD = 15.0\%$ ) than in the normal muscle ( $M = 54.6\%$ ,  $SD = 3.8\%$ ). The muscle of four of the children with cerebral palsy had a predominance of one fibre type of over 70%, whereas none of the children with normal muscle had a predominance of this magnitude.

Liber and Fridén (2002) found that the sarcomere lengths of spastic flexor carpi ulnaris muscle with the wrist fully flexed ( $M = 3.48\mu\text{m}$ ,  $SD = 0.44\mu\text{m}$ ) were longer than those of normal flexor carpi ulnaris muscle ( $M = 2.41\mu\text{m}$ ,  $SD = 0.31\mu\text{m}$ ). The slope of the sarcomere length-wrist joint angle relationship was normal; the sarcomere lengths of the spastic muscle at all joint angles were consistently longer than those of normal muscle ( $M = 1.36\mu\text{m}$ ,  $SD = 0.20\mu\text{m}$ ), however. Functionally, this result means that spastic muscle generates less force at each joint angle than normal muscle. Liber and Fridén predicted that the flexor carpi ulnaris muscles of the participants with spasticity would be able to generate approximately only 40% of their maximum force, when the wrists are fully flexed, and this percentage would decrease with the extension of the wrists.



Fridén and Lieber (2003) found that the sarcomere lengths at which passive tension is developed in muscle fibres from children with spastic cerebral palsy ( $M = 1.84\mu\text{m}$ ,  $SD = 0.05\mu\text{m}$ ) were significantly shorter than normal ( $M = 2.20\mu\text{m}$ ,  $SD = 0.04\mu\text{m}$ ). Fridén and Lieber also found that the elastic modulus (i.e., the slope of the stress-strain relationship, calculated as the change in fibre stress divided by the change in fibre strain) of spastic muscle fibres was almost double that of normal muscle fibres. Although these findings suggest that there was substantial remodelling of both intracellular and extracellular components of muscle structure (i.e., titin and collagen), the mechanisms by which these structural changes occur remain to be elucidated.

In summary, various differences have been found between spastic muscle, found in many people with cerebral palsy, and normal muscle. These differences include that spastic muscles were abnormally short (with abnormally long tendons), had abnormal distributions of fibre sizes and types, had abnormally long sarcomeres, and developed passive tension at abnormally short sarcomere lengths.

#### The Physical Health of Adults with Cerebral Palsy

Of the research conducted with people who have cerebral palsy, relatively few studies have focused on adults with the condition. As Bottos et al. (2001) have pointed out, cerebral palsy has been viewed as a paediatric condition, especially where therapeutic interventions have been concerned. There is evidence, however, that cerebral palsy adversely interacts with the ageing process (Turk et al., 1995). Given that most adults with cerebral palsy survive into adulthood (Blair et al., 2001), greater focus on the needs of these people is warranted. In this section, I review the literature on the physical health of adults with cerebral palsy. In areas where there is a lack of research on adults with cerebral palsy, the review will be supplemented by studies on children and adolescents with the condition. This research on adolescents and children is valuable, because it may provide insight into health issues that adults with cerebral palsy may face.

Bottos et al. (2001) followed up 72 adults with cerebral palsy, who had been patients at three paediatric rehabilitation clinics in Italy. The participants were aged from 18 to 65 years of age ( $M = 33$ ,  $SD = 9.2$ ), and had either spastic (66.2%) or dyskinetic (33.8%) cerebral palsy. Intelligence was normal or borderline in 39.7% of participants, and mild, moderate/severe, and profound intellectual impairment was present in 19.1%, 19.1%, and 22.1% of participants, respectively. The most common health problems of participants included feeding (31.9%), epilepsy (25.0%), bladder (18.1%), bowel (18.1%), speech (12.5%), and visual (12.5%) impairments. Half of the participants did not have any health problems. Frequency of contact with health and rehabilitation services reduced after 18 years of age, with only 23 participants continuing treatment after turning 18 years old.

Secondary conditions to cerebral palsy were also found in 63 women with the condition ( $M_{\text{age}} = 37.7$ ,  $SD = 12.7$ ) who were residing in community living arrangements (Turk et al., 1997). Most women perceived themselves as being healthy despite having cerebral palsy (87%), with a large proportion of the women exhibiting healthy behaviours by abstaining from smoking (98%), not consuming alcoholic beverages in the past month (95%), and engaging in at least one physical activity (83%). The most common secondary conditions were pain (84%), hip and



back deformities (59%), bowel problems (56%), bladder problems (49%), poor dental health (43%), increased spasticity during menstruation (35%), gastroesophageal reflux (28%), and increased incontinence during menstruation (24%).

Murphy, Molnar, and Lankasky (1995) highlighted the lack of preventive medical care for adults with cerebral palsy. In their study of 101 adults, who ranged in age from 19 to 74 years ( $M = 42.6$ ), over 90% of the participants did not have their general health evaluated on a periodic basis. Almost all of the females in the sample (90%) did not have regular breast examinations, Pap smears, or pelvic examinations. Likewise, over 90% of men did not have regular prostate examinations. Cardiovascular risk factors were being followed in less than 10% of participants and a similar small percentage of those over 40 years of age had recent electrocardiography. Contributing to the lack of preventive care for some of these adults was the inability to access services that had examination rooms adequately set-up and with equipment for use with people who had severe physical impairments.

Participants at the National Invitational Colloquium on Aging and Cerebral Palsy (Turk et al., 1995) identified that these and other physical issues (e.g., musculoskeletal, oral, gastrointestinal, urologic, and reproductive problems) needed to be addressed by health care professionals. Musculoskeletal problems are symptomatic of both cerebral palsy and the ageing process. The combination of cerebral palsy and ageing, however, often means that these problems have an earlier onset in people with cerebral palsy than in the general population.

*Musculoskeletal issues.* Bottos et al. (2001) found that deformities of the musculoskeletal system were related to the type of cerebral palsy, but no clear association was found between deformities and the severity of motor impairment. The most common deformities were scoliosis over  $30^\circ$  (20.3%) and subluxation or dislocation of one or both hips (28.2%). Orthopaedic surgery to correct musculoskeletal problems was undergone by 53.7% of participants. These procedures primarily involved surgery to the hamstrings, adductors, and triceps brachii.

Associated with these musculoskeletal problems, adults with cerebral palsy commonly experienced decrements in mobility and functioning, increases in pain and fatigue, concerns over osteoporosis and fractures, and the adverse impact that previous medical treatments had on musculature (Turk et al., 1995). Although loss of mobility and functioning is a normal aspect of the ageing process, it is often more marked in people with cerebral palsy. This loss of functioning may be attributable to apparent increases in spasticity, accompanied by pain and fatigue, when a person with cerebral palsy ages. More research is needed, however, to determine if changes are age-related or part of a pathological process.

Aside from spasticity, pain can be caused by soft tissue injuries to the nerves, ligaments, tendons, or muscles (Turk et al., 1995). This pain is often misdiagnosed as arthritis, the complaint is minimised or ignored, or, if accompanied by fatigue, misdiagnosed as depression or a psychosomatic issue.

In a study that investigated pain in adults ( $M_{\text{age}} = 38$  years,  $SD = 14$ ) with cerebral palsy, Schwartz, Engel, and Jensen (1999) found that 67% of participants (62 of 93) were experiencing pain that had lasted at least 3 months. These participants experienced pain in an average of three locations, with the most

common sites of pain being the lower extremities (66%), back (63%), neck and/or shoulders (45%), and buttock/hip area (39%). On average, these pains had persisted for a number of years, with the longest duration of pain being for the buttock/hip area ( $M = 20$  years,  $SD = 14$ ), lower extremities ( $M = 15$  years,  $SD = 14$ ), back ( $M = 14$  years,  $SD = 17$ ), and upper extremities ( $M = 8$  years,  $SD = 8$ ). For 56% of participants, pain was experienced on a daily basis, with a mean intensity, for the week prior to the research being conducted, of 3.16 ( $SD = 2.45$ ) on a 10-point pain intensity scale, which was anchored by *no pain* and *pain as bad as could be*. The pain intensity of the prior 3 months was a little higher ( $M = 4.45$ ,  $SD = 2.34$ ). Despite this pain, the participants reported that it interfered minimally with their activity level and social or work functioning. The mean interference was 2.03 ( $SD = 2.50$ ) on a 10-point scale anchored by *no interference* and *unable to carry out any activities*. Factors that the participants reported would exacerbate pain included fatigue (81%), stress/depression (79%), overexertion (74%), and weather changes (74%). In contrast, factors that relieved pain included exercise (92%), stretching (89%), resting (82%), massage (81%), sleeping (77%), and staying active (71%).

Fatigue has been found to be more prevalent among adults with cerebral palsy than among the normal population (Jahnsen, Villien, Stanghelle, & Holm, 1993). Although Jahnsen et al. did not calculate effect sizes for the differences between groups, Cohen's  $d$  values could be estimated from the statistics provided. Compared with the Norwegian population, adults with cerebral palsy in Norway had significantly higher levels of physical fatigue ( $d = 0.26$ ,  $p < .001$ ), but not mental fatigue ( $d = 0$ ). The magnitude of these effects suggested very little difference exists in the fatigue levels of adults with cerebral palsy with respect to the general population. A higher prevalence of fatigue was reported by adults with moderate cerebral palsy (22%) than those with mild (12%) or severe cerebral palsy (15%).

Osteoporosis and fractures are critical concerns for people with cerebral palsy as they age (Turk et al., 1995). Due to a number of factors, the chances of developing osteoporosis may be greater for people with cerebral palsy. These factors include infrequently performing weight-bearing exercises, seizure medication that impedes calcium absorption, poor nutrition, and endocrine problems. Osteoporosis increases the susceptibility of bones to breakage in accidents, such as falls.

Treatments people may have received in their early years may have had a positive or negative impact in present musculature (Turk et al., 1995). Some treatments may have been deleterious in the long term, because of factors, such as the incorrect alignment of joints to bear weight, and the additional stresses to muscles and tendons from lifting such weight. Other treatments, started in childhood and continued through adolescence, may have been discontinued in adulthood, resulting in a possible loss of improvements to the musculature.

*Oral issues.* Oral problems have been identified as important clinical concerns (Turk et al., 1995). Bottos et al. (2001) identified issues with feeding as the most common health problem among adults with cerebral palsy. Although people with severe cerebral palsy commonly find eating and swallowing a difficult task, the problems increase as they get older, with poorer dental health and diminishing saliva production. It is unknown how the ageing process affects

the acts of eating and swallowing. A further issue is that access to adequate dental care for people with more severe cerebral palsy is often difficult.

*Gastrointestinal issues.* Although the findings of the Bottos et al. (2001) study suggested gastrointestinal problems were important health issues for adults with cerebral palsy, there is a lack of research in this area (Turk et al., 1995). Gastrointestinal issues include gastroesophageal reflux, constipation, and inadequate nutrition. Associated with gastroesophageal reflux is aspiration (i.e., food or fluid in the airways), which, especially in people with severe cerebral palsy, can cause recurrent bouts of pneumonia.

*Urologic issues.* Both men and women with cerebral palsy have reported urinary incontinence and retention problems (Turk et al., 1995). Reasons for these problems can have a neurological basis, can result from limited perception of the fullness of the bladder, or, in women, can be related to the menstrual cycle. Environmental issues may also contribute to urinary problems, such as the unavailability or inaccessibility of toilets. As yet, there is no information on whether men with cerebral palsy have the same problems as other men with regards to prostate enlargement as they age.

*Reproductive issues.* Although there is a lack of research on reproductive issues in people with cerebral palsy, Turk et al. (1995) reported many concerns regarding the reproductive health of people with this condition. For men, concerns included impotence and lack of physical ability to meet their own sexual needs. For women, concerns regarded menopause, fertility, and the ability to maintain a pregnancy and give birth. Concerns were also expressed about birth control, sexually transmitted diseases, acquired immune deficiency syndrome, reproductive health, Pap smears, and, for those with severe physical impairment, the issue of using a third person to facilitate sex. As with other health issues, adequate access to professional health services was identified as an area of significant concern.

In summary, many people with cerebral palsy have reported the onset of health conditions secondary to cerebral palsy (e.g., musculoskeletal, oral, gastrointestinal, urologic, and reproductive problems). The presence of cerebral palsy means that several health issues occur at an earlier age than they do in people from the general population. These issues can have environmental, physical, and psychological bases. The health issues are sometimes compounded by the difficulties involved with seeking the services of health care providers and the providers' lack of knowledge about cerebral palsy.

#### The Role of Exercise in the Management of Cerebral Palsy

A multidisciplinary approach assists in the management of cerebral palsy and, in particular, the spasticity that occurs in most people with cerebral palsy (Graham & Selber, 2003). Recently, an entire issue of the *Journal of Child Neurology* was devoted to reviews of the literature on cerebral palsy and spasticity and consensus statements that emanated from a conference on the management of spasticity (Maria, 2001). Treatments that are used in the management of spasticity include physical management (Helsel, McGee, & Graveline, 2001), oral medications and intrathecal baclofen (Krach, 2001), botulinum toxin (Edgar, 2001), orthopaedic management (Woo, 2001), and neurosurgery (Boop, 2001). Given that great variation is present in the physical manifestations of cerebral palsy, the most appropriate treatment is dependent on the characteristics of each

case. Another type of intervention that could be beneficial in the management of cerebral palsy and spasticity is exercise (Brunstrom, 2001). In her model of spasticity, mobility, and the management of cerebral palsy, Brunstrom included physical fitness as a core factor, contributing to both the mobility and independence of people with cerebral palsy. In this section, I report on the physical activity levels, energy expenditure, and physiology of exercise in people with cerebral palsy, before considering the effects of aerobic and strength training on people with this condition. The subsection concludes with information regarding the prescription of exercise for people with cerebral palsy.

*Physical Activity Levels in People with Cerebral Palsy*

For the general population, the USDHHS (1996) recommended that people engage in physical activity, of a moderate intensity and duration, on most, if not all, days of the week. For people with cerebral palsy, however, Rimmer (2001) contended that higher fitness levels, than those of the general population need to be maintained to offset decline in function due to natural ageing and to changes related to their condition (e.g., contractures, pain, reduced mobility, spasticity). Despite this greater need for physical activity, little information is available on the physical activity levels of adults with cerebral palsy. Moreover, the findings from research into the physical activity levels of young people with the condition are not encouraging (Bandini et al., 1991; Blum et al., 1991; Longmuir & Bar-Or, 2000; van den Berg-Emons et al., 1995). This part of the subsection reports on the physical activity levels of adults with cerebral palsy (Heller et al., 2002; Turk et al., 1997) and supplements these findings with the results from studies of the physical activity levels of young people with cerebral palsy.

Heller et al. (2002) interviewed the caregivers of 83 adults with cerebral palsy and found that approximately half of their clients exercised. Of those adults who exercised, the most common types of exercise were arm/leg exercises (48.8%), walking (29.3%), and rehabilitation exercises (14.6%). The adults with cerebral palsy exercised, on average, 1.6 times per week.

Investigating the health status of women with cerebral palsy, who were residing in the general community ( $N = 63$ ), Turk et al. (1997) found that 83% reported participating in physical activities during the previous week. The most common physical activities were swimming (63%), walking for exercise (58%), use of exercise equipment (47%), and weightlifting (38%). Over half the women (57%) had done stretching or range-of-motion exercises in the last week. Forty-three percent of participants were engaged in aerobic exercise, with 54% of these women exercising for 30 minutes or more. The women reported that they typically engaged in aerobic exercise three times per week ( $M = 3.0$ ,  $SD = 1.6$ ). Participation in physical activity was positively associated with ambulation ( $\phi = .32$ ) and negatively related to wheelchair use ( $\phi = -.51$ ).

In comparison to youth with other disabilities, those with cerebral palsy are more likely to lead sedentary lives (Longmuir & Bar-Or, 2000). Longmuir and Bar-Or surveyed 987 young people, whose ages ranged from 6 to 20, and who had a range of physical disabilities (PD), chronic medical conditions (CM), visual impairments (VI), and hearing impairments (HI). Youths with cerebral palsy ( $n = 196$ ) represented 57.3% of participants with a physical disability. The participants were invited to respond to questions about their habitual physical activity levels, perceived fitness, and perceived physical limitations. Those participants who had

VI or PD had lower activity levels than people in the other two groups ( $\omega^2 = .08$ ), and of those who had PD, people with cerebral palsy and muscular dystrophy reported the lowest activity levels ( $\omega^2 = .12$ ). Of the young people who had cerebral palsy, almost half (49.0%) were classified as having sedentary lives, whereas 23.0% of those with other physical disabilities, and 24.6% of the total sample, excluding participants with cerebral palsy, were similarly classified. Participants with cerebral palsy generally regarded themselves as being less fit than their peers (54.1%) and limited in the type or amount of physical activity they could do (82.3%).

The examination of physical activity levels was a small part of the Blum et al. (1991) study. Blum et al. found that most of the activities in which youth with spina bifida ( $n = 102$ ) and adolescents with cerebral palsy ( $n = 60$ ) were involved with their best friends were passive, that is, passive entertainment (e.g., television viewing) and minimally active entertainment (e.g., chess).

Comparisons of the ratios for total energy expenditure (TEE) to sleeping metabolic rate (SMR) and TEE to resting metabolic rate (RMR) in children (van den Berg-Emons et al., 1995) and adolescents (Bandini et al., 1991), who had cerebral palsy, and healthy controls have not been positive for the young people with cerebral palsy. In the van den Berg-Emons et al. study, children with cerebral palsy had a significantly lower TEE/SMR ratio ( $M = 1.56$ ,  $SD = 0.19$ ) than healthy children ( $M = 1.83$ ,  $SD = 0.23$ ). This difference may be an overestimate of the extent of physical activity involvement for the children with cerebral palsy, however, because there is typically a higher energy cost of performing the same amount of physical activities for people with cerebral palsy than for people in the general population.

In summary, the physical activity recommendations for the general population may be too conservative for people with cerebral palsy. Most people with cerebral palsy, however, are not engaging in enough physical activity to meet the recommendations for the general population set out in the USDHHS (1996) report. Low involvement in physical activity may be a life-long trend. Environmental factors may partially explain this lack of involvement in physical activity.

#### *Barriers to Participation in Physical Activity*

Significant barriers exist that make it difficult for some adults with cerebral palsy to exercise (Cousminer, 2003; Heller et al., 2002). As yet, however, there is little research in this area. In the Heller et al. study, the caregiver-perceived benefits of exercise for people with cerebral palsy explained 8.1% of the variance in exercise frequency, in a model that explained 24.2% of the variance in exercise frequency.

The caregivers perceived that there were a number of barriers to exercise for adults with cerebral palsy (Heller et al., 2002). These barriers included a lack of exercise equipment at home (82.1%), the cost of exercise programmes (37.9%), a lack of knowledge of where to exercise (34.5%), and a lack of transportation (22.4%). The most important barrier, however, may have been the caregivers' perceptions of the benefits of exercise for adults with cerebral palsy. Only half the caregivers perceived that an exercise programme could help the person with cerebral palsy, with 35.7% perceiving that exercise would not improve the

person's condition, and 16.1% thinking that exercise would make the condition worse.

Cousminer (2003), an undergraduate student with cerebral palsy, provided a personal account of the difficulties he faced when attempting, and then succeeding, to conduct an exercise programme using university facilities. Cousminer's doctor referred him to an on-campus physiotherapist, but attending the physiotherapy sessions was prohibitive, because his insurance would not cover the cost of treatment. After becoming envious of students, who he saw using the new Recreation and Wellness Center, at his university, he decided to join. When he approached the building, however, he felt that the machines would be awkward to use and that he did not belong in such a place. Over six month later, Cousminer's doctor referred him to a trainer at the Recreation and Wellness Center. In his appointment with the trainer, Cousminer was told that there was no one working at the Center, who was qualified to work with him, and that his disability was a liability. Several months later, and with help from his doctor, Cousminer met with another trainer. This trainer helped him to try a variety of machines, wrote him an exercise programme, and then assisted him to do the programme during subsequent exercise sessions. This form of assistance was turned into a programme, called "Assisted Workouts," for people with a disability or injury, so that they could use the facilities with the assistance of a trainer. Cousminer's experiences demonstrated how difficult it can be for some people with cerebral palsy to engage in exercise.

In summary, only a small number of studies have investigated the potential barriers facing people with cerebral palsy who wish to be involved in physical activity. The perceptions of people who are in a position to facilitate physical activity for people with cerebral palsy have had an influence (largely negative) on their involvement in exercise. With a combination of persistence and coming into contact with people who can provide assistance, people with cerebral palsy can be actively involved in a physical activity programme.

#### *Energy Expenditure in Adults with Cerebral Palsy*

The energy requirements of people with cerebral palsy are typically greater than for people without this condition (Hemingway et al., 2001; Johnson et al., 1993; Johnson et al., 1996; Johnson et al., 1997; Rose et al., 1990; Rose et al., 1989). Focusing on adults with cerebral palsy, Johnson and her colleagues established that the RMR was higher in adults with cerebral palsy than in age-matched controls without physical impairment (Johnson et al., 1993), the RMR was higher in adults with athetosis (Johnson et al., 1996), and the TEE was higher in adults with cerebral palsy, who were ambulatory (Johnson et al., 1997).

Comparing 21 adults with cerebral palsy with 50 able-bodied adults of similar ages (18 to 50 years), Johnson et al. (1996) found that, after controlling for the effect of fat-free mass on RMR, adults with cerebral palsy had a 14% higher RMR (1,742 kcal/day) than the adults, who were the controls (1,534 kcal/day). Athetosis was an important predictor of RMR. A multiple regression analysis showed fat-free mass was the strongest predictor of RMR ( $r = .65$ ), followed by athetosis (multiple  $R = .83$ ). The findings suggest that the hypermetabolism in adults with cerebral palsy, in comparison to the adults of similar ages, may be attributable to athetosis.

Johnson et al. (1997) found that there was a large amount of variation in the TEE of 18 males ( $M = 2,455 \text{ kcal/day}$ ,  $SD = 622$ ) and 12 females ( $M = 1,986 \text{ kcal/day}$ ,  $SD = 363$ ) with cerebral palsy. Predictors of TEE were RMR, percentage body fat, ambulation, and gender. Adults, who had a higher TEE, had a higher RMR, greater percentage body fat, were ambulatory, and were male. The high degree of TEE variation and the effect of ambulation make estimating energy requirements for people with cerebral palsy difficult.

In summary, research has suggested that adults with cerebral palsy typically expend more energy than people from the general population. The presence of athetosis and ambulatory status were important contributors to the higher level of energy expenditure. Estimating energy requirement for people with cerebral palsy is difficult, however, due to a high degree of variation in TEE and to the effect of ambulation.

#### *Physiology of Aerobic and Anaerobic Exercise for People with Cerebral Palsy*

In people with cerebral palsy, an inability to sustain certain tasks over a prolonged period of time may be due to the high metabolic costs of performing those tasks (Bar-Or, 1986). On tasks, such as walking, running, arm cranking, cycling, and propelling a wheelchair, oxygen uptake can be greater in people with cerebral palsy than in the general population (Bar-Or et al., 1976; Berg & Bjure, 1970; Lundberg, 1975; Rose et al., 1990; Rose et al., 1989). This part of the subsection reviews the aerobic capacity and anaerobic capacity of people with cerebral palsy.

#### *Aerobic Capacity*

Although the maximal oxygen consumption of children and adults with cerebral palsy has been shown to be equivalent to that of people without physical impairment, the physical working capacity (PWC) of people with cerebral palsy is approximately half that of people who do not have the condition (Lundberg, 1978, 1984; Tobimatsu et al., 1998; van den Berg-Emons et al., 1996). In the Tobimatsu et al. study, for example, the cardiorespiratory fitness of 12 men with cerebral palsy ( $M_{\text{age}} = 21$ ) and 7 men without disability ( $M_{\text{age}} = 23$ ) was measured using an arm ergometer. Maximum oxygen uptake ( $\text{VO}_{2\text{max}}$ ) did not differ between the men in the two conditions, or between people with cerebral palsy, who were ambulatory, and those who used wheelchairs.  $\text{PWC}_{\text{peak}}$  was 62% lower, however, in people with cerebral palsy than in people in the control group. The mean heart rate at the time  $\text{PWC}_{\text{peak}}$  was reached was 10% lower in people with cerebral palsy, suggesting that cardiovascular fitness was not limiting PWC. Tobimatsu et al. reported that arm muscle fatigue had caused participants to stop rotating the handles, rather than dyspnea.

A further limiting factor is mechanical efficiency (ratio of energy generated to energy expended; Lundberg, 1976, 1978). Lundberg (1976) found differences between people with spastic cerebral palsy, people with dyskinetic cerebral palsy, and people without disability in their mechanical efficiency at higher workloads on a bicycle ergometer. Although at light workloads there was little difference between the mechanical efficiency of people in the three groups, at the highest workloads people with spastic cerebral palsy had lower mechanical efficiency ( $M = 12.1\%$ ,  $SD = 4.0\%$ ) than people with dyskinetic cerebral palsy ( $M = 16.6\%$ ,  $SD = 2.4\%$ ), who had lower mechanical efficiency than people without disability ( $M = 21.6\%$ ,  $SD = 1.8\%$ ). Lundberg proposed that the differences

between people in the three groups were probably due to the additional energy expenditures of involuntary movements.

Impaired coordination and spasticity are further reasons for low mechanical efficiency (Bar-Or et al., 1976). In the Bar-Or et al. study, adolescents with spastic cerebral palsy performed a submaximal continuous test using an arm ergometer. The low mechanical efficiency during cranking ( $M = 15.1\%$ ,  $SD = 5.1\%$ ) was attributed to impaired coordination and muscle spasticity.

Comparing children with cerebral palsy and children without disability, Unnithan, Darling, Frost, and Bar-Or (1996) found that cocontraction of leg muscles in children with cerebral palsy accounted for a substantial proportion of the variability in oxygen uptake. At a walking speed of 3 km/hr, children with cerebral palsy had a higher oxygen uptake, worked at a greater percentage of their maximum oxygen uptake, and had higher heart rates, than the able-bodied children. Muscle cocontraction in the thighs (vastus lateralis and hamstring group) and lower legs (tibialis anterior and soleus) of children with cerebral palsy were strongly related to oxygen uptake ( $r_s = .72$  and  $.66$ , respectively).

Bhambhani, Holland, and Steadward (1992) demonstrated the importance of testing for  $VO_{2max}$  using the mode of ambulation with which the participants were most familiar. In the participants ( $n = 4$ ), who were able to perform both a wheelchair and a cycle ergometry test, a weak association was found between  $VO_{2max}$  values obtained through these testing methods during two trials of each method ( $r_s = -.24$  to  $.31$ ).

In summary, the  $VO_{2max}$  of children and adolescents with cerebral palsy is equivalent to that of children from the general population. The PWC of these people with cerebral palsy, however, is substantially less than the PWC of their able-bodied counterparts. Reasons for the lower level of PWC include muscle fatigue, not related to aerobic fitness; mechanical inefficiency, due, in part, to involuntary movements, impaired coordination, and spasticity; and muscle cocontraction.

#### *Anaerobic Capacity*

Similar results to those reported for aerobic capacity have been obtained in tests of anaerobic capacity (Bar-Or, 1986; van den Berg-Emons et al., 1996). R. J. van den Berg-Emons et al. found that peak power (W/kg) was, on average, 55% lower in children with cerebral palsy than children without the condition, and mean power (W/kg) was, on average, 50% lower in children with cerebral palsy. The Bar-Or research with 11 boys, who had cerebral palsy, produced similar results. The mean leg power (W/kg) of eight of the boys was over two standard deviations below the mean of healthy children.

Using anaerobic threshold as an outcome variable in research on people with cerebral palsy can be problematic. Although maximum aerobic power can be reliably determined (Bhambhani et al., 1992; Holland, Bhambhani, Ferrara, & Steadward, 1994), reliably measuring the anaerobic threshold, using non-invasive methods, has proven difficult (Holland et al., 1994). Using the ventilatory threshold as a measure of the anaerobic threshold, Holland et al. found that there was a poor association between the oxygen uptake at the first and second trials, as determined by two experienced evaluators ( $r_s = .45$  and  $.43$ ). The researchers concluded that the variation between trials may have been caused by the individuals' cerebral palsy. Lactate concentration in the blood was variable, as



evidenced by the weak association ( $r = .26$ ) in lactate concentration in the blood following the two maximal exercise trials.

In summary, the findings of research into the anaerobic and aerobic capacities of children with cerebral palsy are similar. That is, the peak power of children with cerebral palsy is substantially less than the peak power of normal children. Difficulties in reliably measuring the anaerobic threshold of people with cerebral palsy have restricted the progress of researchers investigating this topic.

### *Cerebral Palsy and Aerobic Training*

Research has shown that it is possible to train the cardiovascular system of a person with cerebral palsy (Bar-Or et al., 1976; Berg, 1970; Emons & Van Baak, 1993; Fernandez & Pitetti, 1993; Lundberg et al., 1967; van den Berg-Emons et al., 1998). Berg (1970) trained 22 children and young persons ( $M_{\text{age}} = 14$  years) with severe cerebral palsy and found that substantial increases in maximal oxygen uptake could be achieved. The training was conducted on a bike, if possible, and lasted for 20 mins, three times per week. The duration of the programme for each individual varied between 1.5 and 16 months. Despite the slight to moderate intensity of the programme, a 25% or greater increase in maximal oxygen uptake was achieved by over half of the participants ( $n = 12$ ). A further eight participants improved their maximal oxygen uptake by 10-15%. A detraining effect occurred during the participants' 3.5-month summer vacation, in which they were not involved in the organised training programme. Berg also noted that, in some participants, a training effect was not immediate. One participant trained for nine months before a training effect was observed.

Fernandez and Pitetti (1993) found that an 8-week training programme was effective in increasing the PWC of seven adults with spastic cerebral palsy, who were ambulatory. The programme consisted of two 30-minute exercise sessions per week that elicited heart rates of between 40% and 70% of the participants' PWC and was performed on a Schwinn Air-Dyne ergometer (SAE), which incorporates cycling and a push-pull action with the arms. Participants were tested using the SAE and an arm cranking ergometer. Significant differences were found, using the SAE, for PWC and PWC/body weight. Differences between pretest and posttest arm cranking scores, however, were not significant. Fernandez and Pitetti concluded that this result was probably due to the differences between the modes of testing and training.

Studies have shown programmes that run over an extended period of time can have beneficial effects (Bar-Or et al., 1976; van den Berg-Emons et al., 1998). Bar-Or et al. conducted a 12-month, twice weekly training programme, in which adolescents and young adults with cerebral palsy ( $n = 17$ ) participated in a range of physical activities, including individual games performed while standing (adapted bowling, dart throwing, shuffleboard, table tennis), mat exercises, and swimming. Adolescents and young adults, who did not start the programme, or dropped out within the first two months, were the inactive controls ( $n = 9$ ). On the arm ergometer, both active and inactive participants had lower heart rates after 12 months at the three submaximal exercise rates (75, 150, 225 kpm/min). Bar-Or et al. did not comment on the improvement of the inactive participants, but possible reasons for the decrement in heart rates include less stress performing the test for a second time due to greater familiarity with the test, some inactive participants taking part in the training programme for up to 2 months, and physical growth,

and, therefore, strength increases, of inactive participants. Bar-Or et al. did not calculate the magnitudes of changes between the two groups, but Cohen's  $d$  values could be estimated from the statistics provided. The magnitudes of the decreases, at the three exercise rates, were greater for the active participants ( $ds = 0.73, 0.75, \text{ and } 0.47$ , respectively) than for the inactive participants ( $ds = 0.30, 0.40, \text{ and } 0.27$ , respectively). Maximal aerobic power ( $\text{VO}_{2\text{max}}$ ) improved for the active participants ( $d = 0.45$ ), but remained constant for the inactive participants ( $d = 0.17$ ).

In a more recent study, van den Berg-Emons et al. (1998) demonstrated that a 9-month sports programme had a beneficial effect on daily physical activity levels, fat mass, peak aerobic power, and isokinetic muscle strength of children with spastic cerebral palsy. Two 9-month sports programmes, which emphasised aerobic activities, were conducted over a two-year period. In the first 9-month period, participants were placed in the sports programme (four 45 min sessions per week) or the control group (no extra physical training). In the second 9-month period, participants from the sports programme and control groups were provided the opportunity to take part in the next sports programme (two 45min sessions per week) with no control. Their physical activity ratio (TEE/SMR or TEE/RMR), for the participants completing four-sessions-per-week programme, increased from 1.34 ( $SD = 0.25$ ) to 1.55 ( $SD = 0.18$ ) over the 9-month period. Although van den Berg-Emons et al. did not state the magnitude of this effect, a Cohen's  $d$  of 1.02 could be calculated from the statistics provided. Fat mass increased consistently for the participants in the control group, but not for those participating in the sports programme four times per week. Participants in the four-times-per-week and two-times-per-week programmes increased their aerobic power by 35% and 21%, respectively. During the second programme, flexion peak torque increased in the most and least affected legs by 28% and 39%, respectively. Extension peak torque increased in the most and least affected legs by 24% and 12%, respectively.

In summary, the limited amount of research to date suggests that aerobic training does cause beneficial adaptations of the cardiovascular system. Although the exercise programmes used in these studies were not strenuous, sizable effects were found in the previously untrained individuals. The studies highlight the importance of training and testing specificity, in that participants showed greater improvements in aerobic fitness, when they were tested using the same equipment with which they were trained.

#### *Physiology of Strength Training in People with Cerebral Palsy*

The use of strength training in the treatment of people with cerebral palsy has traditionally been uncommon (Fowler et al., 2001). Several conflicting assumptions underlying the likely outcome of strength training, and the relationship between spasticity and strength, have meant that exercise programmes that include strength training have not been prescribed for people with cerebral palsy. First, Bobath and Bobath (1984) stated that strength training would promote increased spasticity and associated reactions in people with cerebral palsy. Second, Reimers (1990a, 1990b) proposed that spastic muscle is strong muscle. An associated assumption is that there would be a strength imbalance in opposing muscle groups. For example, spasticity in the hamstrings would be related to weak quadriceps. Third, and contrary to the second

assumption, Rab (1992) suggested that spastic muscle is weak muscle, and weakness increases with damage to the pyramidal tracts. Fourth, some researchers have inferred that there is no association between spasticity and strength (Giuliani, 1991; Rose & McGill, 1998). Fifth, Gage (1991) suggested that, in the lower extremities, muscles have greater spasticity and less strength distally than proximally.

With regard to the first assumption, Fowler et al. (2001) found no changes in spasticity resulted from a single session of resistance training. In 24 children and adolescents with spastic diplegic cerebral palsy ( $M_{\text{age}} = 11.4$  years,  $SD = 3.0$ ), spasticity was measured before and after the performance of three forms of exercise: isometric, isokinetic, and isotonic. Spasticity was measured using the pendulum test, with the outcome measures being first swing excursion in degrees, number of oscillations, and duration of oscillations. The pendulum test involves the researcher lifting one of the participant's legs, while the participant is seated, so that the leg is straight, and then releasing the leg to let it swing freely. Fowler et al. did not calculate effect sizes, but Cohen's  $d$  values could be estimated from the statistics they provided. For the exercised right limb, negligible effects were found for the isometric, isokinetic, and isotonic exercises, as measured by first swing excursion ( $ds = 0.22, 0.00$ , and  $0.04$ , respectively), number of oscillations (all  $ds = 0.00$ ), and duration of oscillations ( $ds = 0.07, 0.00$ , and  $0.00$ , respectively).

To test the remaining assumptions, Ross and Engsberg (2002) investigated the relationship between spasticity and strength in 60 individuals with spastic diplegic cerebral palsy ( $M_{\text{age}} = 12.0$  years,  $SD = 8.9$ ). In support of the inferences of Giuliani (1991) and Rose and McGill (1998), no association between strength and spasticity was found. No relationships were found between knee flexor spasticity and both knee flexor maximum torque ( $R^2 = .0009$ ) and work ( $R^2 = .0009$ ), and only small relationships were found between ankle plantarflexor spasticity and both ankle plantarflexor maximum torque ( $R^2 = .06$ ) and work ( $R^2 = .06$ ).

In regard to strength imbalance in opposing muscles, Ross and Engsberg (2002) found no relationship between the spasticity in one muscle group and the strength of the opposing muscle group. Very low correlations were reported for the relationships between knee flexor spasticity and both knee extensor maximum torque ( $R^2 = .04$ ) and work ( $R^2 = .01$ ), and between ankle plantarflexor spasticity and both ankle dorsiflexor maximum torque ( $R^2 = .03$ ) and work ( $R^2 = .00005$ ). The muscle imbalance at the knee joint (flexion:extension maximum and flexion:extension work) of individuals with cerebral palsy did not differ significantly from the imbalance found in 60 people without disabilities. The results from the ankle joint, however, were conflicting. The maximum plantarflexion values were larger than the maximum dorsiflexion values, whereas the dorsiflexion work values were higher than the plantarflexion work values.

The Ross and Engsberg (2002) research supported the final assumption that muscles in the lower extremities have greater spasticity and less strength distally than proximally. Spasticity, measured in joules per (degrees per second), was greater in the ankle plantarflexors ( $M = 0.026$ ,  $SD = 0.021$ ) than in the knee flexors ( $M = 0.017$ ,  $SD = 0.018$ ). Although not reported by Ross and Engsberg, Cohen's  $d$  can be estimated from the statistics provided to be  $0.46$ .

In summary, empirical evidence does not support assumptions relating to the possible negative outcomes of strength training by people with spastic cerebral palsy. Recent research has been unable to find a relationship between strength and spasticity, and to show that strength training has an effect on spasticity. Therefore, the conjectures of earlier authors seem an insufficient basis on which to exclude people with cerebral palsy from strength training.

### *Cerebral Palsy and Strength Training*

Research has supported the view that strength training can be of benefit to people with cerebral palsy (Allen et al., 2004; Blundell et al., 2003; Dodd et al., 2002; Taylor et al., 2004). Dodd et al. (2002) conducted a systematic review of strength-training programmes for people with cerebral palsy. Studies that were conducted from 1966 through 2000 were included in the review. Because most of the studies were observational, rather than being randomised controlled trials, a meta-analysis was not performed. Ten empirical papers and one review paper met criteria for inclusion in the study. The criteria were that each study's participants had been diagnosed with cerebral palsy; the intervention was a strength or progressive resistance training programme; the outcomes were specified in terms of changes in strength, activity, or participation; and the research was deemed to be of sufficient quality to be included in the review. Nine of the 10 studies prescribed exercises 3 times per week, with the durations of the interventions ranging from 6 to 10 weeks. All studies reported that participants gained strength as a result of the interventions, with effect sizes (Cohen's  $d$ ) ranging from .24 (Lockwood, 1993) to 5.27 (Damiano et al., 1995). In only 3 of the 10 studies (Lockwood, 1993; Toner, Cook, & Elder, 1998; Tweedy, 1997) did the confidence intervals of the effect sizes contain negative values. The power in these studies was low, however. Therefore, the research seems to support the efficacy of using strength-training programmes to increase strength in people with cerebral palsy.

The participants in these studies were predominantly children and adolescents (Dodd et al., 2002), with only one study (Lockwood, 1993) including participants over 20 years of age. In Lockwood's research, six people with spastic, hemiplegic cerebral palsy ( $M_{\text{age}} = 29.5$  years,  $SD = 11.8$ ) and eight people without neurological impairment ( $M_{\text{age}} = 28.5$  years,  $SD = 6.3$ ) participated in a 10-week strength-training programme, which was conducted on an isometric dynamometer. From pretest to posttest, in the participants with cerebral palsy, there was little difference in arm girth (preferred arm,  $d = -0.06$ ; non-preferred arm,  $d = -0.04$ ) or grip strength (preferred arm,  $d = -0.13$ ; non-preferred arm,  $d = 0.20$ ). The largest gain in strength for the people with cerebral palsy was in the non-preferred arm in the extension phase of the movement. Effect sizes ( $ds$ ) for changes in peak torque at  $90^\circ/\text{s}$ ,  $150^\circ/\text{s}$ , and  $210^\circ/\text{s}$  were 0.30, 0.43, and 0.55, respectively.

Strength training interventions have also had functional (Damiano & Abel, 1998; Darrah et al., 1999; MacPhail & Kramer, 1995; O'Connell & Barnhart, 1995) and psychological (Darrah et al., 1999) benefits. In Damiano and Abel's study, for example, the largest functional benefits of a 6-week, individualised strength-training programme were found in the assessment where children ( $M_{\text{age}} = 8.81$  years,  $SD = 2.32$ ) were asked to walk as fast as they could, without running. Velocity at the fastest walking speed increased from pretest to posttest ( $d = 0.44$ ), which was mainly due to an increase in cadence ( $d = 0.64$ ), rather than

an increase in stride length ( $d = 0.13$ ). At the fastest speed, children also achieved greater stability in stance.

In a recent study, Blundell, Shepherd, Dean, and Adams (2003) found that a 4-week functional strength training programme produced similar changes in walking speed ( $d = 0.51$ ) in eight children with cerebral palsy ( $M_{\text{age}} = 6.3$  years,  $SD = 1.3$ ). Contrary to the findings of Damiano and Abel (1998), however, the increase in speed was due to increases in stride length ( $d = 0.81$ ), rather than cadence ( $d = 0.16$ ). This contrast in findings may be due to differences in the strength-training programmes. The programme used in the Blundell et al. study had functional exercises using the children's own body weight as resistance. Exercises included standing balance exercises and sit-to-stands. The Damiano and Abel programme, however, involved exercises for targeted leg muscles, using velcro-attached free weights. Both approaches were effective at increasing walking speed, and the most appropriate form of strength training may be dependent on the needs of the individual with cerebral palsy.

Darrah et al. (1999) measured the effect of a 10-week exercise programme on the perceived competence of 23 individuals with cerebral palsy ( $M_{\text{age}} = 14.2$  years,  $SD = 2.3$ ). The programme took place three times per week and incorporated both aerobic and strength training. A substantial increase in the physical appearance subscale of the Self Perception Profile for Adolescents (Harter, 1988) occurred from pretest to posttest ( $z = -2.75$ ), for those participants aged over 12 years. Although a control group was not included in this research, the findings provide strong encouragement for more research on the effects of exercise on the psychological well-being of people with cerebral palsy.

In summary, all studies included in the Dodd et al. (2002) systematic review of literature reported strength gains for people with cerebral palsy who engaged in strength training programmes. Several of these studies reported functional improvements as a result of the strength training programmes. There has been little research on the effects of strength training on adults with cerebral palsy, and few studies have included psychological measures as part of a testing protocol.

#### *Prescription of Exercise for People with Cerebral Palsy*

Information regarding the prescription of aerobic exercise and strength training for people with cerebral palsy is limited. The available literature pertains to a range of chronic illnesses and disabilities (Durstine et al., 2000) or is dated and does not account for the difficulties people with cerebral palsy may have in performing aerobic exercise (Pink, 1988) or strength training (Cusimano & Davis, 1988). Durstine et al., for example, listed accessibility, safety, effectiveness, and enjoyment as important exercise programming considerations. Prescription guidelines are clearly necessary, because inappropriate exercise (e.g., bearing weight on joints that are poorly aligned, stress on muscle tendons or joints due to poorly controlled movements) can have deleterious long-term effects on a person with cerebral palsy (Turk et al., 1995). Recently, however, the *American College of Sports Medicine* has published recommendations for exercise testing and programming for people with cerebral palsy (Blanchard & Darrah, 1999; Laskin, 2003).

An exercise programme for the average person with cerebral palsy would include aerobic, endurance, strength, and flexibility exercises (Laskin, 2003). It is

recommended that aerobic exercise be performed on equipment suitable to the person, such as a lower limb or arm ergometer. Duration of exercise should be emphasised over intensity, with 3 to 5 sessions completed per week, each session lasting 20 to 40 mins, and the intensity being 40-85% of  $\text{VO}_{2\text{peak}}$  or HR reserve. Endurance exercise involves one to two sessions per week of 6 to 15 min walks for ambulatory persons or 6 to 15 min pushes for those people in wheelchairs. Strength exercises can be performed using free weights or weight machines. With resistance set as a level that can be tolerated, the recommended programme involves three sets of 8 to 12 repetitions of each exercise, performed 2 days per week. Flexibility exercises should be conducted prior to and following aerobic and endurance exercise, and include stretching of both involved and uninvolved body parts.

Laskin (2003) highlighted several special considerations for the practitioner to increase the effectiveness of exercise sessions for people with cerebral palsy. Because unwanted movement, caused by spasticity and/or athetosis, can make performing exercises difficult, the use of straps, wraps, or gloves can be useful to secure or stabilise specific body parts. In using these aids, however, care must be taken to avoid them being too tight, which may cause skin breakdown. Further, if these aids are causing pain or discomfort, spasticity may increase, which may result in a decrease in exercise performance. Certain exercises require a spotter to be present for safety reasons. For example, when using a treadmill, a spotter needs to be provided in case of a fall.

Medications taken by some people with cerebral palsy to control epileptic seizures (e.g., phenobarbital, phenytoin, carbamazepine) or spasticity (e.g., benzodiazepines, baclofen) can confound the results of exercise testing and have an adverse effect on exercise performance (Laskin, 2003). The antispasticity medications benzodiazepines and baclofen, for example, have sedation and weakness as common side effects (Krach, 2001). The use and dosage of such medications should be established during the physical screening of the person with cerebral palsy.

In summary, only recently have comprehensive guidelines been published for the prescription of exercise for people with cerebral palsy. Although several considerations need to be taken into account by practitioners in their prescription of exercise, people with cerebral palsy can perform aerobic, endurance, strength, and flexibility exercises.

## APPENDIX B

### MATERIAL FOR PARTICIPANTS

#### Study 1: Covering Letter

**Victoria University of Technology**

PO Box 14428  
MELBOURNE CITY MC VIC 8001  
Australia

Telephone:  
(03) 9688 4000  
Facsimile:  
(03) 9688 4569



**Footscray Park Campus**

Ballarat Road  
Footscray

Dear Recipient,

We are researchers at Victoria University investigating the relationship between physical activity levels, well-being, and health-related quality of life of adults with cerebral palsy (CP). We would like you to be part of this study by completing a questionnaire. The questionnaire asks about your physical activity levels, general health, feelings, and behaviour. Responses to the questionnaire involve ticking boxes, circling numbers, and short answers. The questionnaire will take about 40 minutes to complete, however, you are under no pressure to complete it within this time. The questionnaire is completely anonymous and all answers you give will remain strictly confidential.

We understand that some people with CP will have difficulty writing their answers on the questionnaire. If you are one of these people, please feel free to ask another person to write your answers for you. We must stress, however, that the responses on the questionnaire must be your answers and not the answers of the person writing on the questionnaire.

We also understand that it may be the caregiver of a person with CP who receives this letter, because the person with CP has an intellectual disability. Unfortunately, people with significant intellectual disabilities cannot be included in the research because they will find it difficult to comprehend what is being asked of them. If this is the case, then please return the questionnaire unanswered with a note attached saying that the recipient could not respond to the questionnaire due to an intellectual disability.

If you have any questions regarding this questionnaire, please do not hesitate to contact the researchers: Cadeyrn Gaskin (email: [Cadeyrn.Gaskin@research.vu.edu.au](mailto:Cadeyrn.Gaskin@research.vu.edu.au)), Professor Tony Morris on 9688 5353 (email: [Tony.Morris@vu.edu.au](mailto:Tony.Morris@vu.edu.au)), or Associate Professor Mark Andersen on 9687 7086 (email: [Mark.Andersen@vu.edu.au](mailto:Mark.Andersen@vu.edu.au)).

Thank you very much for your time.

Yours sincerely,

Cadeyrn Gaskin

## Study 1: Information Sheet

### Victoria University of Technology

PO Box 14428

MELBOURNE CITY MC VIC 8001

Australia

Telephone:

(03) 9688 4000

Facsimile:

(03) 9689 4069



### Footscray Park Campus

Ballarat Road

Footscray

## Information Sheet for Participants Involved in Research

### Participation in Physical Activity by People with Cerebral Palsy

#### INFORMATION TO PARTICIPANTS:

##### Who are the researchers and where can they be contacted?

This study is being conducted by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadeyrm Gaskin from the School of Human Movement, Recreation and Performance at Victoria University. Professor Morris can be contacted on 9688-5353, Associate Professor Andersen can be contacted on 9687-7086, and Cadeyrm can be contacted on 9688-4066.

##### What is the survey about?

The research considers the level of physical activity that you undertake.

##### What will I be asked to do?

You will be asked to complete a questionnaire on how much physical activity you are undertaking in your life. You will be requested to return the questionnaire in the postage-paid envelope required.

##### How much time will be involved?

The process will take around 40 minutes to complete.

##### What can I expect from the researchers?

If you choose to take part in this study you have the right to:

- contact the researchers at any time to discuss any aspect of the study;
- temporarily stop or permanently withdraw from the study at any time;
- access Dr Harriet Speed (phone 9689 8637) or Dr Daryl Marchant (phone 9688 4035) if you feel distressed by anything you are asked to do in the study, and would like to talk with a counsellor about your experiences;
- provide information on the clear understanding that it is completely in confidence to the researchers, to be used only for the purposes of research;
- request information about the results of the study on its completion.

Thank you very much for your co-operation.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).



## Study 1: Questionnaire

### The Cerebral Palsy Questionnaire

This questionnaire asks about your general health, feelings, and behaviour. Some of the questions ask about sensitive and personal matters. Please try to answer all the questions as honestly as possible, although if you feel uncomfortable about any question, move on to the next one.

The questionnaire takes about 40 minutes to complete. If you feel tired before completing the entire questionnaire, please feel free to take a break and complete the remaining sections at another time. Please ask someone to assist you if you need help reading or marking the questionnaire.

All the answers you give will remain strictly confidential.

If you have any questions regarding this questionnaire, please do not hesitate to contact the researchers: Cadeyrn Gaskin on 9688 4066 (email: [Cadeyrn.Gaskin@research.vu.edu.au](mailto:Cadeyrn.Gaskin@research.vu.edu.au)), Professor Tony Morris on 9688 5353 (email: [Tony.Morris@vu.edu.au](mailto:Tony.Morris@vu.edu.au)), or Associate Professor Mark Andersen on 9687 7086 (email: [Mark.Andersen@vu.edu.au](mailto:Mark.Andersen@vu.edu.au)).

Thank you very much for your time.

**Section A**

1. Age: \_\_\_\_\_ years old
2. Gender: ☐ Male ☐ Female (Tick one box.)
3. Type of cerebral palsy
- 3a. Please indicate how many parts of your body are affected by cerebral palsy. (Tick one box.)
- ☐ Quadriplegia – all four limbs, head, neck, and trunk
  - ☐ Triplegia – three limbs, usually both arms and a leg
  - ☐ Diplegia – all four limbs, but the lower limbs are affected more severely
  - ☐ Hemiplegia – upper and lower limbs on one side of the body and trunk
  - ☐ Monoplegia – one limb, usually an arm
- 3b. Please indicate what type(s) of movement disorder you have. (Tick one, two, or three boxes.)
- ☐ Spastic CP – tight, stiff muscles that are resistant to being stretched
  - ☐ Dyskinetic CP – difficulty in coordinating and controlling movement
  - ☐ Ataxic CP – full or partial loss of balance and depth perception
  - ☐ Other, please state: \_\_\_\_\_
4. What other long-term medical conditions, if any, do you have?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

5. Please indicate how severely you are affected by cerebral palsy. (Tick one box.)

- ☐ Level One  
You walk indoors and outdoors, and climb stairs without limitations. You perform large physical movements, including running and jumping but speed, balance, and coordination are reduced.
- ☐ Level Two  
You walk indoors and outdoors, and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines, and walking in crowds or confined spaces. You have at best only minimal ability to perform large physical movements such as running and jumping.
- ☐ Level Three  
You walk indoors and outdoors on a level surface with a physical aid, such as a cane or walking frame. You may climb stairs holding onto a railing. Depending on upper limb function, you propel a wheel chair manually or are transported when travelling for long distances or outdoors on uneven terrain.
- ☐ Level Four  
You sit on a chair but need adaptive seating for trunk control and to maximise hand function. You move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with your arms. You may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. You may rely on wheeled mobility at home, work, and in the community. You may achieve self-mobility using a power wheel chair.
- ☐ Level Five  
Physical impairments limit voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and physical aids. You have no means of independent mobility and are transported. You may have achieved self-mobility using a power wheel chair with extensive adaptations.

6. Are you receiving help reading or marking this questionnaire? (Tick one.)

☐ Yes

☐ No

Section B

Exercise
----------

1. Do you currently exercise? (Tick one box.)

- ☐ Yes
- ☐ No, go on to question 2.

1.1 If yes, what kind of exercises do you do? Please write down the activities you do, and how many minutes per day and days per week you spend on each activity. Some examples would be running for 30 minutes a day on 3 days of the week, and swimming for 45 minutes on one day of the week.

Activity	Min/Day	Day/Week
1.11		
1.12		
1.13		

Leisure-Time Physical Activity
--------------------------------

2. Do you currently participate in any sports, recreational, or physical leisure activities? (Tick one box.)

- ☐ Yes
- ☐ No, go on to question 3.

2.1 If yes, what type of activities do you do? Please write down the activities you do, and how many minutes per day and days per week you spend on each activity. Some examples would be playing basketball for 30 minutes on one day a week, and going ten-pin bowling for 60 minutes on one day a week.

Activity	Min/Day	Day/Week
2.11		
2.12		
2.13		

Household Activity
--------------------

3. Are most of your indoor household activities done by you or someone else? (Tick one box.)

- ☐ You
- ☐ Someone Else, go on to question 4.

3.1 If most of the indoor household activities are done by **you**, please write down what kind of activities you do and how many minutes per day and days per week you spend on each activity. Some examples would be washing dishes for 15 minutes per day on 7 days a week, and vacuuming for 90 minutes on one day of the week.

Activity	Min/Day	Day/Week
3.11		
3.12		
3.13		
3.14		

4. Do you do any outdoor household activities, such as gardening? (Tick one box.)

- ☐ Yes
- ☐ No, go on to question 5.

4.1 If yes, what kind of outdoor activities do you do? Please write down the activities you do, and how many minutes per day and days per week you spend on each activity. Some examples would be mowing the lawns for 30 minutes once a week, and gardening for 60 minutes per day on 2 days of the week.

Activity	Min/Day	Day/Week
4.11		
4.12		
4.13		

Time Indoors
--------------

5. From Monday through Friday, how many waking hours a day do you usually spend inside your home? (Please write down how many hours.)

\_\_\_\_\_ Hours

6. On Saturday and Sunday, how many waking hours a day do you usually spend inside your home? (Please write down how many hours.)

\_\_\_\_\_ Hours

7. On average, how many hours a day are you sitting or lying down, excluding sleeping at night? (Please write down how many hours.)

\_\_\_\_\_ Hours

**Section C**

This section asks for your views about your health. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (Circle one number.)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate your health in general now? (Circle one number.)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

3-12. The following items are about activities you might do during a typical day. Does your health, including your cerebral palsy, currently limit you in these activities? If so, how much? (Circle one number on each line.)

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3.	Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports	1	2	3
4.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5.	Lifting or carrying groceries	1	2	3
6.	Climbing several flights of stairs	1	2	3
7.	Climbing one flight of stairs	1	2	3
8.	Bending, kneeling, or stooping	1	2	3
9.	Walking more than a mile (1.6 kilometres)	1	2	3
10.	Walking several blocks	1	2	3
11.	Walking one block	1	2	3
12.	Bathing or dressing yourself	1	2	3

13-16. During the **past four weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?** (Circle one number on each line.)

		Yes	No
13.	Cut down on the amount of time you could spend on work or other activities	1	2
14.	Accomplished less than you would like	1	2
15.	Were limited in the kind of work or other activities	1	2
16.	Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

17-19. During the **past four weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (Circle one number on each line.)

		Yes	No
17.	Cut down on the amount of time you spent on work or other activities	1	2
18.	Accomplished less than you would like	1	2
19.	Didn't do work or other activities as <b>carefully</b> as usual	1	2

20. During the **past four weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? (Circle one number.)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5



21. How much **bodily** pain have you had during the **past four weeks**? (Circle one number.)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very Severe	6

22. During the **past four weeks**, how much did **pain** interfere with your normal work (including work both outside the home and housework)?

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

23-31. These questions are about how you feel and how things have been with you **during the past four weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. (Circle one number on each line.) How much of the time during the **past four weeks** . . .

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23.	Did you feel full of energy?	1	2	3	4	5	6
24.	Have you been a very nervous person?	1	2	3	4	5	6
25.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26.	Have you felt calm and peaceful?	1	2	3	4	5	6
27.	Did you have a lot of energy?	1	2	3	4	5	6
28.	Have you felt downhearted and blue?	1	2	3	4	5	6
29.	Did you feel worn out?	1	2	3	4	5	6
30.	Have you been a happy person?	1	2	3	4	5	6
31.	Did you feel tired?	1	2	3	4	5	6

32. During the **past four weeks**, how much of the time has your **physical health or emotional problems** interfered with your **social activities** (like visiting with friends, relatives, etc.)? (Circle one number.)

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

33-36. How TRUE or FALSE is each of the following statements for you. (Circle one number on each line.)

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33.	I seem to get sick a little easier than other people	1	2	3	4	5
34.	I am as healthy as anybody I know	1	2	3	4	5
35.	I expect my health to get worse	1	2	3	4	5
36.	My health is excellent	1	2	3	4	5

Section C

Below is a list of statements that describe different types of social support. Please read each one carefully. Then circle one number on each line to indicate the extent to which you agree or disagree with the statement.

		Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree Or Disagree	Somewhat Agree	Agree	Strongly Agree
1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7

Section D

Below is a list of words that describe feelings people have. Please read each one carefully. Then circle one number on each line that best describes how you have been feeling during the past week, including today.

		Not at all	A little	Moderately	Quite a bit	Extremely
1.	Tense	0	1	2	3	4
2.	Angry	0	1	2	3	4
3.	Worn out	0	1	2	3	4
4.	Unhappy	0	1	2	3	4
5.	Lively	0	1	2	3	4
6.	Confused	0	1	2	3	4
7.	Peeved	0	1	2	3	4
8.	Sad	0	1	2	3	4
9.	Active	0	1	2	3	4
10.	On edge	0	1	2	3	4
11.	Grouchy	0	1	2	3	4
12.	Blue	0	1	2	3	4
13.	Energetic	0	1	2	3	4
14.	Hopeless	0	1	2	3	4
15.	Uneasy	0	1	2	3	4
16.	Restless	0	1	2	3	4
17.	Unable to concentrate	0	1	2	3	4
18.	Fatigued	0	1	2	3	4

Please continue to circle one number on each line that best describes how you have been feeling during the past week, including today.

		Not at all	A little	Moderately	Quite a bit	Extremely
19.	Annoyed	0	1	2	3	4
20.	Discouraged	0	1	2	3	4
21.	Resentful	0	1	2	3	4
22.	Nervous	0	1	2	3	4
23.	Miserable	0	1	2	3	4
24.	Cheerful	0	1	2	3	4
25.	Bitter	0	1	2	3	4
26.	Exhausted	0	1	2	3	4
27.	Anxious	0	1	2	3	4
28.	Helpless	0	1	2	3	4
29.	Tired	0	1	2	3	4
30.	Bewildered	0	1	2	3	4
31.	Furious	0	1	2	3	4
32.	Full of energy	0	1	2	3	4
33.	Worthless	0	1	2	3	4
34.	Forgetful	0	1	2	3	4
35.	Vigorous	0	1	2	3	4
36.	Uncertain about things	0	1	2	3	4
37.	Weary	0	1	2	3	4

Section E

Below is a list of statements that describe different physical qualities. Please read each one carefully. Then circle one number on each line to indicate the extent to which you agree or disagree with the statement.

		Strongly Disagree	Somewhat Disagree	Slightly Disagree	Slightly Agree	Somewhat Agree	Strongly Agree
1.	I have excellent reflexes.	1	2	3	4	5	6
2.	I am not agile or graceful.	1	2	3	4	5	6
3.	I am rarely embarrassed by my voice.	1	2	3	4	5	6
4.	My physique is rather strong.	1	2	3	4	5	6
5.	Sometimes I don't hold up well under stress.	1	2	3	4	5	6
6.	I can't run fast.	1	2	3	4	5	6
7.	I have physical defects that sometimes bother me.	1	2	3	4	5	6
8.	I don't feel in control when I take tests involving physical dexterity.	1	2	3	4	5	6
9.	I am never intimidated by the thought of a sexual encounter.	1	2	3	4	5	6
10.	People think negative things about me because of my posture.	1	2	3	4	5	6
11.	I am not hesitant about disagreeing with people bigger than me.	1	2	3	4	5	6
12.	I have poor muscle tone.	1	2	3	4	5	6
13.	I take little pride in my ability in sports.	1	2	3	4	5	6

Please continue to circle one number on each line to indicate the extent to which you agree or disagree with the statement.

14.	Athletic people usually do not receive more attention than me.	1	2	3	4	5	6
15.	I am sometimes envious of those better looking than myself.	1	2	3	4	5	6
16.	Sometimes my laugh embarrasses me.	1	2	3	4	5	6
17.	I am not concerned with the impression my physique makes on others.	1	2	3	4	5	6
18.	Sometimes I am uncomfortable shaking hands because my hands are clammy.	1	2	3	4	5	6
19.	My speed has helped me out of some tight spots.	1	2	3	4	5	6
20.	I find that I am not accident prone.	1	2	3	4	5	6
21.	I have a strong grip.	1	2	3	4	5	6
22.	Because of my agility, I have been able to do things which many others could not do.	1	2	3	4	5	6



**Section F**

We would like to invite you to participate further in this research on physical activity, health-related quality of life, and psychological well-being of people with cerebral palsy. Future studies are designed to investigate how physical activity may be used to improve the quality of life and well-being of people in this population. If you would like to receive information about how you can be involved in this research, can you please record your contact details below. Please note that this information will be removed from the survey so that your responses remain anonymous.

Name: \_\_\_\_\_

Postal Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Daytime Phone Number: \_\_\_\_\_

Evening Phone Number: \_\_\_\_\_

Email Address: \_\_\_\_\_

## Study's 2 and 3: Information Sheet

### Victoria University of Technology

PO Box 14428  
MELBOURNE CITY MC VIC 8001  
Australia

Telephone:  
(03) 9688 4000  
Facsimile:  
(03) 9689 4069



### Footscray Park Campus

Ballarat Road  
Footscray

## Information Sheet for Participants Involved in Research

### Life History Interview

#### INFORMATION TO PARTICIPANTS:

##### Who are the researchers and where can they be contacted?

This study is being conducted by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadeyrm Gaskin from the School of Human Movement, Recreation and Performance at Victoria University. Professor Morris can be contacted on 9688-5353, Associate Professor Andersen can be contacted on 9919-5413, and Cadeyrm can be contacted on 9688-4066.

##### What is the research about?

The research considers the effects of exercise on the health-related quality of life and psychological well-being of people with cerebral palsy.

##### What will I be asked to do?

As a participant in this study, you will be asked to take part in interviews about your life, with a special focus on your involvement in physical activity. Interview questions will focus on your participation in, and experiences while involved in, physical activity and the influences of significant people in your life. The interviews will be audiotaped. Personal risks are minimal. You may, in recalling past events, feel some distress. If this unlikely event happens, we can stop the interview or postpone our discussion, and if you would like to speak to a counsellor, the names of two people are provided below.

##### How much time will be involved?

The initial interview will take approximately 2 hours, and the follow-up interview will take 1-2 hours. Subsequent interviews may be needed to clarify specific areas of a persons life, but will be brief.

##### What can I expect from the researchers?

If you choose to take part in this study you have the right to:

- contact the researchers at any time to discuss any aspect of the study;
- temporarily stop or permanently withdraw from the study at any time;
- access Dr Harriet Speed (phone 9919 5412) or Dr Daryl Marchant (phone 9688 4035) if you feel distressed by anything you are asked to do in the study, and would like to talk with a counsellor about your experiences;
- provide information on the clear understanding that it is completely in confidence to the researchers, to be used only for the purposes of research;
- request information about the results of the study on its completion.

Thank you very much for your co-operation.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).

Study's 2 and 3: Consent Form

**Victoria University of Technology**  
PO Box 14428 Telephone:  
MELBOURNE CITY MC VIC 8001 (03) 9688 4000  
Australia Facsimile:  
(03) 9689 4069



**Footscray Park Campus**  
Ballarat Road  
Footscray

Consent Form for Subjects Involved in Research

INFORMATION TO PARTICIPANTS:

We would like to invite you to be a part of a study into the effects of exercise on the health-related quality of life (HRQL) and psychological well-being of people with cerebral palsy.

CERTIFICATION BY SUBJECT

I,

of

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study entitled:

The effects of exercise on the HRQL and psychological well-being of people with cerebral palsy, being conducted at Victoria University of Technology by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadeyrn Gaskin.

I certify that the objectives of the research, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Cadeyrn Gaskin, and that I freely consent to participation involving these procedures.

Procedures:

You will be asked to take part in interviews about your life, with a special focus on your involvement in physical activity. Interview questions will focus on your participation in, and experiences while involved in, physical activity and the influences of significant people in your life. The interviews will be audiotaped.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this research at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: .....

Date: .....

Any queries about your participation in this project may be directed to the researchers (See information sheet for details). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

## Study 4: Weight Training Programme Information Sheet

### Victoria University of Technology

PO Box 14428  
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Telephone:  
(03) 9688 4000  
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### Footscray Park Campus

Ballarat Road  
Footscray

## Information Sheet for Participants Involved in Research

### Life History Interviews and Weight-Training Programme

#### INFORMATION TO PARTICIPANTS:

##### Who are the researchers and where can they be contacted?

This study is being conducted by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadey Gaskin from the School of Human Movement, Recreation and Performance at Victoria University. Professor Morris can be contacted on 9688-5353, Associate Professor Andersen can be contacted on 9687-7086, and Cadey can be contacted on 9688-4066.

##### What is the research about?

The research considers the effects of weight training on the health-related quality of life and psychological well-being (HRQL) of people with cerebral palsy.

##### What will I be asked to do?

*Life History Interview:* As a participant in this study, you will be asked to take part in interviews about your life, with a special focus on your involvement in physical activity. Interview questions will focus on your participation in, and experiences while involved in, physical activity and the influences of significant people in your life. The interviews will be audiotaped. Personal risks are minimal. You may, in recalling past events, feel some distress. If this unlikely event happens, we can stop the interview or postpone our discussion, and if you would like to speak to a counsellor, the names of two people are provided below.

*Weight-Training Programme:* You will need to get medical clearance from your doctor to participate in this study. A letter to your doctor and a medical clearance form for him/her to complete are included with this information sheet. The medical clearance form needs to be completed and returned to the researchers before exercise begins. You will be asked to complete a survey that has questions relating to your HRQL and psychological well-being before the start of the weight-training programme. You will be asked to return the measures by postage-paid envelope or directly to the student researcher on the first day of the weight-training programme. You will be asked to participate in a programme that will run for 45 minutes, two times per week, over 10 weeks. Small risks are involved in weight training. They will be minimised by providing you with assistance into weight machines and an individualised programme. At weeks 5 and 9, you will be asked to complete the survey for a second time and a third time, respectively.

##### How much time will be involved?

Survey completion will take around 30 minutes on each occasion. The initial interview will take approximately 2 hours, and the two follow-up interviews will take 1-2 hours. Subsequent interviews may be needed to clarify specific areas of your life, but will be brief. The weight-training programme will take 45 minutes, 2 times per week, for 10 weeks, plus additional travel and changing time before and after each session.

##### What can I expect from the researchers?

If you choose to take part in this study you have the right to:

- contact the researchers at any time to discuss any aspect of the study;
- temporarily stop or permanently withdraw from the study at any time;
- access Dr Harriet Speed (phone 9919 5412) or Dr Daryl Marchant (phone 9688 4035) if you feel distressed by anything you are asked to do in the study, and would like to talk with a counsellor about your experiences;
- provide information on the clear understanding that it is completely in confidence to the researchers, to be used only for the purposes of research;
- request information about the results of the study on its completion.

Thank you very much for your co-operation.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).

Study 4: Weight Training Programme Consent Form

**Victoria University of Technology**  
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Australia  
Telephone:  
(03) 9688 4000  
Facsimile:  
(03) 9689 4069



**Footscray Park Campus**  
Ballarat Road  
Footscray

Consent Form for Subjects Involved in Research

**INFORMATION TO PARTICIPANTS:**  
We would like to invite you to be a part of a study into the effects of exercise on the health-related quality of life (HRQL) and psychological well-being of people with cerebral palsy.

**CERTIFICATION BY SUBJECT**

I,

of

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study entitled:

The effects of exercise on the HRQL and psychological well-being of people with cerebral palsy, being conducted at Victoria University of Technology by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadeyln Gaskin.

I certify that the objectives of the research, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Cadeyln Gaskin, and that I freely consent to participation involving these procedures.

**Procedures:**

You will be asked to take part in interviews about your life, with a special focus on your involvement in physical activity. Interview questions will focus on your participation in, and experiences while involved in, physical activity and the influences of significant people in your life. The interviews will be audiotaped. You will be asked to participate in a 10-week weight-training programme and to complete surveys, which have questions about your HRQL and psychological well-being, before the programme begins and at weeks 5 and 9.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this research at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: ..... Date: .....

Any queries about your participation in this project may be directed to the researchers (See information sheet for details). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

## Study 4: Weight Training Programme Letter to Physician

### Victoria University of Technology

PO Box 14428  
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Australia

Telephone:  
(03) 9688 4000  
Facsimile:  
(03) 9689 4069



### Footscray Park Campus

Ballarat Road  
Footscray

Dear Physician,

We are researchers at Victoria University investigating the effects of exercise on the health-related quality of life and psychological well-being of people with cerebral palsy. The project will involve a 10-week weight-training programme, designed for people who are not involved in any form of regular physical activity. The programme will consist of two supervised training sessions per week. The sessions will be approximately 45 minutes and will involve a warm-up and cool down.

If you have received this letter, your client has expressed interest in participating in the above-mentioned exercise programme. Prior to exercise testing and the commencement of the programme, participants have been asked to obtain medical clearance from their physician. Participants in the exercise programme have been informed of the risks involved for people with cerebral palsy. Although all reasonable precautions will be taken, preliminary screening will help to ensure the safety of the exercise test and programme.

We would appreciate your help by completing the medical clearance form on the next page. Please state any reason(s) why your client should not participate in the exercise programme or certify that they may participate.

The project has been approved by the Victoria University Human Research Ethics Committee. Any queries about this project can be directed to the researchers Professor Tony Morris (9688 5353, [Tony.Morris@vu.edu.au](mailto:Tony.Morris@vu.edu.au)), Associate Professor Mark Andersen (9687 7086, [Mark.Andersen@vu.edu.au](mailto:Mark.Andersen@vu.edu.au)), Cadeym Gaskin (9688 4066, [Cadeym.Gaskin@research.vu.edu.au](mailto:Cadeym.Gaskin@research.vu.edu.au)), or to the Secretary of the Victoria University Human Research Ethics Committee (9688 4710).

Yours sincerely

Cadeym Gaskin   Professor Tony Morris   Associate Professor Mark Andersen

Study 4: Weight Training Programme Medical Clearance Form

**Victoria University of Technology**  
PO Box 14428 Telephone:  
MELBOURNE CITY MC VIC 8001 (03) 9688 4000  
Australia Facsimile:  
(03) 9689 4069

**Footscray Park Campus**  
Balarat Road  
Footscray



**Medical Clearance Form**

If there are any reasons why your client is unable to participate in the exercise programme, please state below:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

If your client does not have any conditions that may exclude him/her from the exercise programme, please complete the form below:

I, \_\_\_\_\_ of \_\_\_\_\_  
(name) (clinic)

certify that \_\_\_\_\_ has been cleared  
(client's name – PLEASE PRINT)

to participate in the water-based exercise programme.

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

Please indicate whether I am able to contact you during the programme by supplying a contact number below:

Contact telephone number: \_\_\_\_\_

## Study 4: Warm Water Aerobic Programme Information Sheet

### Victoria University of Technology

PO Box 14428 Telephone:  
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Australia Facsimile:  
(03) 9689 4069



### Footscray Park Campus

Ballarat Road  
Footscray

## Information Sheet for Participants Involved in Research

### Life History Interviews and Warm-Water Aerobic Programme Study

#### INFORMATION TO PARTICIPANTS:

##### Who are the researchers and where can they be contacted?

This study is being conducted by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadeyrn Gaskin from the School of Human Movement, Recreation and Performance at Victoria University. Professor Morris can be contacted on 9688-5353, Associate Professor Andersen can be contacted on 9919-5413, and Cadeyrn can be contacted on 9688-4066.

##### What is the research about?

The research considers the effects of warm-water aerobic exercise on the health-related quality of life (HRQL) and psychological well-being of people with cerebral palsy.

##### What will I be asked to do?

*Life History Interviews.* As a participant in this study, you will be asked to take part in interviews about your life, with a special focus on your involvement in physical activity. Interview questions will focus on your participation in, and experiences while involved in, physical activity and the influences of significant people in your life. The interviews will be audiotaped. Personal risks are minimal. You may, in recalling past events, feel some distress. If this unlikely event happens, we can stop the interview or postpone our discussion, and if you would like to speak to a counsellor, the names of two people are provided below.

*Warm-Water Aerobic Programme Study.* You will be asked to complete a survey that has questions relating to your HRQL and psychological well-being before the start of the warm-water aerobic programme. You will be asked to allow the student researcher to observe your participation in the warm-water aerobic programme that is being run by your day service. At weeks 5 and 9, you will be asked to complete the survey for a second time and a third time, respectively.

##### How much time will be involved?

Survey completion will take around 30 minutes on each occasion. The initial interview will take approximately 2 hours, and the two follow-up interviews will take 1-2 hours. Subsequent interviews may be needed to clarify specific areas of your life, but will be brief.

##### What can I expect from the researchers?

If you choose to take part in this study you have the right to:

- contact the researchers at any time to discuss any aspect of the study;
- temporarily stop or permanently withdraw from the study at any time;
- access Dr Harriet Speed (phone 9919 5412) or Dr Daryl Marchant (phone 9688 4035) if you feel distressed by anything you are asked to do in the study, and would like to talk with a counsellor about your experiences;
- provide information on the clear understanding that it is completely in confidence to the researchers, to be used only for the purposes of research;
- request information about the results of the study on its completion.

Thank you very much for your co-operation.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).



Study 4: Warm Water Aerobic Programme Consent Form

**Victoria University of Technology**  
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**Footscray Park Campus**  
Ballarat Road  
Footscray

Consent Form for Subjects Involved in Research

**INFORMATION TO PARTICIPANTS:**  
We would like to invite you to be a part of a study into the effects of exercise on the health-related quality of life (HRQL) and psychological well-being of people with cerebral palsy.

**CERTIFICATION BY SUBJECT**

I,  
of

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study entitled:  
The effects of exercise on the HRQL and psychological well-being of people with cerebral palsy, being conducted at Victoria University of Technology by Professor Tony Morris, Associate Professor Mark Andersen, and student researcher Cadeyrr Gaskin.

I certify that the objectives of the research, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Cadeyrr Gaskin, and that I freely consent to participation involving these procedures.

**Procedures:**  
You will be asked to take part in interviews about your life, with a special focus on your involvement in physical activity. Interview questions will focus on your participation in, and experiences while involved in, physical activity and the influences of significant people in your life. The interviews will be audiotaped. You will be asked to allow the student researcher to observe your participation in the warm-water aerobic programme that is being run by your day service and to complete surveys, which have questions about your HRQL and psychological well-being, before the programme begins and at weeks 5 and 9.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this research at any time and that this withdrawal will not jeopardise me in any way.  
I have been informed that the information I provide will be kept confidential.

Signed: ..... Date: .....

Any queries about your participation in this project may be directed to the researchers (See information sheet for details). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

## APPENDIX C

### PSYCHODYNAMIC THEORY USED IN THE LIFE HISTORY INTERPRETATIONS

In this appendix, I provide an overview of the psychodynamic theory that I used in the interpretations of the life histories. Throughout, I principally focus on the work of Freud, Erikson, Adler, and Basch. From Freud, I have mostly used his descriptions of the defence mechanisms. I look at Basch's contribution to psychodynamic theory, which is a blend of classic Freudian theory and more recent knowledge from the psychological sciences. I then look at human development from psychosocial perspectives, through highlighting theories from Erikson and Adler. I also discuss these theorists' viewpoints on several concepts that emerged during my analysis of the life history data: narcissism, depression, and suicide.

#### Defence Mechanisms

The ego seeks to avoid being overwhelmed by excessive stimulation from the external world and by the demands of the id (Freud, 1940/1993). The anxiety evoked from these sources may be reduced or prevented through rational methods or through denying or distorting reality. To this latter end, defence mechanisms are unconscious devices that the ego uses to avoid anxiety, danger, and unpleasure (Freud, 1937/1964). In the following subsections, I describe some of the defence mechanisms that emerged in the life histories.

##### *Repression*

Freud (1915/1991b) wrote that "*the essence of repression lies simply in turning something away, and keeping it at a distance, from the conscious*" (p. 147). He distinguished between two types of repression, primal repression and repression proper. In primal repression, a psychical representative of the instinct is denied access into the conscious. The representation remains cathected (i.e., attached with libido) to the instinct and persists in attempting to enter the conscious. In repression proper (hereafter, repression), mental derivatives of, and trains of thought associated with, the repressed representations become similarly repressed. This repression operates through two mechanisms, acting cooperatively. First, the subject matter to be repressed is expelled from the conscious. Second, the primal repression attracts everything, into the unconscious, with which it can establish a connection. That is, the repressed matter forms a cathexis with the unconscious and an anticathexis (repulsion) with the preconscious (Freud, 1915/1991c). An example of repression is the forgetting of painful events in the past.

##### *Denial*

Denial represents the rejection of an idea to prevent the ego from being overwhelmed (Freud, 1927/1991a). Freud suggested that denial could be differentiated from repression, in that in repression the affect is turned away from the conscious, whereas in denial the idea is that which is turned away. That is, whereas repression has internal origins, denial relates to events in the external world. For example, individuals may deny that a traumatic event has happened because they are unable to cope with the consequences.

##### *Identification*

Identification is "the assimilation of one ego to another one, as a result of which the first ego behaves like the second in certain respects, imitates it and in a

sense takes it up into itself" (Freud, 1933/1991, p. 94). Although identification is crucial for the development of the super-ego (i.e., father- and mother-identification, Freud, 1923/1991), it is also a defence mechanism, associating an ego with other egos, causes, or organisations considered to be worthwhile. For example, individuals sometimes support sport teams, especially when they are winning, and bask in the reflected glory when their teams are successful.

### *Projection*

Projection occurs when "an internal perception is suppressed, and, instead, its content, after undergoing a certain degree of distortion, enters consciousness in the form of an external perception" (Freud, 1911/1991, p. 204). In this way, the ego behaves as though a danger or threat comes from an external source, and not from its own instinctual impulses (Freud, 1917/1991a, 1915/1991c). For example, individuals who project their anger onto others may believe that it is those others who are angry with them.

### *Rationalisation*

Rationalisation refers to justifying irrational, and often unacceptable, behaviour "by distorting the mental processes concerned and providing a false explanation that has a plausible ring of rationality" (Jones, 1908, p. 166). This defence mechanism reduces anxiety by concealing the true reason for the behaviour. For example, some athletes who lose sporting contests may attribute the result to external factors (e.g., crowd, equipment, facilities, officials) rather than their own abilities.

### *Regression*

Regression refers to the ego's return to an earlier stage of development, with the aim of attaining satisfaction (Freud, 1917/1991c). This defence mechanism is a reaction to powerful external influences. The ego's propensity to regress to earlier stages of development, when faced with external difficulties, is influenced by the strength of the fixations at one or more of these earlier stages. Fixations are "one instinct or instinctual component [that] fails to accompany the rest along the anticipated normal path of development, and, in consequence of this inhibition in its development, it is left behind at a more infantile stage" (Freud, 1911/1991, p. 205). That is, when faced with an anxiety-provoking situations, individuals may adopt immature behaviours from their past. For example, a child who becomes frightened at school may revert back to infantile behaviours, such as crying and thumb sucking. Adults who have experienced recent trauma may regress back to patterns of dependency on others.

### *The Developmental Spiral*

Basch (1988) rejected Freud's concepts of the ego and the id, and the underlying motive for behaviour being instinctual aggressive and sexual drives. Instead of discussing the ego and id, Basch formulated a theory based on the brain's decision-making functions and the self-system. Basch contended that striving for order, competence, and self-esteem are the underlying motives for human behaviour, rather than the discharge of instincts (Freud, 1915/1991a, 1940/1993). The attributes of order, competence, and self-esteem are core to Basch's developmental spiral. People regularly make decisions about the activities in which they will engage. When engaging in those activities, they typically have an idea of how they would like to complete the activity. One possible outcome is that competence is displayed. If competence is achieved, the self-esteem of those

individuals is enhanced. This enhanced self-esteem may lead individuals to make the decision to engage in the behaviour again. In sum, Basch viewed development as an upward spiral incorporating behaviour, competence, self-esteem, and decisions.

Basch (1988) observed that human development, however, does not always proceed in an upward spiral. The failure to display competence may lead to decreased self-esteem, and the decision to not engage in the behaviour again. Within one individual, also, development may happen with respect to some tasks, but be delayed or retarded with respect to others. For example, an individual may excel at athletic activities, but struggle to show competence at academic endeavours.

When individuals' developmental spirals become arrested, assistance from others may be needed to restore the upward progression of their developmental spirals (Basch, 1988). In this event, the others may enter into their developmental spiral through influencing the individuals' behaviours, feelings of competence, senses of self-esteem, or decision-making. In the exercise setting, for example, a trainer may enter into the developmental spirals of new clients through teaching them how to perform exercises. This input will, hopefully lead to the clients achieving competence, gaining self-esteem, and deciding to persist with the exercises.

The inclusion of competence as a core aspect in the developmental spiral follows the lead of other authors (e.g., Klein, 1976; White, 1959), who have also argued that competence is central to motivation. Basch (1988) contended that competence can be represented in many ways. Behaviourally, for example, competence is demonstrated through the control of one's environment. In terms of introspection and reflection, competence is represented by the growth or decline of self-esteem. Basch argued that the importance of competence as a core component of motivation has empirical support. This support comes from studies conducted with babies and pre-verbal infants, who are at ages that are formative in personality development. These studies, which Basch cites, provide experimental evidence of the strivings for competence by babies and pre-verbal infants.

#### Psychosocial Development

In psychodynamic theory, the foundations of personality are formed in early life. It is here where I wish to depart from Freud's writings, and introduce Erikson's contribution to psychodynamic theory. Erikson (1985) expanded on Freud's (1940/1993) work on psychosexual development through the inclusion of psychosocial factors. Erikson conceptualised the human life cycle to encompass eight psychosocial stages. At each stage, there is a nuclear conflict (critical turning point in psychosocial development), which represents an opportunity for

the development of new ego qualities. The eight stages are: oral-sensory, muscular-anal, locomotor-genital, latency, puberty and adolescence, young adulthood, adulthood, and maturity.

In the first stage, oral-sensory, a baby meets the first nuclear conflict, basic trust versus mistrust (Erikson, 1985). Babies demonstrate their trust in others through their depth of sleep, ease of feeding, and relaxation of bowels. They become increasingly receptive to sensory experiences, and start to recognise the consistency within the environment. It is here that the first social modality, *to get*, is learned. There may also be the recognition of the difference between the inner and outer worlds. This stage is where the defence mechanisms of introjection and projection may be first developed, as babies internalise pleasure and externalise pain. The resolution of this conflict may be seen in later patterns of trust and mistrust. *Hope* (the belief that one's wishes will be fulfilled) is the ego quality that denotes the successful development in this stage.

The muscular-anal stage comes about through the maturation of the infant's muscles (Erikson, 1985). The nuclear conflict of this stage, autonomy versus shame and doubt, is grounded in the social modalities of *holding on* and *letting go*. Both these modalities have benign and destructive forms. Holding on can relate to care, and it can also relate to restraining and retaining in destructive and cruel ways. Letting go can be relaxed, as in "to let be," and can be destructive in "letting loose." As children begin to explore their environments, there is the danger that they will experience shame and doubt. Shame is a state where people feel that they have been exposed in front of others and feel conscious of those others looking at them. Doubt is concern over that which is unseen (i.e., what is "behind"). The inadequate resolution of this conflict may be seen in later patterns of sensitivity towards being shamed or threatened from behind. *Willpower* (being determined to exercise freedom of choice and self-control) is the ego quality that emerges from the successful resolution of the nuclear conflict at this stage.

The locomotor-genital stage coincides with the development of ambulation, and incorporates the conflict of initiative versus guilt (Erikson, 1985). Initiative is differentiated from autonomy in the sense that it involves undertaking a task with the motive of being active, rather than as an act of defiance, as is often the case in the previous stage. The social modality of *making* is derived through the newfound mobility and infantile genitality. Erikson borrowed Freud's (Freud, 1916/1991, 1917/1991c) Oedipus complex in his description of infantile genitality. In this stage, the superego develops and parental regulation is supplanted with greater self-regulation. The danger inherent in this stage is that children experience guilt over the actions they have contemplated or the behaviour they have initiated. *Purpose* (having courage to develop and work towards valued goals) represents the ego quality attained through successful negotiation of this psychosocial stage.

In the latency stage, children make their entrances into school life and are confronted with the conflict of industry versus inferiority (Erikson, 1985). Children begin to receive systematic instruction in the skills and uses of tools that will assist them in becoming productive members of society. The danger in this stage is that children do not develop their skills and competences for using tools, and, instead, end up with a sense of inadequacy and inferiority. These feelings may result in children despairing and regressing to the previous stage of

psychosocial development. Socially, this stage can be one of the most decisive. Achieving industry involves doing things alongside or in cooperation with others. Divisions of labour develop, and with them some children may gain a sense that factors other than their skills will decide their worth. Such factors may include race, parental background, and style of clothing. This inequality may cause children to constrict their horizons, and be servants of technology, and of those who are able to control it. *Competence* (belief in one's ability to perform important tasks) is the ego quality that represents successful completion of this psychosocial stage.

Puberty and adolescence mark a period where many of the battles of earlier years are re-fought, with often well-meaning parents as adversaries (Erikson, 1985). This stage encapsulates the nuclear conflict of identity versus role confusion. Adolescents readily and strongly identify with their idols and ideals. The inherent danger of this stage is role confusion. Adolescents experiencing role confusion may have minimal direction as to where their lives are heading. For example, many adolescents experience difficulty in settling on an occupation. Other forms of role confusion (e.g., sexual identity) may also occur, and can lead to delinquency and adverse psychological outcomes. Adolescents sometimes clarify their identities through falling in love. They project the image of their egos on other people, see their egos reflected back, and gradually refine their egos. Much of this process happens through conversation. Adolescents protect their identities by forming strong associations with like-minded people, and through the exclusion of others who are "different." *Fidelity* (the ability to maintain loyal relationships despite differences in value systems) is the ego quality developed from successful resolution of this stage.

For young adults, the identities they have been developed in the previous stage are ready to be joined with the identities others (Erikson, 1985). Young adults are ready to face the challenges of increasing their commitments to affiliations and to partnerships, and of developing their ethical strength to make these pledges of loyalty, even if it calls for substantial compromise and sacrifice. The nuclear conflict, in this stage, is intimacy versus isolation. Intimacy requires abandonment of the ego in situations, such as in close affiliations, in sexual unions, in close friendships, in physical combat, in experiencing inspiration from teachers, and in intuition from self. If young adults fear ego loss through engaging in such situations, isolation and self-absorption may develop. The danger, at this stage, is that the avoidance of contacts that involve commitments to intimacy may lead to isolation. *Love* is the ego quality that represents the successful passing of the nuclear conflict at this psychosocial stage.

In adulthood, mature people turn their attention toward guidance of the next generation (Erikson, 1985). Although popular thought focuses on the dependence of the younger generation on those who are older, the mature adult also needs guidance and encouragement from younger people. The nuclear conflict at this stage is generativity versus stagnation. Generativity refers to the establishment and guidance of the next generation. Some people have special gifts and apply them to other directions, rather than to their offspring. Productivity and creativity are parts of generativity, but are not synonymous with it. The danger of this stage is that stagnation occurs. *Care* for the new generation is the ego quality that comes from the successful negotiation of this stage.

Maturity is the final stage of the human life cycle (Erikson, 1985). Having negotiated the previous seven stages, mature adults face the last nuclear conflict, ego integrity versus despair. Ego integrity refers to having experienced a productive and meaningful life, and not being afraid of the death that is to come. Lack of ego integrity is characterised by despair over the brevity and worthlessness of life, with the knowledge that it is too late to begin another life. *Wisdom* is the ego quality represents successful development at this psychosocial stage.

### Birth Order

Adler (1932) also took a psychosocial view of human development in his contention that birth order affects personality. Because I have not made extensive use of Adler's theory on birth order, I shall limit my review to the two birth order positions that I have mentioned in the life histories: first born and only children.

First-born children are typically spoiled and are the centre of their families' attention. If the parents have no more children, then this privileged position in the family is likely to be prolonged. If, however, the parents have additional children, this position is upset. The arrival of the second born means that the first born is removed from the centre of attention (Adler, 1932). The consequences, for the first born, of a new rival are dependent on the preparedness of the first born to handle the change in circumstance. Unprepared children will try to regain the mothers' appreciation, attention, and love. These children may try to worry or fight their mothers, in an attempt to regain what has been lost. The danger in performing these tricks, however, is that mothers get tired of their children's antics, and the children come to experience what it is like to lose their mother's love. If mothers engage in battles with their first born, the children will become critical, disobedient, high-tempered, and wild. They are also likely to try to win the attention and affection of their fathers. First-born children may idolise the past (i.e., the time without the rival) and be pessimistic about the future. For those first-born children who have been prepared for the arrival of the second born, a different set of consequences exists. Teaching the concept of cooperation is central to the preparation of the first-born. This preparation may manifest itself later in life in wanting to protect and to help others. In some cases, this protection may exaggerate into a desire to keep others dependent.

Only children share the characteristics of first-born children, with the exception that they do not have rival brothers and sisters (Adler, 1932). In this situation, children's competitive feelings may go against the father. The children can develop a "mother complex" because they are pampered by, and have the attention of, their mothers.

### The Goal of Perfection and Inferiority Feelings

Adler (1933/1979a) disagreed with Freud's (1915/1991a, 1940/1993) arguments that drives are at the core of human behaviour. Instead of drives, Adler contended that the psychological movement of individuals has the goal of perfection. He viewed perfection to be synonymous with security and completion. The meaning of perfection, completion, and security rests within each individual, rather than being objectively determined. This meaning develops early in a child's life, in which they lack language and concepts.

While striving for the goal of perfection, individuals sometimes experience feelings of incompleteness, insecurity, and inferiority (Adler, 1933/1979a). Adler

regarded these feelings as the “minus situation,” and argued that they could provide impetus to the goal of perfection. This minus situation may be intensified in cases of organ inferiority, pampering, and neglect (Adler, 1932/1979). With respect to organ inferiority, children who have such weaknesses need not experience them as a minus situation. Children who experience the weaknesses in social tasks may be impelled to reorganise themselves through eliminating or avoiding the inferiority. How children overcome their organ inferiority in the first three or four years of life shapes their patterns of goal formation in later life. In the case of pampering, individuals show a similar life pattern to those who have been affected by organ inferiority. By pampering, Adler meant parents who assume responsibility for tasks that their children should fulfil, and who hover over their children, rather than parents who love and caress their children. Pampering styles are not only the creations of parents and grandparents, however. The children also cultivate these styles. Such children can develop parasitic qualities, ranging from those who will not accept the suggestions or influence of others, to those who are dependent on the assistance of others. With regard to neglect, feelings of neglect can intensify feelings of inferiority. Although external circumstances may contribute to the feelings of neglect, it is children’s perceptions of the neglect that will determine how strongly feelings of inferiority will manifest.

Feelings of inferiority can have a positive outcome (Adler, 1933/1979a). The greater the extent to which individuals have been trained in social interest (see *Social Interest*) during their childhood, the greater and more valuable will be their accomplishments from their feelings of inferiority. These accomplishments are associated with high feelings of value, identical to experiencing happiness.

Negative outcomes from feelings of inferiority can also occur (Adler, 1933/1979a). In circumstances where there is insufficient social interest, feelings of inferiority may develop into an inferiority complex, which manifests as, for example, crying, complaining, fear, stage fright, and stuttering, and physical changes, such as, blushing, headache, fatigue, heart palpitations, insomnia and the urge to urinate. The goal of overcoming the inferiority, however, has not been lost. The manifestations of the inferiority complex promote sympathy from others and thoughts of what could have been accomplished if the disturbance (e.g., fear, stage fright) had not resulted, from sources, such as, hereditary, education, and other people. People with inferiority complexes, therefore, try to conceal them through the development of fictitious superiority complexes (belief that they are better than others), which exploit the social interest (see *Social Interest*) of others.

#### Social Interest

Adler (1933/1979b) contended that the direction of the goal of perfection was toward social interest. He defined social interest as meaning, “*feeling with the whole, sub specie aeternitatis*, under the aspect of eternity” (p. 34). Social interest represented mankind in its ultimate form, in which all questions of life have been solved. The movement of an individual, or group of individuals, can be deemed valuable if it contributes to the development of mankind. Conversely, those individuals lacking in social interest (e.g., criminals, neurotics, problem children, suicide cases) disturb the cooperation of the community. Individuals are guided by the community ideal, in that they are praised or advanced for displaying social interest, and are impeded or punished for their lack of social interest. Like the goal



for perfection, Adler claimed that social interest was innate, but was developed in social context in the midst of children's lives.

### Narcissism

Narcissism is "the attitude of a person who treats his own body in the same way in which the body of a sexual object is ordinarily treated" (Freud, 1914/1991, p. 65). Adler (1931/1979) argued that Freud's conception of narcissism was too narrow, however, and could represent one of many forms of self-love. Adler contended that the most important aspect of narcissism was the permanent removal of others from the social sphere.

A number of authors have investigated narcissism and people with physical disabilities (e.g., Freud, 1916/1990, 1914/1991; Freud, 1917/1991c; Niederland, 1965; Rousso, 1985). Drawing on the small number of writings on narcissism and physical disability, Rousso (1985) concluded that the relationship is complex and influenced by various developmental, environmental, and physical factors. In cases of organic illness, inflammation of an organ, or painful stimulation, Freud (1917/1991c) suggested that the libido detaches from its objects to assist the ego. Within the ego, the libido develops an increased cathexis to the diseased body part. But here, it seems, Freud is discussing acquired health conditions, and not congenital conditions, such as cerebral palsy.

Niederland (1965) took Freud's advice, to study cases of organic illness, in his investigation of narcissism in eight adults, who had minor physical abnormalities or imperfections, which were scarcely noticeable, in two cases, and not noticeable in six cases. The physical defects were either congenital or occurred during the first year of life. Narcissistic features were present in all cases. Common features of Niederland's patients, which were evidence of an unresolved narcissistic injury (permanent psychical scar from failure and loss of love), included compensatory narcissistic self-inflation (greater self-love to make up for the prior loss or failure), poor reality testing, outbursts of aggression, birth-rebirth and revenge fantasies that were part of other rich fantasies (e.g., sadomasochistic fantasies, revenge fantasies, eroticised megalomaniac daydreams, greatness fantasies, immortality fantasies), intense reconstructive strivings, distorted body image (i.e., disproportional disfigurement), concealment of physical abnormalities from others, attribution of damaged body part with magical qualities, and compensatory hypercathexis to the confluence of the damaged body part and the rest of the body or a zone distal from the site of the abnormality.

Narcissism can also be viewed from the perspective of the parents of a child with a physical abnormality. Parents typically fantasise of a healthy, normal baby, and so the birth of an abnormal child comes as a narcissistic blow (Lantican et al., 1994). Freud (1933/1991) thought it was usual for the mother of a child who is unwell to respond with a superabundance of love. He briefly reported the example of Wilhelm II, who had a congenital defect in one of his limbs. Although the biographer of Wilhelm II claimed that his development, to become a man of great power, was based on a sense of inferiority, due to his physical defect, Freud argued that the actions of Wilhelm II suggested that he had never forgiven his mother for her withdrawal of love for him.

### Depression

Freud (1917/1991b) described melancholia as having several distinguishing features, including "a profoundly painful dejection, cessation of

interest in the outside world, loss of the capacity to love, inhibition of all activity, and a lowering of the self-regarding feelings to a degree that finds utterance in self-reproaches and self-revilings, and culminates in a delusional expectation of punishment” (p. 252). In a note to Freud’s paper, Richards (1991) stated that melancholia would probably be regarded as *depression* in modern terminology (p. 92). Freud considered the features of melancholia to be the same as of mourning, but without the disturbance of self-regard. To Freud, melancholia represented the reaction to losing a loved object, of a loss of this kind. Unlike in the case of mourning, where the object that has been lost is known, in melancholia a person may know whom, but not what, has been lost.

A typical element of melancholia is various accusations against the self (Freud, 1917/1991b). Investigation of these self-accusations, however, suggests that they commonly relate to someone else, and not the person making the accusations. Therefore, melancholia more aptly represents a loss to the ego, rather than the loss of an object.

The normal consequence of a shattered object-cathexis would be that the libido from this object is withdrawn, and displaced on another object (Freud, 1917/1991b). In melancholia, however, the free libido is withdrawn into the ego, where it is used to establish ego identification with the object that had been abandoned. The strong fixation to the loved object, and the libido’s lack of resistance to being withdrawn by the ego, suggests that the original object-choice had a narcissistic basis.

In melancholia, ambivalence towards the loved object may also become evident (Freud, 1917/1991b). In such cases, the ego identifies with both the feelings of love and hate for the object. Self-torment, as is evident in some cases of melancholia, thus relates to the abandoned object, which now has been replaced by the ego.

Although Basch (1988) agreed with Freud (1917/1991b) that some cases of depressive retreat may have their origin in hate towards an external object, the libido of which had since been withdrawn into the ego, Basch contended that depression and hate towards an object are not necessarily associated. Basch preferred to conceptualise depression as a possible consequence of the self-system’s failure to cope with some stress. Depression is a sign that the self-system is unable to cope with the demands that have been placed upon it, and has retreated to a lower level of functioning. It is also a signal to the world that the self-system is no longer functioning the way it has in the past, and that help is required.

### Suicide

Freud’s (1917/1991b) explanation of suicide extended from his description of melancholia. The conditions under which the ego can be destroyed must be sufficiently powerful to overwhelm the ego’s vast amount of narcissistic libido. These conditions arise in melancholia when the libido, which once related to hostility towards an object, is withdrawn into the ego. This hostility towards the object in the external world is now applied to a person’s own ego, and overpowers the ego’s narcissistic love for itself.

Like in Freud’s (1917/1991b) understanding of suicide, Adler (1937/1979), conceived the act as a way of hurting others. Adler described people who commit suicide as those who thought too much of themselves, and too little

of other people. Suicidal ideations stem from confronting, urgent problems from the external world, together with insufficient social interest. The direction and development of the suicidal ideations depends on the degree of activity within these people.

#### Transference and Countertransference

Transference refers to “bringing or transferring old patterns of expectation to new situations so as to organize the experience of the moment” (Basch, 1988, p. 134). In the researcher-participant relationship, for example, researchers may behave (e.g., by making comments) in ways that produce strong affective reactions in participants, which may seem out of place in the present relationships. The sources of these strong feelings are not solely the researchers’ behaviour, however, but are reactions to some past experiences the participants had with other people. Participants may seek to interact with the researchers as they had done in these past experiences. The reasons for the participants’ affective reactions may be unconscious to them.

Countertransference is the same concept, but in the opposite direction (Basch, 1988). Staying with the previous example, countertransference is when participants behave in fashions that produce strong affective reactions in the researchers, the sources of which lie in the researchers’ past relationships.

#### Summary

I used psychodynamic theories to interpret the lives of the participants with cerebral palsy. These interpretations were principally based on the work of Freud, Erikson, Adler, and Basch. Defence mechanisms were useful in understanding how participants coped with anxiety-evoking situations during their lives. I made extensive use of the theories of human development, as proposed in Erikson’s (1985) psychosocial model and Basch’s (1988) developmental spiral. Adler’s (1932) writings on birth order also contributed to this discussion. I also used the cornerstones of Adler’s theories (i.e., striving for perfection, feelings of inferiority, social interest) in my interpretations. I reviewed psychodynamic theory regarding narcissism, depression, suicide, and transference and countertransference because they were pertinent to some of the cases interpreted.