KEEPING CONNECTED

Identity, social connection and education for young people living with chronic illness

A project report from:

keeping>>>connected
YOUNG PEOPLE, IDENTITY & SCHOOLING

Lyn Yates, Lyndal Bond, Mary Dixon, Sarah Drew, Peter Ferguson, Trevor Hay,
Julianne Moss, Pamela St Leger, Hannah Walker, and Julie White

The 'Keeping Connected' project was a three year project (2006-2009) co-funded by the Australian Research Council and The Royal Children's Hospital Education Institute.

Its focus was on young people who experience chronic illness-related interruptions to their schooling. Its aims were to make visible the young people, their experiences, voices, and concerns, and to explore the ways in which they were being supported or hampered in various aspects of their education trajectories.

The project brought together a large multi-disciplinary research team working in collaboration with the RCH Education Institute with the aim of achieving a better understanding of issues related to the support and engagement of young people living and learning with ongoing health conditions.

Who and what do young people feel is important in creating, strengthening, and maintaining educational and social connections in their lives? What do parents feel are significant supports or challenges for young people (and their families) experiencing interrupted schooling due to ongoing health issues? What do education and health care professionals see as key areas of focus in supporting young people to maintain social and educational connections?

This report highlights the clear and pressing need for a system of advocacy on the part of young people and families within both health and education systems—and between schools and hospitals. The Royal Children's Hospital Education Institute is well positioned to influence policy and practice across these sectors.

An Australian Research Council Linkage Project with The Royal Children's Hospital Education Institute

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Keeping Connected: Young people, identity and schooling

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Acknowledgements

Many thanks go to all of our participants, particularly the 31 young people and their families who so generously invited us into their homes and their worlds for three years. All of the researchers involved in this project feel privileged to have had the opportunity to get to know these vibrant and determined young people and their families, to witness the ups and downs of their lives, their successes and challenges, and the sheer determination of these young people to make the most of their often difficult lives.

Many of the participants agreed to use digital cameras and were asked to take photos that would help the researchers get to know them and the sorts of things that were going on in their lives. All the images in this report come from the photos taken during the project and are used with full permission of the participants. Pseudonyms have also been used instead of people's real names to protect privacy, except for one young person who was adamant (with family support) that their own name should be used.

Table of Contents

Executive Summary

1. About the project

The Keeping Connected project is an ARC Linkage Project investigating identity and education and social connection issues of young people with chronic illness.

- Its principal method was 31 qualitative longitudinal case studies using visual, narrative and ethnographic methods.

- Other components of the study included interviews with parents and health professionals; focus group interviews with education professionals; retrospective interviews with past students; a small survey; and an analysis of data-base categories.

2. Findings

(i) Young peoples' voices

<u>Identity</u>

- The young people in this study were articulate, knowledgeable and capable in relation to their health. They aimed not to be defined by their health issues, working instead to establish and maintain a personal identity that focused on being a regular young person.

- Encounters with difference and being different are spoken about by the young people and their families – as a young person, as a student and with regard to their bodies and sense of self. Participants who had visible manifestations of their health conditions described how that influenced the way others reacted to them, especially noted in cases where these manifestations were misinterpreted, changed or disappeared over the time of the study.

- There was a strong desire of these young people to be accepted as 'normal' teenagers.

- They also had an awareness of vulnerability, both as a physical reality, and a characteristic of their awareness of their illness as something always in the background and as producing an unpredictable element in their ongoing lives and future plans.

- The desire for a sense of 'normalcy' created some social and management dilemmas for participants who wanted to be seen as normal by other people, but at the same time needed to acknowledge their limitations and the need for external support.

Connections

- On a day-to-day basis, family, friends, pets and favourite hobbies were highlighted as important in the lives of these young people.

- For many young people with chronic illness various kinds of disconnections in relation to family, social lives and education were repeatedly experienced.

- Triggers for disconnection included general health setbacks such as medical procedures, depression or fatigue; family disruption as a consequence of the illness; a lack of awareness and sensitivity on the part of school; and the waxing and waning of friendships.

- Instances of bullying and teasing were common across the group of young people in this study.

- Access to learning can be sporadic and catching up was constant. Levels of support varied widely as did experiences of failure, exclusion and the quality of schools, teacher, and school support.

- School processes and rules for claiming special consideration tend to focus on identifiable absences or markers of physical incapacity. They do not deal adequately with the experience of a chronic condition as an uneven and continuing process over time.

- Schools which have overall orientations or programs supporting diversity worked well for this group, who can thereby be supported well without being singled out as different.

Aspirations and pathways

- Long term aspirations were very important to this group, and many had a link with specific educational goals.

- Realizing aspirations, no matter how small these might seem to others, had a major positive impact on the young people's sense of achievement and wellbeing.

- Life experiences associated with their health conditions often influenced longer term career and study aspirations. Goals and aspirations were tempered by pragmatic considerations about what might be possible and when.

- Transitions (change of school, and school to post-school) proved to be particularly disruptive times for this particular group. The transition away from school introduced some new daily management issues as the young people grew more independent and for many it presented a whole new range of challenges.

(ii) Parents' voices

- Parents commonly showed strong commitment to their child's education and worked hard to communicate information and needs with schools.

- Some parents reported very positive experiences with schools; others quite negative. Many indicated their awareness that schools varied greatly as an environment for their child, and went to a lot of effort to select an appropriate school.

- Many parents felt responsibility to be the main mediator of the young person's needs in relation to education; and that they often lacked support and expertise to do this well.

- Some parents felt that their efforts to advocate for their child were at times interpreted as inappropriate by school and health professionals.

- The haphazard nature of school communication and a lack of systematic approaches to supporting and reviewing the progress of young people with serious ongoing health issues in schools were major concerns consistently raised by parents in this study.

- Few parents reported knowledge of the role and purpose of the RCH Education Institute.

- Parents identified a need for a consistent contact person in each school to liaise with families and keep classroom teachers fully informed about health events and educational requirements.

- Parents reported that even when their child was well, they were still absent from school in order to attend clinics at The Royal Children's Hospital, often scheduled without regard to educational commitments.

- Parents saw value in the social as well as learning dimensions of school participation. When a young person's energy levels were compromised the social dimension of school was often prioritized, along with attendance at selected classes to maintain specific academic proficiencies.

- Some parents expressed concern that teachers did not always share their emphasis on the importance of both social connection and achievement at school in order that the young person could access a range of post school choices in spite of chronic health issues.

- Parents highlighted that some teachers were unsure of what academic demands they should place on these young people, and frequently reduced their expectations and demands without consultation with the young person or parents in the mistaken belief that only the social experience was important and that not much should or could be expected academically.

- Parents of older study participants drew attention to the lower than anticipated final year results that were achieved by their daughter or son.

(iii) Education and health professionals' voices

- Most health professionals and teachers reported that social relationships and isolation were issues for young people and therefore helping them to maintain school connection was a priority.

- Health professionals reported that, due to advances in medical knowledge over the last two decades and consequently longer life expectancy, the orientation of their practice has shifted from a narrow focus on the illness, to a multidisciplinary approach that focuses on building capacity of the young person to self-manage his or her condition within the context of broader life goals.

- Education advisors expressed concern that relentless health treatment schedules that involve multiple clinicians could be disempowering for the young person.

- Most teachers viewed young people as individuals and were aware of how important it was for these young people to fit in to school life and not be labeled as 'sick kids'.

- Teachers, health professionals and education advisors reported the need for better communication between health professionals, teachers and families and, more broadly, within and across sectors about how to best support individual young people in achieving their broader life and educational goals.

- Teachers, health professionals and education advisors advocated a single point of contact in schools such as a student welfare coordinator to establish and maintain communication within the school and between the hospital, school and parents. They stressed that the success of the young person's connection to school is reliant on the quality of the work done by the person in that role.

- Education advisors reported that a whole school culture of inclusion is significant in supporting the connection of young people with ongoing health conditions.

- According to education advisors, young people regard contact from the school as an indicator of the care of the school and as an indicator that they are valued members of the school community.

- Teachers, health professionals and education advisors highlighted the need to build teachers' knowledge of how best to support young people with ongoing health conditions, particularly in relation to disclosure, meeting social and academic needs, academic expectations, flexibility in curriculum, managing behaviour, and meeting the needs of siblings and classmates.

- Student welfare coordinators and education advisors acknowledged that supporting a young person with ongoing health conditions may place additional financial demands on schools.

- Education advisors expressed concern about a minority of young people with whom they have had contact experiencing severe social isolation with very little support from families, school and friends.

- Education advisors' descriptions of their work suggests that there is a role for personnel from the RCH Education Institute to support young people who are disengaged with school to reconnect with their school or find a new one, that is, take on a role of advocacy.

3. Key themes and issues for attention

Four main themes are highlighted from this project:

- The binary themes of 'normalcy' and difference in the lives of these young people - of being the same as everybody else and yet being particularly vulnerable -and the impact of this in making it difficult for schools to see, arrange and claim appropriate support needs.

- The importance of perceiving the young people's situations as a process, not a checklist, and the implications of this for policies and practices of support.

- The need for diversity to be 'seen and heard'. Young people's needs and wants are not all the same and cannot simply be deduced or interpreted from the condition they have.

- The need for better communication, advocacy and protection of rights for this group must be recognized and addressed. Better avenues of communication are required between institutions, families and young people; and greater clarity about rights, entitlements and means of access to support are also sorely needed.

1. About the project

1.1 Background and project team

Keeping Connected: Young People, Identity and Schooling, was funded by the Australian Research Council in conjunction with the Royal Children's Hospital (RCH) Education Institute, for the period 2006-2009 under the ARC Linkage Project Scheme. This project arose out of an ongoing collaboration of several years between the RCH Education Institute and education researchers from the University of Melbourne to understand better the situation of the young people with whom it deals; the ways in which education is socially meaningful to young people; and the ways in which schooling, individual identities, family relationships and other social contexts support or work against their continued engagement with education. It took a multi-disciplinary approach to gaining new knowledge about young people in the situations the RCH Education Institute encounters, and to providing new and better perspectives on the professional and institutional practices that could better support them.

The Chief Investigators on the project were: Professor Lyn Yates, Dr Trevor Hay, Dr Peter Ferguson, Dr Pam St Leger, Dr Julianne Moss all of the Melbourne Graduate School of Education, University of Melbourne; Dr Julie White of the Faculty of Education, La Trobe University, Associate Professor Mary Dixon of the Faculty of Arts and Education, Deakin University, Professor Lyndal Bond MRC/CSO Social and Public Health Sciences Unit, Glasgow; and Dr Sarah Drew of the Centre for Adolescent Health, Royal Children's Hospital and the University of Melbourne. Project management and research assistance was provided by Hannah Walker (2009-2010), Dr Ria Hanewald (2008-2009), Dr Katie Wright (2007) and Ms Amy Basile (2007-2008). Partner investigators on the project from The Royal Children's Hospital Education Institute were Ms Margaret Robertson, then Director of the Institute, in 2007; Dr Julie Green, Deputy Director and Head of Research (since 2008); and Mr Tony Potas.

1.2 Aims and methodology

The aims of the project were to investigate for young people with chronic illness, their own perspectives and identity in relation to education, social relationships, and experiences with education and health professionals; and the ways parents, teachers and health professionals see those needs. Using a mixed methodology, but emphasizing qualitative and longitudinal investigation of the perspective of the young people themselves, the project aimed to:

- Provide a new systematic account of the trajectories and experiences of young people in this situation;
- Use new narrative and visual methodologies to develop multiple case studies that could more directly communicate the young people's own perspectives on their experience;
- Identify key elements, differentiations, and foundations for better practice in relation to young people in this situation.

1.3 Overview

The core of the project was 31 qualitative longitudinal case studies   with young people to provide new kinds of evidence about them and their relationship to education over time. As discussed in the section that follows, this qualitative research is seen as knowledge building in its own right, not simply an illustration or proxy or prelude to larger data-sets such as survey data. At the same time, the project included a number of components designed to explore the larger context and interacting perspectives from which the case studies were drawn. It included adolescent health surveys of the larger cohort, and a one-year follow-up; interviews with parents; interviews with education professionals both in schools and the RCH Education Institute; interviews with health professionals; and retrospective interviews with past clients of the Institute who are now in their 20s (see figure 1).

Figure 1: Keeping Connected Participants and Data Collection

1.4 The case studies

Aims, approach and analysis

The intention of the project design was to undertake a study that would (1) put at its centre the young people and the stories they wanted to tell or show us about who they were and what mattered to them; and (2) focus on identity and on education and social connectedness. The young people were selected purposively from those having contact with the RCH Education Institute in the first half of 2007, in the age range 10-18 years, to maximize variation: to have a variety of health conditions (some since birth, some recent onset); to include girls and boys, and a diversity of demographic characteristics – rural, fringe and urban locations, SES, family characteristics, etc. In each of the 31 case

studies an individual researcher or a pair of researchers interacted with and interviewed an individual young person in their home for up to four cycles of visits over 3 years. Throughout this period case study participants were invited to produce photographic, video and verbal narrative accounts of themselves and their concerns, also to revisit earlier interview conversations and photographs over that time. The interviews and meetings were ethnographic in style, with a broad agreed focus of questions each time, but intended to develop as an extended conversation. In setting up the case studies our main question was not 'how does your health issue affect you?' or 'how are you managing your health issue?' it was how are you managing your life in relation to schooling and other people and into the future? How do you see yourself? What is impacting on you?'

During early interactions at the start of the study, the young people were each given a camera and invited to take photographs that they felt would help provide insight into who they were. Participants discussed these photographs in a subsequent visit by the researcher. This approach provided a window into many of the main influences within their lives as well as providing an extremely good vehicle for starting conversations about their experiences.   Subsequent participant generation of visual material and interviews focused on connections and changes associated with school, changes in their health condition, or changes within family and peer relationships. The longitudinal nature of the data collection allowed new insights into the lives of the young people and was an invaluable way of situating the participants (and their health conditions) within the broader contexts of their ongoing lives and interactions with family, friends, school and community.

The key questions that were the backdrop of each round of visits were:

- Who is significant to them (in general? In relation to school?)

- What is foregrounded in their identity (at different times during the project) – is it the event/illness/trauma? (Where) does this overwhelm other things? What changes over time? Are there patterns of difference in relation to identity between those presenting through accident or disability, and those presenting with chronic illness?

- What are they concerned about in relation to school? What might they miss? (e.g. relationships, knowledge, certification?)

- When do connections/ contact from school appear helpful and when not?

- How do they see the ways others relate to them?

Analytical approaches to the qualitative (visual and narrative) data included thematic coding and attention to narrative form. Two particular aspects of the project distinguish it methodologically: the use of narrative and visual methods as central components of the case studies; and the explicit engagement with the perspectives that different disciplines and different professionals across the team brought to the analysis.

Digital and video materials were coded as a 'narrative' of each individual's story with its own particular themes. Themes were elicited from the photos and the videos, taking into account the researchers' ideas about the unconscious selection of approach by the participant as well as the more conscious selection they communicated to the interviewer. The photos were often the catalyst for the young people to tell a particular story or speak about an element of their lives with the researchers. For the case studies, each researcher took responsibility for coding and presenting the holistic interpretation of each case

that they dealt with; but these, as well as their approach and issues they encountered, were presented to analysis meetings of the team as a whole. Via group discussions team members jointly identified categories for cross-case thematic analysis. These meetings also included several full days of intensive analytical workshops with external facilitators.

New kinds of evidence

The value of this kind of qualitative longitudinal methodology was that it allowed us to examine both direct and indirect evidence from these young people. Directly, they were invited to produce visual and narrative accounts that could be circulated publicly and to professionals as the stories they want others to hear. Indirectly, treating them as research evidence, our research team also analysed the interview encounters and the visual and narrative material produced, this time as indirect as well as direct evidence of the young people's hopes and desires, their anxieties and problems, and the adequacy of their institutional encounters.

We chose to begin the research by inviting the young people to take photographs for a number of reasons. Visual methods are often a more appealing activity for young people than asking them to fill out a survey or have an intensive one-to-one interview with a researcher; and they are also a well-established means of opening up further talk – most people talk more freely when they've got some objects there to talk about, rather than simply being asked to 'tell us about who you are'. We can look at photographs both as evidence about what the person taking the photographs wanted to show us; and also can look for what is captured incidentally, for example about the environment they are in. And photographs can be helpful to return to, to get later perspectives from the young people on what was going on at the time of the photograph, and what they were thinking about then. For conveying experiences to others, photographs can convey some things more immediately or powerfully than words.

To add to the photographs, a range of other methods were used. In each case the researcher or pair of researchers visited and had conversations with the young person a number of times over the study. Later sets of photographs were produced by young people and in some cases video footage; and we had incidental conversations with parents as we visited their homes, as well as an interview with them at the end of the study. In interviews we can see body language and facial expressions, and there are opportunities for young people to return to things that matter to them, or qualify what they said earlier. Visiting homes we can see something of how they and their family construct their environment. Having a series of visits, not just a single data collection, allows a more considered perspective of the meaning of the set of photographs or the talk produced in a single interview.

For example, after the first round of interviews and photographs it was clear that one story almost all the young people wanted to tell was 'we are just normal teenagers' – they had selected photographs to tell that story, and this was an intended message they wanted to give about who they were. At the same time, as we visited and revisited these young people at different times, and recognized some of the work that they were also engaged in because of dealing with their illness, we could see those accounts as evidence: as a deliberate selection on their part – and we could add more to what they meant. Photographs are selected and constructed, just like talk is; they are powerful and complementary as a research tool, but

need to be considered and used critically and carefully in the way that any other research methods are.

A humanistic method but more than just individual stories

Of its nature, the case study makes us focus on the person and what is specific about their situation. That is emphasized even more when we use photographs and stories; and when we take a longitudinal approach where we visit people in their homes a number of times, and where relationships are built. It is a humanistic method in that it does not let the person and their pain and hopes and fears be reduced to some technical guidelines about how to deal with things; you do keep on seeing the participants as people and as individuals. At the same time because this project involved a relatively large number of researchers and cases, and because of the longitudinal form, we were able to use the research team and the cohort of cases as a whole to focus on patterns as well as individual stories.

For example, one issue that was often raised by the young people across the case studies was whether it is helpful or unhelpful to tell the class at school about what is going on. In our interviews we found that some young people were grateful when a school did this, and others really wanted their condition to be kept private. Using a survey approach, it would only be possible to say that this proportion liked this approach and this proportion liked that approach. Using the case study interpretive approach, the research team is able to not only see what participants said about this issue but also what is motivating them and what might be good guidance to schools in the light of the differences in what then young people said they wanted. For example, part of what was motivating them here was their knowledge that in some (but not all) schools making something public would lead to bullying. Generalization from this kind of case study is not just about 'they all say x', but is about showing what is to be made of it when they say different things (for example, that school cultures frame what works; or that these young people need to be consulted by schools as to what they need).

Another important issue that our longitudinal method let us see across the case studies was the 'ups and downs' that are part of the experience of this group: to really see the way their condition affects them as a continuing process over time. This is a finding with important ramifications for good practice: that a process in which there is a physical and emotional ebb and flow needs attention in a different way from something that can be ticked off as a category.

1.5 Other components of the study

Retrospective interviews

The purpose of these interviews was that different insights about the influence of a situation on one's identity and experiences during the school years are possible when one is older and more distanced from it. These are not necessarily more accurate than the views we get from the case study synchronous perspectives but can show us a longer term trajectory, and provide more or less critical understandings of some elements of things talked about by the case study participants. (Note that it proved remarkably difficult to track and contact retrospective individuals in an ethically appropriate manner, and we

are immensely appreciative of the many hours of work done by Tony Potas with Ria Hanewald to make our seven interviews possible).

Other interview groups

The voices and needs of young people, at least in the research and professional literature, are more commonly heard via proxy report through adults and 'experts' than from young people in their own right. Nevertheless we wanted to include some focus groups and interviews with the various relevant adults to see what coherence or lack of coherence existed in the categories, emphases and values they expressed compared with the young people whose stories were the starting point and primary emphasis of the study.

Parents

Initially we had intended to get parent perspectives from parents of other young people living with chronic illness, and not from parents who were related to the young people in the study. This was to make clear to the case study participants that we were not seeking to replace their voice with another. However it became clear interviewing the young people in their homes how close was the relationship with the parents, and that many had no objection to a parent interview, and in some cases talked more freely themselves when the mother was present. At the same time, our visits to the homes soon made it clear that the parent (usually the mother) had a story they wanted to tell, and had their own very important perspectives on the education/health interface and the processes and relationships that had impacted on their child. We negotiated a revised ethics application and permissions (including from the young person) and interviewed the parent as part of the final phase of visits. Two young people specifically requested that their parents not be interviewed and those requests were respected.

RCH Education Institute professionals

Focus group interviews with 11 education advisors from the RCH Education Institute were held in the first year of the study. It was important to obtain their perspectives because, in their role at the time, they worked closely with schools and hospital medical teams in negotiating how best to meet the health and educational needs of the young people whilst they were in the care of the hospital. Subsequently, the Education Advisor positions were replaced with Teacher positions as a result of a review of the organization and new strategic directions which were identified. Nevertheless the interviews help to show some of the issues and tensions experienced by those most directly charged with working across the education/ health interface, and who feel both institutional and individual responsibilities.

Education professionals

To gain a school perspective on supporting young people with ongoing health conditions we invited 26 education professionals from the state, Catholic and independent sectors. Of these, 15 indicated their willingness to participate. Three subsequently withdrew; leaving 12 who were interviewed during April and May 2009. These included 10 staff from schools in metropolitan Melbourne or regional Victoria (three principals, two assistant principals, three student support/welfare coordinators, a classroom teacher, a PE teacher/ Head of House), a manager from the Catholic Education Office and the manager of a special learning needs program.

Health professionals

The RCH Education Institute staff connections with medical teams and clinicians enabled us to obtain 35 names of health professionals who could provide a hospital perspective on supporting young people in their care. Of these, 22 indicated their willingness to participate. Not surprisingly, due to the nature of their work, there were apologies on the days of the scheduled focus groups that took place in May and June 2009. In total, there were 12 participants. Ten health professionals based at the Royal Children's Hospital, and the Centre for Adolescent Health took part in three focus groups. One additional person was interviewed and another responded to questions by email. Participants were mostly senior staff who had worked at the hospital for many years. Their roles comprised three senior clinicians, six senior nurses, a speech pathologist and three occupational therapists. The range of medical areas included respiratory medicine, gastroenterology, orthopaedics, nephrology, general medicine, eating disorders, Victorian Paediatric Rehabilitation Service, and the Children's Cancer Centre.

Cohort surveys

Some 1500 young people are admitted to The Royal Children's Hospital, Melbourne each year as a result of illness or accident trauma, with a sufficiently long-term stay to be registered with the RCH Education Institute. This group of young people experience disruption to their lives on more than one front: the illness/trauma event itself, the situation of being in a different place, a different kind of institution, and often periods of absence from significant others.

Although some basic data is routinely collected about those registered with the RCH Education Institute, and clinicians routinely undertake a psycho-social HEADSS[1] assessment, there has not been a systematic collection of data about these young people's school connectedness, family and peer relationships, or their health risk behaviours.

To address this gap in the literature we planned to survey all adolescents with chronic illness referred to the RCH Education Institute in one year, twice, once in 2008 and a follow-up survey 12 months after the initial survey. The survey included questions about the young people's mental health (depressive symptoms and anxiety)[2] and physical functioning[3], connectedness to school, victimization, family and peer support, and health risk behaviours such as substance use and sexual activity, for which the Centre for Adolescent Health has data from representative samples[4]. This was a web-based survey designed to be completed in approximately 45 minutes although participants had the option of completing in shorter intervals and saving their answers if their health did not permit them to complete it in one sitting. The design of the survey was user friendly; including wording that would be appealing to young people.

Possible participants were to be identified by the RCH Education Institute staff when a young person was referred to them. A clear protocol was adopted to appropriately discuss and enrol the young people into the study. Written parent consent was required

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[1] See http://en.wikipedia.org/wiki/Adolescent_medicine

[2] Angold's Short Moods and Feelings Questionnaire

[3] PEDSQL

[4] Bond et al, (2000) Improving the Lives of Young Victorians in Our Community: A Survey of Risk and Protective Factors. Melbourne: Centre for Adolescent Health

before a young person could take part in the study. Although the researcher who managed this component of the study worked closely with the RCH Education Institute staff, and the survey was strongly and actively supported by the RCH Education Institute management, it became clear by about twelve months into the study that of the 700 referrals to the RCH Education Institute only 200 were being brought to the researcher's attention and of these, about 50% of parents consented for their child to participate. With such low rates of recruitment this component of the study was stopped. No longitudinal data was collected from the 90 young people who had completed the first survey.

Of the 90 participants:

- 66% were female

- Average age was about 15 (range 10-19)

- 28% had more than 5 hospital admissions in the last 12 months

- About 50% lived in metropolitan Melbourne

- 92% were attending primary or secondary school

- Age of diagnosis was between 10-14 years for 40% and <5yrs for 30%

In terms of mental health and health risk behaviours:

- Higher rates of depressive symptoms (31% females, 23% males) were reported than representative samples of adolescents (being 23% and 12% respectively

- Lower rates of smoking (92% never smoked) were reported compared with representative samples (40% never smoked), lower rates of binge drinking in last two weeks (8% vs 17%), and never used marijuana (94% vs 80%)

- School engagement, feelings of belonging and participation were high, although only 58% believed that they could go to their teacher 'with things on their mind'.

These are interesting findings; some showing that these young people's circumstances are similar to others their age, some indicating their circumstances are better, and some worse. The use of substances was likely to be under-reported given that the young people were completing the survey in a setting where they would be aware such behaviours would be greatly discouraged, generally and because of their ill-health. And of course, given the fact that this was not a representative sample of young people in the hospital and referred to the RCH Education Institute, we cannot say much about the health or health behaviours of the group as a whole. Given these interesting findings, it was regrettable that we could not continue with this component and in particular, could not collect any longitudinal data. The difficulties encountered in implementing this survey related particularly to the context of the institution through which recruitment took place as well as to the particular health circumstances of the population being surveyed. These issues are pertinent for others to consider if developing research protocols and ethics applications for a studies with a similar focus.

Database analysis

An initial step of the project was to review the RCH Education Institute database in order to build up a picture of what was happening to clients over time. For example, the

length clients stayed registered with the Education Institute, the number of contacts they had with the Education Institute, as well as summarizing data by age, gender, city or rural, condition etc. These data were useful for describing the population seen by the Education Institute, and for reviewing the categories of data being collected at that time (for more information see Appendix A: Client Database Audit Report).

The database analysis also proved to be an important part of the early relationship building and partnership work that has been a sustained feature of the success of this cross-institutional collaboration. Part of the motivation for the RCH Education Institute to become involved in this Linkage Project was that the organization was seeking research evidence to inform their approach with young people, as well as seeking to draw on the expertise of the Keeping Connected research team to help build the research capacity of staff at the Education Institute. Tony Potas was heavily involved in the database analysis and drew on this involvement to inform the recent review and redevelopment of the Education Institute database platform and associated record keeping practices.

The RCH Education Institute currently has a burgeoning research capacity of its own, but was only beginning to develop this focus at the point that the Keeping Connected collaboration was established.
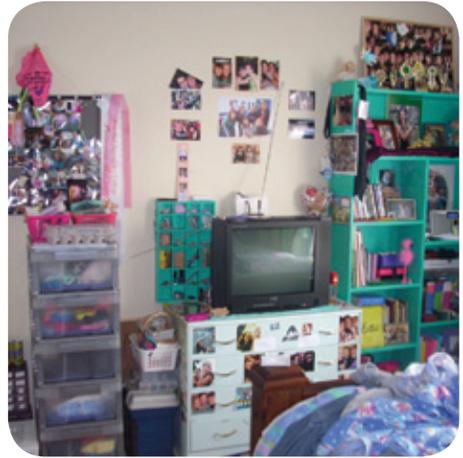
2. Keeping Connected: Young people, identity and schooling

2.1 The case studies

Introduction

The central focus of the Keeping Connected project was to investigate over a three year period the lives of 31 young people to build a picture of their perspectives on themselves and their experiences of living with an ongoing health condition. Our approach resulted in narrative and visual accounts in various forms, including semi-structured conversations that continued and were revisited over extended time periods. The longitudinal design of the study, the range of conditions within the group of young people, as well as the diversity in social background and geographical locations of the participants fostered the development of rich and detailed data.

The young people lived in Victoria apart from one young person from Tasmania, and another who relocated to Queensland through the course of the study. The mix of age, gender, and health conditions are summarized in Appendix B. The group lived in a diverse range of family and social circumstances which influenced their narratives significantly.

As the study was longitudinal the importance of the themes identified in these narratives varied for any given individual at different times of the study. Most of the young people had periods of stability, optimism and confidence as well as times of crisis and concern. We started by asking the young people to tell us about their lives and invited them to take some photographs to show and tell us about themselves. We asked them to do this again at several points through the study. Some photographs are included in this section.

Fixed generalizations (of the kind 'all young people are x') were not easy to make about the participants and their lives, and few, if any, apply to the entire group. However, key patterns of commonality and difference (of the kind 'young people in this situation are trying to negotiate school') did become apparent through analysis. Even here, one of the things we found was that over time and with changing circumstances in the participants' lives, many of the themes identified came to have almost opposing manifestations. For example concerns about visibility were countered by concerns about invisibility, evidence of resilience was apparent but so was evidence of vulnerability.

The majority of the 31 participants revealed their commitment to achieving long-term goals in spite of significant and often repeated instances of illness-related interruptions and hardships that they experienced, complicating and challenging their access to and participation in education – almost in defiance of their ill health and its dominance in their lives.
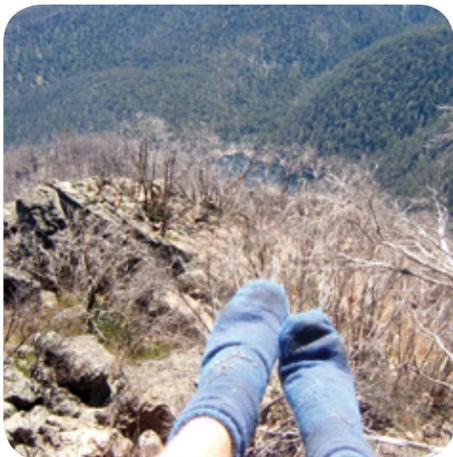
Identity work: Navigating illness and feeling 'normal'

Well, before chronic fatigue I was the popular sporty academically awesome kid and now I'm none of that any more. I'm not sporty, I'm not popular and I'm not academic because I can't even get to school any more and so it's just ruined my life completely and I hate having it so that's me now. (Heaven)

I love playing sport. I am an ex-football player but that was quite a few years ago. I've given up playing footy – I just play cricket.…The good thing is, friends accept me for who I am, so they see the person inside and I'm the same with them. (Joe)

Collectively the participants took hundreds of photographs full of vivid pictures of friends and activities. They reacted to the task of taking photographs with a sense of energy, recording their interest in fashion and music and showed their bedrooms being decorated with posters of pop stars and sports heroes, like any other young person. They also demonstrated their sense of humour in this process. This was the story that most told initially—a story of regular teenage identity. Early in the case studies most participants hardly touched on their illness at all —and it was only later that they began to reveal more complicated aspects of their lives.

Adolescence is a term used predominantly in the fields of psychology and biomedicine to describe what is understood as a specific period of physical and psychological development, and to accentuate a developmental change from the dependence of childhood to the independence of early adulthood. It is understood as a time where young people undertake significant exploration of personal identity and values. It is also understood as a period that can be fraught with change and experimentation, potentially placing young people at odds with the influential adults in their lives. It can be a problematic time for many young people, but for the group within this study the impact of their health condition on their lives brought an added layer of complexity to this period of transition.

One clear message told by almost all the young people in our study was that they were 'not their illness', in the sense that they did not want it to define their identity. Rather they portrayed (and described) themselves primarily as 'typical' adolescents with adolescent interests as much as their health condition allowed. They described how their illness was sometimes in the background and sometimes in the foreground of their lives. Some key points made by young people about living with a chronic health condition are summarized below.

- My health condition sometimes reduces the options available to me but it doesn't define who I am.

- I have a strong sense of who I am and the relationships that are important to me such as my family, my friends and my pets.

- I really enjoy sport and other physical activities and try to do as much as I can manage.

- I'm determined to have the best quality of life I can get.

- My perspective on life is shaped by the challenges I've faced and how I've had to deal with things.

- I find it hard to decide how much to tell my boyfriend or girlfriend and other friends about my health condition.

- Sometimes I find it helps to talk to other people who've had a similar experience.

- Sometimes I just feel like spending time with my pets.

Pip and Mary-Kate described the pressures caused when health issues work against efforts to live a 'regular' lifestyle:

> *If you actually keep thinking about you having the diagnosis with something – you're just going to keep thinking about that and you're not actually going to get on with your life. You just have to get over it and thank God for what you've got. That's how I go…Yeah one step at a time and I think I've learned my lessons from this as well and I think it's kind of changed me as a person. (Pip)*

> *[It's hard] to make plans and go to parties because I never know when I'm going to be sick, so it's pretty hard. I'd say that I'm good with family and I love pets… It's hard for me… but I'm getting through it. Me and mum are getting through it. (Mary-Kate)*

The participants in the study told us clearly that they were trying to get on with their lives as much as possible, while dealing with the challenges that life, particularly in the form of their health issues, presented them with. However, their health conditions were only one aspect of their lives and they were actively trying to make the most of their often difficult situations. They also negotiated their way through a range of family and social issues, with some having more success than others. However, all of the young people were determined to live interesting and rewarding lives.

Identity and place

For many of our participants – and for the researchers themselves – the physical, domestic environment and human geography formed a vital part of their telling of 'identity', and our interpretation of it. This was particularly evident in the many situations where participants lived in rural, regional or outer suburban areas. This emphasis on place and landscape in young people's stories helped us understand the great range of social circumstances that our participants were living in. An important message from this group was that it is easier to say 'I am not my illness' in some circumstances than in others, and that some participants were able to draw strength from different things than others.

For example, Millie lived a chaotic, almost transient lifestyle, during renovations to alternative accommodation necessitated by a house fire, but the chaos contributed very positively to both her identity and her very evident ability to cope with a range of challenging circumstances. At one point the two researchers working with Millie thanked

her mother and stepfather for sharing their home and were abruptly told that this was not their home, that they were not 'trailer trash'. An associated sense of persistence permeated much of the household, and seemed to have become a kind of defiance in Millie herself. Millie loved the natural beauty of the surrounding countryside, and like the rest of the family was oblivious to the clutter and impermanence in her household. Factors at work here were rural lifestyle (horses, dogs, chores, an occasional barter system of employment for her stepfather and sporadic town work for her mother) and distance from central facilities in the nearby town. This freedom to live in an idiosyncratic manner might create anxiety or poor self-image in a more affluent urban or regional centre, yet for Millie it provided an environment in which she had the social freedom to assert herself as much more than her disease.

Hilary, by contrast, had a more orderly and permanent home environment in the outer suburbs of a large regional city but the environment which contributed most to her resilience and identity was her secondary school. Her first secondary school was a disaster as bullying was not adequately addressed, but her transition to a new school appeared to have rescued her and set her life back on course.

Normalcy and visibility

Whether directly or indirectly, all the participants illustrated a strong desire to be perceived as 'normal' adolescents, living as many possible elements of regular adolescent lives. When participation in these regular activities was realized it was celebrated and made a major contribution to the young people's sense of wellbeing. However when there were medical setbacks, there was often an overall deflating effect for the young people.

Heaven had left regular school during junior secondary years and done a year of part-time distance education before returning to her previous school for her senior secondary years. She described the process of getting back to regular school, the excitement of preparing for her school Debutant Ball, and the lack of focus afterwards.

> Well it was hard, it was really hard at the start [of the year] because like I just didn't want to be there [at school] because it was too hard like to get up out of bed and go there but then it wasn't so much about the fact that I didn't have any friends or anything… and then I started to make heaps of friends and yeah now I'm there [But] afterwards I sort of went through a slump again because it was such a big thing to look forward to that like I sort of had nothing left after that, it felt like. It was a really great thing at the time but then it sort of, there was a bit of repercussion afterwards. (Heaven)

This desire for a sense of 'normalcy' created some social and management dilemmas for participants particularly at school. In their quest to fit in and appear normal, many slipped under the radar altogether, and missed out on required educational support. This raised significant issues of identity management or 'visibility' management for the participants.

Participants who had visible signs of their health conditions described how that influenced the way others reacted to them, especially in cases where these were misinterpreted, changed or disappeared over time. In terms of identity, Sophie's view of

herself was largely positive – she said teachers saw her as a good student and she tended to be the centre of her friendship group. When she started TAFE she was able to establish friendship networks reasonably quickly. However two matters related to her condition had a difficult impact for her. The illness and weight-loss associated with her health condition began in her teenage years, in year 10, and it took a long time, well into Year 11 (and many different doctors and bouts of hospitalization) before a correct diagnosis was reached. Sophie was hit by this not only in terms of the physical debilitation, but psychologically. She particularly resented her condition potentially being mistaken to be an eating disorder and she was also very self-conscious when she first went back to school after her hospitalization and had a visible tube.

Image was important to Meredith (fashionable clothes, shoes, and her overall appearance) and there were many examples throughout her photo portrayal. She described how appearance had played a role in how she was treated post her accident. Initially when she returned to school she had a shaved head and prominent scar, but within a year her hair (and therefore her appearance) was back to her old self. She described how when the scar was evident she was treated very supportively by everyone, including teachers. However, once her hair grew back she was *treated as normal again, even though I was still experiencing the problems associated with the injury*.

Both examples point to the ambiguity and dilemmas involved in this notion of normality, particularly in terms of participating in education. Others found a degree of invisibility allowed them greater normalcy, but came at a cost regarding consideration and support in education. Brendon described his return to school after a major operation:

> When I came back from hospital a fair few of [the teachers] just sort of, I mean they were probably trying to help but it kind of made me feel like I was an idiot like they were saying, they were giving me easier work to do which I probably needed but it just… I think the other kids' sort of thought I was odd.

And yet others preferred their health conditions to be totally visible. After she got back to (primary) school the first time, Angela gave a talk to her class about her illness. She decided to do it *because there were rumours about why I was away and people kept asking me about it*.

Resilience and vulnerability

The young people in this study did not use the term 'resilient' to describe themselves. This did not appear to be due to excessive humility, but rather that they simply did not perceive themselves in those terms. However, those around them (parents and health professionals) regularly referred to their resilience, often specifically using that term. Joe was one young man who acknowledged his health condition had impacted on his life in several ways yet he made considerable efforts to participate in activities of his age group. Joe described himself as located consistently within a particular group of friends. Because he had a genetic condition that his mother and grandmother also had, he was close to family members who understood what he was going through and who were keen to help him set up a positive future for himself within any limitations that might accompany development of his condition. Joe had a strong interest in cricket and football but because of his health

could no longer participate in these sports. He had made efforts to get involved in sports umpiring as a way to stay involved in these activities and to keep connected with the community that it offered. Joe's situation suggested that social connection was something he worked hard to achieve and maintain and it appeared to be something he persistently and actively pursued.

In conveying their stories and experiences these young people have shown that in spite of diverse social circumstances, strengths and sources of support, they all negotiated identity issues around being different and being the same. Central to that identity work are the considerable efforts these young people made in order to do - and project an impression of doing – 'normal' things.

There are four key inter-related elements of these dilemmas. The first element is how adamant young people are not to be defined by their illness; but their experiences also illustrate that it can be easier not to be defined by ill health in some circumstances than in others. The second element is how loath young people often are to be seen as visibly different to their peers and the significant extent to which young people value being seen as normal, participating in regular activities similar to their peers, and working to fulfill regular/normal ambitions. The third element is that, as a byproduct of these efforts to avoid being identified as different and to make the most of their lives, these young people are often seen by others as resilient. However, being viewed as resilient and coping well is a double-edged sword because it can hide significant vulnerability, including a tendency towards emotional distress. The final element is that passing as the 'same' in spite of health-related difference can also make accessing support and achieving regular goals more difficult. In combination all four elements that characterize these dilemmas have distinct potential to cost young people access to valuable support and resources.

Connections: Belonging, achieving, struggling

And yeah, it's hard at school…like I'm a step behind because I'm constantly, you know, I can't pay attention in class because I'm tired and stuff and I miss days that I'm sick. So it's like at school I'm playing from behind at the moment just trying to catch up, constantly trying to catch up. (Luke)

[My first] high school it was pretty much a lot of negative – negativity around my life and getting to [my 2nd high school] just brought me out of that a bit. Yeah just learning to find the positives which has been really helpful because a lot of the time I've been surprised that I don't have depression because of everything I've been through at school and like socially and emotionally and that sort of thing so I'm quite happy that I haven't got to that point. (Lillie)

The stories young people initially told about themselves (about being like any other teenager) gradually became increasingly complex over time. For many the upbeat narrative of coping well and being resilient gave way to tales of their significant challenges and periods of distress, anxiety and disengagement.

Education and school

I saw the Principal and he's like 'Now you can always come back and use our resources like the library and the computer lab and all that and not consider yourself as not a student [at the school] because you always will be. We all love you here', and because I've always been like a perfect A grade student like I've always had straight A's and like I've never been in trouble or anything. Oh God that sounds really selfish but… they were all kind of sad to lose me and stuff and I was really sad to go but having him say 'Don't think of yourself as not being a…[name] College student' was really good, like it really touched me in a way and made me feel like important to the school. (Heaven)

Remaining connected with school, both academically and socially, was an ever present and challenging issue for most of the young people. Connection with school varied considerably across the group but education remained important, even when school became problematic.

I suppose the most important thing to do is always stay on top of all your schoolwork because…the reality is you get back to school and you're really behind and you have to try and catch up and everything. Yeah, there are a lot of things that make it difficult like all the thoughts that keep going through my head about my [health condition] and stuff, so you know it's a bit hard, like socially sometimes as well, and they're the things that go through my mind,[that] sometimes make it hard to concentrate on school work. (Greg)

Forming and maintaining social connections was seen as particularly important to most of the participants. Fiona was 18 when she was finally diagnosed with her condition in April 2007. In Year 11 at the Catholic College in her large regional town, her parents had separated the previous year and she was living with her mother and three younger sisters. Prior to the onset of her illness, she was a highly motivated, achieving student and an elite cyclist who had won Victorian titles, a bronze medal at the Oceania Games and was training for the ' Nationals' in Sydney. Admitted to the Royal Children's Hospital in late March 2007, she spent three months in hospital followed by three months as an outpatient attending the hospital daily.

For Fiona, as for other young people living in regional and rural areas undergoing an extended stay in the Melbourne hospital, the experience was one of greater isolation from friends than for young people living locally to the hospital.

From the perspective of the young people, responses of schools to their health issues, absences and associated needs in education were often inflexible, confusing and erratic. The young people were frequently not consulted within their schools and important decisions were made about them that added to their alienation.

> *Well at [my new school] they [the teachers] pretty much say: 'Tell us when you're not feeling well'….a teacher [from my old school] said to me: 'If you're not feeling well, do what you have to do'… I mean it didn't seem as though she cared, but she meant you can go to the sick bay or you can just go outside and sit for a while. (Nicola)*

What troubled Nicola, in particular, was the lack of understanding and interest on the part of the teacher at her former school who also told Nicola that her continued absences, due to hospitalization, meant that she would be unable to produce the necessary folio for Visual Communications and that she should choose an alternative subject. The other subjects on offer did not interest her, so Nicola changed schools, managed to complete Visual Communications and has now begun a fashion design course that she studies part-time. This type of inflexibility on the part of the teacher was not an isolated case, and also featured in the school narratives of other participants.

Many of the young people stressed the need for greater consultation and improved communication so that pathways and support could be negotiated to assist them through the challenges and disruptions they experienced. The comments below each point to this pressing issue and are summarized in our words:

- *Going back to school after having time off [because of illness] can be a big change and it makes things easier when teachers and schools are flexible with how much work I can manage at different times – options to do more work at home would help – as long as it was something I agreed would be helpful at the time.*

- *I like being able to talk things through with my family and my teachers and tell them what I can manage.*

- *I usually find one person at school who I can talk to, maybe a teacher who knows something about my health condition or is just really supportive.*

- *I really appreciate it when a staff member at school keeps an eye on me and asks me how things are going, particularly after I've been back at school for a while and it is easy for people to forget I might still need help with stuff.*

However some participants preferred to keep silent about their health issues at school in order to maintain a low profile. This meant that negotiation of appropriate educational support was difficult.

I didn't want anyone to know anything about my condition, not even my teachers but my Mum had told my teachers. The more that my Mum told about my condition the more I just got used to it and got over it. And so then for me it's better to be safe than sorry; I tell my friends what my condition is in case something does happen to me; they know what's wrong with me and they can call the teacher or whatever just for safety reasons. (Pip)

Several young people reported a particularly positive experience at schools where innovative Year 9 programs, seemed to work very positively. In these cases, the Year 9 program was not singling them out, but did seem to engender a generally more positive interpersonal set of peer relationships. For example in the final year of interviews Nancy was in Year 9 and much more talkative and positive about her year at school. Both she and her mother in their final interviews made it clear that this had been a transformative year for Nancy.

A small number of schools had systematic and efficient support in place, but young people mostly received support as the result of one interested teacher who took it upon themselves to act as communicator and advocate.

Yeah [my teachers are] really good. My English teacher at the start of the year she had depression and she still suffers anxiety and stuff so she was really supportive and she moved to South Africa for the rest of the year so she still emails me and stuff which is really good and she sort of has been emailing the other teachers to make sure that they're still understanding and that sort of stuff as well. (Heaven)

In other cases school support was ineffective or actually caused additional concerns for the young people.

Yeah and like I'm trying to catch up on my work like when I'm there I just forget about everyone else and just do the work but like if you need help you ask the teacher and it will be like wait a second and then like twenty minutes later they're like 'Oh so what did you want?', because they're too busy dealing with the kids and like I've been trying to catch up like going to catch up classes after school which they're an extra hour and like just doing my work at lunch and stuff so I've been trying to catch up. (Mary-Kate)

Chrons disease – it doesn't affect me much any more because of the operation except before it made me get lots of stomach aches and then because the medicine used to give me nausea and that made me miss a lot of school yeah…When I had the operation I missed a lot of subjects and the teachers didn't really follow it up or anything yeah and they didn't give me any work to do or anything... I missed

three weeks and then it was just the holidays after that… only my coordinator [knew I was off for an operation], the teachers didn't know. (Bob)

Bullying

Instances of bullying were common across the group of young people in this study, sometimes verbal, occasionally physical and often via the internet. A number of the young people or their parents reported instances of bullying on the school bus. In some cases this was resolved after parent complaints or alternative transport arrangements were made.

For Hilary, the physical manifestation of her condition led to bullying. Initially her former friend started calling her a 'hunchback', and other students at the school joined in. The school did not address the issue adequately despite repeated reports by the young person and her family. Eventually this was resolved by changing schools. Kylie was bullied at school and on MySpace, and when she was physically threatened (with her leg held together with a brace and pins) the school responded by wanting to put Kylie and her tormentor together in the same room to 'sort it out'.

The denial of a teacher aide meant that Kylie was reliant on the goodwill of her fellow students for assistance and this dependence had a profound effect on her friendship group. Kylie expressed gratitude for the support of two girls who wheeled her into class and were themselves late as a consequence. She described a culture of fear and intimidation, which permeated her school. A falling-out with one girl resulted in the girl 'Making up all this stuff about me,' and posting it on My Space.

One mother shared with one of the researchers a post she had made on her own Facebook site:

> *My beautiful girl has just turned 16, not bad considering I was told she would be dead by the time she was 12 months old huh!!!! Over the years she has always been a fragile wee girl and we didn't know what was wrong with her – people calling her an anorexic mole, and to go eat cake!!!! Little do those people know she has a rare muscle disease, heart defect, lung disease and has just had high risk corrective surgery for her spine, all due to a rare genetic disorder!!. (Parent, Facebook entry, 2009)*

Inappropriate and insensitive remarks by teachers were also reported by several participants. For example, Simon reported that one of his teachers had referred to him as a 'cripple'. After Simon's friend jumped to his defence, and tempers flared, both boys were subsequently suspended.

Hospitalization and disconnection

All of the young people had periods of long term hospitalization. Some were regular scheduled visits, but for others returning to hospital occurred unexpectedly. The young people described the impact of being separated from the support of family, friends and being away from their familiar home environment.

Family networks were reported as maintaining the young people during their initial and ongoing periods of hospitalization, providing high levels of support and care, and over

extended periods of time. For one young woman whose life has been transformed by a liver transplant, family mementos are tangible reminders of their support that she cannot remember because she was so sick at the time:

> *My auntie, she gave me balloon flowers that have almost died. Yeah, they've almost lasted a year. Almost. Umm. And Mum and Dad got me a little jar of jelly beans and on top of it it had a smiley face. So I've still got that and it's still filled with helium. Yeah, there are still little tiny trinkets that I've still got from the hospital that make me remember. (Nicola)*

The young people also spoke fondly and otherwise of hospital staff who cared for them, and in some cases this was over many years. One of Angela's photos was of her and her doctor posing with heads together, his arm around her shoulder. In the background children's paintings, drawings and letters are tacked to a noticeboard. The picture exudes warmth:

> *[My doctor] is the nicest person, he's the nicest doctor I've ever had and I love him to bits. He always takes what I want and me into consideration and never does anything without my consent. He's got us involved in the Gutsy Group which is a support group or chrons and colitis patients and he's just a really good friend as well as a doctor, so yeah, he's really helpful to Mum and Dad as well. He explains things really well. He's an all round good guy.*

Likewise they reported on the friendships that they developed during their hospital stays. A common concern expressed by the young people was the frustration over the restricted access to technology such as MSN and reliable communication with family and friends via their familiar social networking and email connections. Electronic methods of communication were important for many in terms of remaining connected through absences, as Patricia explained:

> *I don't know what I'd do without it [MSN, email and text messaging] because like, while I'm out of hospital, that's how you stay in contact with hospital friends and when I'm in hospital that's how you stay in contact with school and stuff. A couple of weeks ago my phone and my computer died in the same week. And then I had people sending me emails saying, 'Are you alright? Are you sick? Are you in another country?' Because like I hadn't been on and they were amazed like it was a week and I hadn't been on. (Patricia)*

Access to this media created some quite strong bonds. Sophie's hospitalization had one unusual up-side – spending time on the internet that year she made contact with a boy in Sydney, whom she invited down for her 18th birthday, and who was to become her fiancé.

Young people who experienced long term stays and more frequent returns to hospitals spoke about the loneliness and isolation, yet they also remembered the comfort they gained from the simple everyday occurrences such as receiving gifts, cards and visits from classmates. For young people whose families lived in outer urban or rural areas, hospital visits were less frequent. Once at home and away from the hospital environment the young people stressed the need for friends and how significant their presence or loss had been on their identity and wellbeing. Lisa, before her stroke, had been a student who was taking

an academic VCE course and excelled as an 'A' grade hockey player. Her sense of social exclusion began with the school administration who told her family that perhaps this school was no longer the place for her. Moving on and getting a fresh start in a new school interstate was a major step for Lisa. When asked what she was looking forward to in her new school she did not mention educational opportunity. The desire to be connected socially was her first priority:

> *Researcher: So what are you hoping for when you move to that new school? What are you looking for… for you?*
>
> *Lisa: I don't really know. Just to find friends.*

Social connections of all kinds were very important to most of the young people and many had experienced some degree of social isolation as a direct consequence of the demands of their health conditions. The participants reported that family members were particularly important. Both Greg and his father really enjoyed the freedom and beauty of the mountains and Greg shared many photos of their hiking expeditions:

> *I love the scenery … being away from everything … gaining altitude …I have a bit of an addiction to it. … I just love the feeling of, you know, when you're up there and you can just spend your lifetime doing it. … I just love it …the trees are awesome.*

For many of the young people pets were a particularly important source of support. Angela described her dog as:

> *psychic, she can tell when you're upset, I think it's an animal thing and then she will come in and give you the big, she's a cocker spaniel, so the big droopy eyes, 'Oh, what's wrong?' … just really cute.*

In two cases the young people went to great lengths to ensure that when the death of a pet occurred they provided the celebration of life that equaled the closeness and intensity of the importance of the pet in their life.

Again, in our words for brevity, these are some of the strategies young people told us were useful in managing their health conditions and enabling social connections to stay strong:

- *I think it is important to tell my family and my doctor how I am feeling so we can manage things together.*

- *Sometimes things feel out of my control but I know I can rely on my family and friends for support.*

- *I enjoy having something to look forward to and I love going on holiday with my family.*

- *My family encourages me to make decisions for myself when possible.*

- *I've become really good at setting goals for myself and prioritizing things so that I don't feel overwhelmed.*

- *It is great chatting to friends on the phone or online, especially when I'm in hospital or away from school.*

It is clear that many of the participants were committed to remaining connected to school, both academically and socially, as much as they could. However, they faced many difficulties. Overall these young people strongly valued their relationships with friends, teachers and hospital staff who worked to help them stay connected and feel valued in spite of their isolating circumstances.
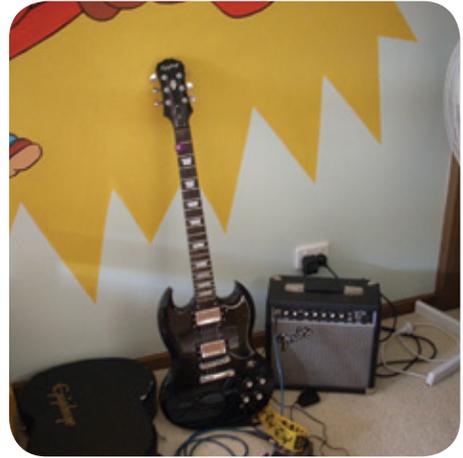
DANCE
Like no-one is watching
LOVE
Like you've never been hurt
SING
like no-one is listening
LIVE
Like it's heaven on earth.
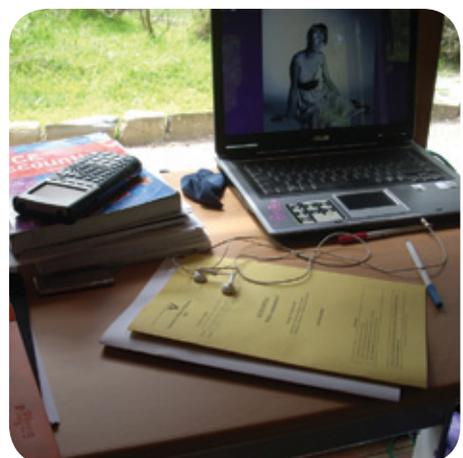
Aspirations, pathways and trajectories over time

I'm thinking of becoming a paramedic now. With all my background and stuff, I find medicine pretty interesting… I'd like to interact with patients and with being a paramedic, you've got to interact with people. You're the first ones there and I just think it would be a rewarding job. (Ben)

Almost all of the young people in the study had long term aspirations that were very important to them. Many of these had a link with their educational goals and many were derived to some extent from the life experiences with their health conditions. Some specifically made the point that their desire to work in supportive or caring professions or careers such as teaching and health was partly because of the support they had received from people working in these fields. Brendon was planning to gain entry into a marine biology course. A combination of the rural area where he lived and the social disconnection by his condition led to an increased importance on the pets in his life. This led to family trips around his interests such as whale watching and diving with whale sharks and an after school job at the local zoo. These experiences influenced his move towards university much more than anything he had done at school. Although still only in Year 10, he already knew the structure and offerings of the course he wanted to undertake, along with entry requirements and had already begun to think about how he would manage living away from home. Francis mentioned in the early stages of the project that his background and life experiences had influenced his decision to become a teacher. He entered university in the second year of the project and was achieving success which he admitted required some negotiation with the university and some careful management.

Like any cohort of young people, not all aspirations were focused on university education. These aspirations included becoming a florist, a child care worker, a landscape gardener, a fashion designer, a teacher, a nurse, a lawyer, and an IT specialist. Meredith described a desire to become a funeral director. She explained that a family member had died recently and that she realized what an important supportive role funeral directors played for people during such times. She had always aspired to a career helping others and she felt that this had probably been influenced by her own health.

Many were aware that as important as aspirations were to them, there were always health factors to be considered. As Angela described:

Everyone is going: 'Oh can't wait till the holidays', I'm going: 'Can't wait till the weekend'; that's as far as I'm looking ahead just for now. Like, I'm saving up for my trip around Europe, but … when I book plane tickets, it will be really hard to set that date in case something happens…so I kind of live from week to week rather than looking so far ahead. I know I want to be a novelist but whether that happens this year or when I turn 30 it doesn't really matter.

Realizing aspirations, no matter how seemingly small to others, had a major positive impact on the young people's sense of achievement and wellbeing. From the beginning of

the study, Simon had commented that his main regret was not being able to play soccer, a sport he loved. During the years of the study his physical condition radically improved in ways that had direct and clear impacts on his daily life. At the commencement of the study his health condition was very debilitating and he spent most of his time in a wheel chair and was unable to walk unassisted. By the end of the study he had grown to the height and weight of a typical adolescent and had totally discarded all walking aids and could in fact kick a football around (although he still had to be careful of physical contact). The newly acquired ability to kick a ball with his mates filled him with optimism and he mentioned it several times during the final interview. Interestingly life now had begun to present Simon with a new set of challenges as a result of his improvement, not the least of which was the testing of new boundaries and learning to grow into his 'new' body.

For some participants the absence of goals and achievements clearly had a negative impact on their lives. When she was in Year 8 Megan suffered a completely unexpected stroke which left her with both a physical and intellectual disabilities. This clearly had a very major impact on her life and throughout the time of the study her state of mind was still one of shock (and even anger and grief to a degree). She lived with her father who retired early to become her full time carer, and although she had not completed school by the end of the study they both spoke about the great uncertainty and stress this would bring. Megan's life through the time of the study was one long stage of uncertainty leaving her angry, confused and unnerved about her potential future and finishing school heightened this fear. School highlighted for Megan what had changed in her life and so her relationship with school and teachers altered dramatically. Both Megan and her father said she was a competent and happy student prior to her stroke but afterwards it seemed to become something of a battleground.

Unlike most participants Megan did not have any clear idea about what she wanted to do in her future and for most of the time of the study she was not academically engaged. In fact by the end of the study she had still not returned to full time school. As Megan's situation fell outside the experience of those guiding students through career choices at her school, no advice about alternative options had been offered. She (and her father) were simply told what support money could be accessed once she finished school. Despite their enquiries there was no help to find out what options might be open to her in terms of career pathways. This further heightened the sense that her life had simply been cut off by the stroke and increased their frustration and anger. However, on the last visit Megan reported that while at school she had been placed into a mentoring role with some younger students and had loved it and was thinking of going on with school to get some qualifications in childcare in the TAFE sector. Once this goal was present she became much more purposeful and focused and much of her confrontational behaviour diminished. Megan's story illustrates how important ongoing, targetted support will be for her to continue to capitalize on the positive developments in her life and be successful in realizing her new aspirations.

Transitions

The age range of the participants in this study (from early to late adolescence) meant that the transitions that many experienced included: the move back into school after prolonged absence; the transition from primary to secondary school; a change of schools, transition

from school into further education or the workplace as well as transition to adult hospitals. Transitions represent a disruptive time for many young people and were particularly difficult for the young people in this study.

Change of school was an issue for many participants, whether as part of regular transitions or as part of specific parental effort to find a more 'suitable' school environment, and was often complicated by their health condition. There were additional events and issues that had a cumulative effect in terms of challenges they had to confront, the greatest of these being those related to their health. Dilemmas faced by the young people relating to change of school and transition included:

- Change of school to find a more supportive culture and/or a fresh start;

- Moving school into the background for periods of time so school-related issues that may have presented as problems are seen as less significant;

- Acceptance of partial disengagement with school through broken attendance and day-to-day priorities, but a longer term link with educational ideals and goals retained; and

- The central role of family in both general support and mutual/supported decision making.

When encountering problems and changes they clearly participated in pragmatic decision making, prioritized the issues in their lives and acted proactively to minimize the longer term impact of risk factors and enhance protective ones.

> *Yeah once I had [made the decision to change schools] … I felt a weight had just lifted off me. … instead of being treated like a child, I felt this is me, I'm doing what I want to do, not what somebody else is telling me to do. (Nicola)*

These changes were often disruptive socially. For example, Hilary's transition to secondary school coincided with a major operation involving the insertion of two titanium rods into her spine. She missed the last month of primary school as well as the usual rite-of-passage celebrations involved in this important time of her life. Throughout the summer holidays she convalesced in order to begin secondary school on the first day of term. Hilary was required to wear a bulky, loud-yellow brace on the outside of her school uniform, to protect her newly straightened spine. Instead of being able to blend in with the crowd—which is certainly a desirable thing at all beginnings, but more particularly so at a new school in early adolescence— she stood out clearly and brightly and was acutely embarrassed most of the time. Her initial impressions of secondary school were; 'I like the teachers in the classes and some of the students but some of them are giving me a bit of a hard time'. However by the end of the second term, Hilary had changed schools. She withdrew from the local secondary college, three blocks from her home, in order to catch a bus to the single-sex Catholic college on the other side of her large regional town. The major reason she provided for this change of schools was the family's dissatisfaction with way the school responded to her reports of persistent bullying.

Hilary's story was not unique among the other participants. Others experienced less embarrassment, but no less social disruption. Hamish had a serious, life threatening health issue, the symptoms of which manifested during Year 5 although it wasn't diagnosed until

he was in Year 7. His transition to secondary school coincided with a particularly anxious time in regard to his health. As soon as he had undergone an operation he was determined to get straight back to school:

> *After the radiotherapy it was like the first day. I went straight to school. That's how I wanted it, to get on going with school.*

He and his mother decided it was a good idea to move to a different secondary school than the one most of his primary classmates had chosen to attend. He continued to speak of the primary school with warmth and clearly had fond memories of the teachers and students and the overall culture of that school. By contrast he was always somewhat reluctant to talk about his new secondary school and the impact of his absence during this transition seemed to adversely affect his friendship group:

> *Because I wasn't there [at the start of secondary school] my friends all split up and I think one of them said I was the one that was keeping them together. When I got back with them they were calling names to each other and I felt like I had no friends.*

Hamish's mother commented that her son,

> *Tended to retreat and I think it was because we were visiting doctors, missing school …he was sick a lot …kids didn't understand it and he got excluded. That was what happened when (he) got to high school.*

The social dislocation remained with him right through the three years of the study and was never really resolved. In the final interview at the end of the study Hamish still described his biggest concern as a 'lack of real friends' although by that time he had managed to catch up with his schooling and was choosing senior subjects that would get him into university.

Conclusion

Much of the data within the case studies tells a story about optimism, courage and hope, but there is also an ever present undercurrent of struggle and challenge. As Heaven explained:

> *I don't think anyone understands I really don't. Unless you've had [a chronic illness] and you go through it like you can read all the information about it but no one knows because like I find that there's no real word that I can think of to describe the pain and there's no real word to describe the depression or you now losing all your friends and completely like it just completely ruins your life and I don't think people really understand that.*

The lives of young people in this study are characterized by significant health-related highs and lows, successes, achievements, frustrations and disappointments. For young people living and learning with chronic illness the experience of adolescence is heightened by additional personal challenges that impact in a variety of complex ways on all aspects of their lives, and where the kinds of support they get from school can seem haphazard or

inappropriate. The management, with support of family and friends of these complexities and challenges is central to their lives, but longer term aspirations and goals appear to assist in bolstering resilience and optimism despite short term crises and setbacks.

Minor aspects of life can take on expanded importance as the struggle for some semblance of normality as a 'typical' teenager continues. This desire for normality can at times inhibit the effectiveness of support frameworks and intentions as the young people actively work to become less visible in places such as school in an attempt to downplay the major difference their life represents. While passing as 'normal' amongst their peers has a range of social and personal benefits for these young people, it also has the potential to bring later repercussions. This can occur in relation to inadequate arrangements during a period of health crisis and at high stakes educational points, such as VCE, when few of the young people are offered part-time or extended study.
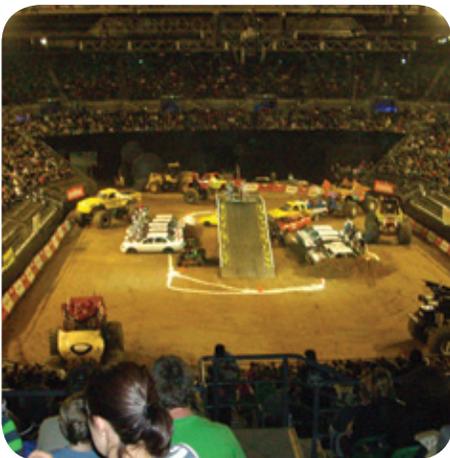
2.2 Past clients of the RCH Education Institute: retrospective interviews

A feature of the Keeping Connected study was the investigation over time of the identity and educational issues for young people living with chronic illness. Interviews with seven past clients of the RCH Education Institute took place in the third year of the project and provided points of comparison and commonality with the case study material from the 31 young people discussed in the previous section. The investigation of what the experience was like for this older group of participants with respect to living with an ongoing health condition and the respective contribution of systems, services and individuals over time, parallel the issues detailed in the young people's case studies. From the retrospective interviews five themes were identified:

1. Identity (role of health condition in daily life and how illness shapes identity)

2. Resilience and vulnerability

3. Relationships (family; friends; other adults; hospital staff)

4. Support networks (peers; hospital; school; family)

5. Pathways and careers (from school to further education and work)

Identity, resilience and vulnerability

These young people have shown inner determination in multiple ways. As resilient adults they remain positive, plan for the future, have reflective outlooks on life and are driving decisions about their health care, their education and their future. However, the stories shared by these young adults also point to their vulnerability. While as indicated above, their wellbeing improved over time, these adults indicated that they had also experienced:

*   disconnection from friends due to absence from school /feeling physically unwell/ friends not understanding their condition

*   body image insecurities

*   partying hard and pushing the limits of what they could cope with, engaging in risky behaviour with alcohol and drugs

*   family issues and lack of support

*   identity and subjectivity issues heightened - being perceived as different amongst friends and within education and community structures

*   major physical limitations from their illnesses/conditions, such as memory loss, low immune system, back issues, anxiety, depression, learning difficulties, low energy, continued even though they had in their terms 'fully recovered'.

The young adults resolve to remain connected to ongoing education was nevertheless very evident. Carl, who lived in rural Tasmania and might be regarded as being very vulnerable to early school leaving given his health condition and geographic location, did not ever consider dropping out of school. He replied in the interview that dropping out of school was the last thing on his mind.

> Oh no I didn't drop out...It really didn't enter my mind even once to be honest, I reckon I just thought I need to do this, I need to finish school so I don't have no future basically. If I didn't want a future, I just kept going with school even if it was so hard and it still kind of is but not learning capacity or anything, but yeah I've kept soldiering through and I've got through fine, I passed college, diploma of music course. I'm pretty happy now.

Less positively, memories of bullying and personal humiliation remained vivid. Noel took the time to email the researcher post interview to make sure that his recall of the proactive action from key school leaders was documented:

> My school has a very strict 'no bullying' policy. About 2 weeks before I came back for half hours and so on at school, my principal and the middle school coordinator called an assembly of all the middle school students. They said that I would be coming back, half hours once a week and so on, and that I would not be the same Noel that was there before. If there was even a rumour or hint that anyone teased or bullied me they would be expelled on the spot, no meetings with parents, they would be thrown out of the school there and then. So I guess that is a massive point…other schools may not do that, they should. I mean I came back pretty much ok, but I know of others who didn't fare so well after accidents, etc.

The interrelationship between identity, health condition and vulnerability was explained by Cate as she recounted how her health was better when belonging and acceptance were present.

> I think because if I'm like happy and not stressing about stuff my sugars go pretty good, as soon as I start to stress I'm at Uni or I found when I had placements in hospitals I was stressing all the time so my sugars would shoot up whereas when I'm working in an Aboriginal community I just enjoy it and it was really good my sugars were fine all the time, I didn't actually have that much trouble controlling it. It was pretty good yeah.

Living with an ongoing heath condition can be characterized by a range of residual factors, the impacts of which will occur at differing life stages. These seven young adults have shown that they have minimized some of these factors by remaining connected to family, education and careers. The way that systems such as health and education are structured, have a significant bearing on future trajectories. Many of these adults have had strong family supports, although one in particular felt her condition had been an embarrassment to her mother and this had caused conflict in their relationship. Particular individuals are often recalled positively by these adults in the health and education systems, including individual doctors, nurses and teachers. What is storied by these adults are memories and recent accounts which show they are most of the time now going along quite well in life, but they remain very aware of their health-related vulnerabilities.

Connections, supports and relationships

Most of the group recalled the quality of their family support as strong and also made mention of their siblings and other friendships. Noel affirmed the importance of family support when he stated:

> *I am willing to guarantee a recovery is far quicker with a solid family support and friendship support behind the kid because, yeah, like I said I was incredibly lucky to have my family there for me when I needed them and to sort of help me get through what I got through. I mean there were some really horrible moments over that, especially when I first came out of surgery there were some really, really horrible things, but yeah, I think if your family is there for you that's all that matters. If your family is not then I think there are severe repercussions afterwards if family and close friends aren't there to stand behind and support someone who suffers a brain injury.*

As was evident in the larger case study group, most had experienced some disconnection from friends during their absences from school. During their early adolescence they recalled the depth of self consciousness, isolation and exclusion as being big issues.

> *I found that like especially like during the last two years since year 11 when I was in and out of hospital a lot because I was going into my local hospital a lot too and my friends became a bit distant, I became a bit distanced from my friends and yeah it was hard. Friends weren't friends any more I wasn't even in Year 12 I was starting to grow and that was hard like when you come back because you'd be gone for like a few weeks and you'd come back and yeah I don't know I found that hard. Yeah. They didn't understand. (Cate)*

When asked about friendships and the role they played in his reconnection to school, Carl replied that his support was not made up through friendship networks, 'I've always been a very solitary person anyway'. More optimistically through their tertiary education most had managed to 'fit back in' and were more upbeat about their friendship networks. As Ada says:

> *Yeah it's been perfect, I've made some of my best friends at Uni so I've got, I've made a few friends with a couple of girls and some of them have become my best friends so it was good because I went to Uni in Burwood, so from here it's quite a hike; so that worked out well because then you know I could stay over at their houses so we got really good friendships, so it's good.*

All of the interviewees spoke about key relationships and services that had provided educational support for them. The support they received came from varying sources teachers, hospital staff, family members, other adults and independent tutors and once in the tertiary sector university disability liaison officers. The memory of direct support from the hospital and knowledge of the RCH Education Institute were reported by some but not all interviewees. Individual teachers, rather than whole school structures were recalled as providing some vital links.

> *YP: The school did nothing.*
>
> *R: But you said there was one teacher.*
>
> *YP: The teacher was very, very good yeah.*
>
> *R: In what sort of way, what did they do?*
>
> *YP: Put more attention onto my struggling to get a grasp of things and stuff and yeah she was great, she gave me different things to do than other people and made sure it was written down which really helped me a lot.*
>
> *R: Okay and tailor the work to you a bit more?*
>
> *YP: Yes, and she got me onto like these memory tools and stuff like that, she was a very nice lady.*

While most felt supported during their hospital contact (a period when they received a lot of attention by staff and their own family and friends), once back to school they struggled with this re-adjustment stage (often lasting more than a year). One young woman affirmed the need to make the adjustment gradually and keeping up educational and social connections with the help of a tutor for educational support and keeping linkages with friends, even when feeling too physically unwell to do so. Underlying the narratives was a desire to return to 'typical school experience'. While they were aware of options such as special consideration, they remained reluctant to use these supports, as activating these arrangements drew attention to them further and further defined them as 'different'. The experience of not wanting to appear to be different also carried over to the tertiary context, but as noted earlier, deeper personal insight and acceptance of the advantages rather than stigmas of using supports were realized. Cate commented on her higher education trajectory and noted:

> *I felt that I wanted to do it by myself and get through and you know I got into honours and stuff without any special consideration but this year she's [the lecturer] said pretty much get the special consideration and yeah there's no shame on special consideration but you know when I started I was like, I don't want to get it because I want to feel like I'm doing it by myself; and you know yeah, so she's been really good and they're really helpful at Uni, yeah they're really, good.*

Pathways and careers

While most of the retrospective interviewees had completed (or were about to complete) higher education through universities or TAFE, the transitions to higher education and then finally securing employment were not even. Six of the group recounted earlier uncertainties about what course they would do and which path of study they would follow. All however had ended up very satisfied with their final outcome, and this included part-time and casual employment. For some of them for the first time in their lives they were dealing with independence and also had formed more meaningful friendships and intimate relationships. Significantly for some higher education was a period when they first accepted that 'special consideration', the term used in higher education to grant additional and/or alternative assessment timing would be useful to them.

Some retrospective interviewees described the difficulties they had faced in career planning after leaving school and then after leaving university. Some had a successful prior academic trajectory, but for these adults the onset of their condition had forced them to learn to live with their changed identity and how this altered their future goals. The interviewees demonstrated that despite the interruptions to their education due to their health condition they were able to draw upon a heightened sense of themselves to navigate the next stage of their lives and how they could get on with living, even if there were further challenges ahead.

Noel a young man who had an acquired brain injury midway through secondary schooling at the age of thirteen spoke about 'milestones', things he had achieved after experiencing a brain injury, which other people take for granted. He preferred not to plan too far ahead given his past experience with his health and how quickly his life had changed.

> *I used to [plan] but the fact that I couldn't like 60% or 70% of the plans I made I couldn't reach so I said 'screw this' so I don't make plans. I mean Christ I [had a brain injury] at thirteen, I didn't plan that, so I sort of look at it like well I didn't plan that, so why should I go planning other stuff? Stuff will happen the way it happens no matter what you plan.*

Conclusion

The themes that emerged through analysis of the retrospective interviews are highly consistent with the findings that have emerged from the 31 case studies. These young people appear to have remained connected to education and family, in spite of considerable health-related disruption. Their retrospective stories have also brought additional insights about the influence of a chronic illness on identity and experiences during the school years because these participants are older and more distanced from it. Indeed, even in young adulthood health-related vulnerability remained significant for some in relation to questions of sameness and difference and finding their place in the world. However, a key point from the retrospective interviews is that these young adults commonly felt more able to accept and buy into processes of special consideration once they left the secondary school environment. Goals and aspirations were important to all the young people, for some this involved further education but for others it related to following their passion for music and so on.

These young adult perspectives have also shown us other aspects of the longer term trajectory for young people living and learning with chronic health conditions. This includes illustrating clearly that while they all experienced challenges achieving a 'typical school experience' they often found that the post-school environment offered them interesting and fulfilling opportunities nevertheless. They all remembered key relationships that were important for support during the school years and during stays in hospital. There also appear to have been increased opportunities for social connections post-school in which other people were more accepting of any health-related difference that these young adults continued to live with. Growing independence was generally discussed by these young adults as a positive step for them in terms of making new friends at university or moving into the workforce, which gave them an important sense of purpose in their lives.

3. Parent contributions to the social and educational connectivity of young people living and learning with chronic health conditions.

Introduction

As previously described, the study was designed to privilege the voices of the young people themselves. Originally it was planned that the parents who were going to be interviewed would not be related to the young people in the case studies because we wanted to send a clear message to the young people that it was their perspectives we were most interested in for this project, not that of their mother or father. Early in the project, researchers made strong efforts to create an atmosphere conducive to supporting the young people to speak freely and openly. Drawing on the researchers' experience with young people in other projects, it was anticipated that these young people would feel more comfortable without their parents present. However it quickly became obvious that the contribution of parents, usually mothers, in supporting and facilitating these conversations was vital and not intrusive or stifling, as anticipated by the researchers. The relationship between the young person with the continuing health condition and their mothers often seemed unusually close to the researchers and the young people did not appear to resent their parents' presence: some even preferred it. Therefore, the role of these parents in their son or daughter's lives was an important element to the story that needed to be conveyed through this research.

For this reason, and with the approval of the young participants, the 31 case studies also incorporates material from 21 mothers, 6 fathers and one grandmother who had a guardian role for one of the participants. The material they provided was a mixture of individual interviews held at the end of the study and ad hoc contributions as part of the 30 months during which the researchers visited the young people in their homes. When interviews with parents occurred, they often lasted for more than two hours because parents had so much to say about their experiences of supporting their son or daughter. Hearing from the parents has increased our capacity to understand the full extent of issues that have influenced the young people's situations because they themselves are often not aware of the degree to which parents (usually mothers) are working behind the scenes to promote their wellbeing. The voices and interests of young people in this study are enabled and supported in a range of areas of emotional, social and educational life by parent support and advocacy – and it was aspects of those stories that we were able to hear in more detail from the parents of case study participants.

Young people in families

A young family member living with a chronic health condition had important bearing on the families in our study. Parents reported on the challenges they faced within their families as well as in their interactions with school staff and health care professionals. They shared their hopes and expectations about their child's future in relation to both health and education systems. Parents also reported other challenges which emerged in tandem with the young person's ill health. For example, financial pressures as a result of parents (usually mothers) having to limit their hours of paid work in order to cater for the specific and unpredictable needs of their unwell son or daughter. While the presence of ongoing health issues provide significant challenges and burdens for any family, parents involved in the Keeping Connected project provided many insightful comments about their own families as well as how schools function and how health care is provided. Across the study, parents showed strong commitment to social and educational goals for their sons and daughters. Parents offered many comments about the communicative and collaborative work it takes to keep young people with chronic health conditions connected and engaged with schooling and friends.

As with the general population there were many different configurations of families present in our study: single mother or father households, two-parent households with both biological parents, two-parent households with one biological parent, households containing extended family members or long-staying guests, and a household headed by a grandmother where both biological parents were absent. Eighteen of the families in our study lived in metropolitan regions of Melbourne including semi rural, outer suburban and inner city locations. Twelve families lived in regional cities or rural locations in Victoria. One family lived in rural Tasmania and one family relocated to regional Queensland during the course of the study. In six of the 31 families, there was a sibling with a significant health or psychological condition who was not a case study participant.

Across the case studies, parents reported both successes and challenges in their interactions with schools and health care. They also shared their experience of accessing a range of support services and resources available to their son or daughter whose attendance and involvement in school life had been repeatedly disrupted and interrupted by experiences of ill health. In this section of the project report some of these successes and challenges are reported. Key issues articulated across the study by parents about parenting a child with a chronic health condition are also raised.

3.1 Education: Positive encounters with schooling

> *I walked into the high school…and it was like walking into this big open room. It was like a weight had been lifted… Lifted from our shoulders. They had us up there and got all of the teachers from Year 7 and we had a round table thing with the Principal there and he goes, 'What can we do to get her through?' (Mother)*

There were several examples where experiences of schooling had gone reasonably well. One mother reported that her young-adult son had experienced significant chronic health issues from birth and had been identified at an early age as having a hearing impairment. Consequently, and on advice from medical staff at the RCH, Joe attended a government

kindergarten, primary school and secondary school all well versed in supporting students with disabilities and associated special needs. While it appears the school was still challenged in responding in an appropriate, ongoing manner to the 'ups and downs' and changes over time associated with Joe's chronic illness, he was one of many young people dealing with health issues and impairment in that school environment and as such was more able to 'fit in'. For example, teaching aides were a taken for granted feature of classrooms, not just in relation to Joe's learning.

Schools which have mainstream orientations and programs supporting diversity appear to work well for young people living with chronic health conditions. In three instances a significant impact was reported as a direct result of the Year 9 programs which were perceived to be particularly important and provided the young people in this study with opportunity to connect with other students through activities and programs in which the emphasis shifted from the traditionally academic to issues of identity and engagement in education.

Several parents reported on the particular efforts of individuals within schools, including teachers, home group teachers, teacher aides, year level coordinators, student welfare coordinators, assistant principals or principals, who took it upon themselves to provide a point of connection and care for the young person, the school and the family. While this occasionally happened as a result of the formal school structures, in most instances it was due to the interest and concern of an individual member of staff and/or the insistence and urging of the parents.

Education: Challenges encountered with schooling

All we got was, 'It's not good enough to be off school!' Well, I'm sorry, but I sat up three-quarters of the night with the child. You're lucky she's here at all. It's only because I've pushed her to be here because I know how important her education is and then…they never ever said it…every time I walked into that school—and it still upsets me. And as I said, the words were never said, but it's like 'She's going to die anyway, what are we doing this for?' (Mother)

Parents were clear that unnecessarily bureaucratic processes in both health care and education often compounded the difficulties in schooling faced by their sons and daughters who were frequently absent from school because of ill health. Across the experiences of these 31 families, levels of institutional support varied widely, as did experiences of academic success, failure, exclusion and quality of assistance and school support. Ensuring school staff understood the seriousness of a condition was also a difficulty. Parents expressed a range of challenges in relation to promoting their child's overall wellbeing and participation in regular aspects of adolescent life. These related to interacting with schools with many examples being provided. Other frustrations related to the scheduling of health care appointments at the hospital. Parents and young people were concerned about the repeated scheduling of appointments during school time, which disregarded the young person's right to education.

Teacher aide support

Parents also expressed anger, dissatisfaction and disappointment with some schools for being inflexible and bureaucratic in response to the circumstances and needs of young people with chronic health conditions. The education system disability funding that supports the employment of teacher aides relies on the school being motivated to write the application, having the support of regional staff and then allocating resources within the school. Only four cases received the support of integration aides (the term used in schools in Victoria). Millie's mother explained how funding was provided to the school to support her daughter, but the principal insisted that the resource was used across the school:

> *Trying to get an aide for Millie at her primary school was just, 'Forget it!' you know? They just didn't…the funding was there, but 'Oh, no. We have to share that with the others.' Excuse me, my child was given this pocket of funding for her aide, for someone to help her… she needs someone to help her.*

The experience of high school, however, was quite different:

> *We get to the high school, it's like 'Right. She's got an aide for this, this and this. What do you think she really needs?' I can turn to them and say… 'I think she's struggling with this, this and this. They'll put aides into a certain group with [Millie] and she'll come home and say, 'Mum, this is so stupid. I've got an aide for such and such and I really don't need one [So it quickly got changed].*

School cultures and supports have been experienced by parents as very haphazard, and consequently parents often put a lot of effort into selecting a school that they feel will best suit the health-related needs and social and educational circumstances of their child.

Communication

The most consistent theme across the conversations with parents was about the challenges associated with communication processes between home, hospital and school when a young person has an ongoing health condition. Specific concerns related to:

- How these processes could (and should) be established and maintained

- Identification of appropriate individuals in schools who could act as points-of-contact in both systems

- How to find a balance between communicating enough information to assist the young person at school and yet respect the young person's desire for privacy

- How to know what sorts of communication processes have worked well before and then duplicate those approaches rather than each family feeling they have to reinvent the wheel to secure support and consideration for their own child

- How parents can be supported to assertively communicate and act as an advocate for their child within health and education institutions.

A particular issue raised by parents was that class teachers were often not informed by school administration that a young person had been in hospital. This led to teachers insisting on their assessment deadlines being met, which was unrealistic and unsupportive

for the young person who had been unwell, and positioned teachers into intractable roles where they were viewed to be uncaring and insensitive. This example serves to illustrate the importance of communication, and how simple and basic communication is needed in schools. Chris's mother related how she intervened at the school when a teacher had been particularly harsh towards her son, and it turned out that the teacher didn't know about his serious illness and recent hospital visit. 'They probably thought I'm a whinging mum making excuses for my son….'

In a further example, Mary-Kate had a serious health condition from birth. She moved from primary to secondary school in the third year of the project. Although she had been experiencing both social and academic difficulties at primary school, she was initially thrilled with her experiences at her new school. However, by second term the situation had deteriorated markedly and at the last point of contact with the research project, Mary-Kate was talking about leaving school and her mother was unsure that there was anything else that she could do to help the situation. In Term 2 at high school, after many absences and several negative encounters with teachers while trying to get access to the work that she had missed, the school principal called Mary-Kate's home. Her grandmother had received a phone call from the principal while Mary-Kate's mother was out of the house and she reported:

> The Principal rang here… so I spoke to her and she said, 'Oh Mary-Kate's not at school today'. I said, 'No she was, but she come home crook…she's all swollen' and she said, 'What do you mean she's all swollen?' And I said, 'She suffers with a life threatening illness'. Then she said, 'Oh my God I didn't know that'. I said 'Her mother infuses her three times a week'. Well she knew nothing…I don't think they realize how serious her sickness is.

Mary-Kate's mother added:

> She had no idea of my daughter's sickness, so it's like hang on, the hospital was meant to go out there and have the meeting with all of them.

The above scenario at least represents a significant breakdown in communication between the primary school, secondary school and parent. Yet it appears a central cause of the inadequate communication was that Mary-Kate's mother assumed the hospital had done some of the explaining to the school and that she therefore did not need to do that herself. There are many points in this scenario where a systematic process of communication with clear lines of accountability and follow up would have reduced the difficulties and distress experienced by Mary-Kate at school. Part of the challenge here was that Mary-Kate's condition was not highly visible. Indeed when she experienced swelling in different parts of her body she made deliberate efforts to conceal the swelling because she did not like the look of it and tried to hide it from other people. Throughout the study many parents reported increased challenges interacting with schools about their child's health condition when it was one that was not readily visible.

For example, in relation to one young man with an eating disorder who was highly involved in sport, his mother commented:

> Look the teachers at the school have been really good [and they know about his illness] but once again I don't think a lot of them had any idea just how serious

it was because he looked okay...it's very hard for teachers to sort of comprehend how it is that there can actually be thinner people around and their heart is working fine and then [my son's] doesn't work fine when he's, you know, at a very low weight. So it's very – it is pretty hard. The day he went to hospital he had won the regional cross country and I was down there watching him win it and I spoke to his teacher down there and I just sort of said, 'Oh look, we're still having problems with his eating', and he just looked at me as if to say 'What are you talking about lady? He's just won a race. It doesn't look to me like there's a problem.' And then that night he was admitted to hospital so it's very, it's sort of hard I suppose.

The following comment from a mother illustrates a clear example of the challenge of communication and the importance of maintaining the privacy of young people:

[My daughter] was very distressed one time because a teacher told the girls…I really can't remember which one it was but it was one of the procedures and one of the staff mentioned it to the girls and one of the girls rang Angela and said 'Oh Miss so and so told us that you're in hospital having this' and [my daughter] hit the roof…Well they have no control over anything in their life when they're unwell. They have procedures done to them that they don't want to have done. They have to do things that they don't want to do. They're ill. They can't control the illness and their lives are pretty much seen as out of control so in [my daughter's] case anything that she could have control over she was very, very protective of her control.

Special consideration

Another consistent theme articulated by parents was their lack of knowledge about avenues for support and assistance, particularly in relation to issues of special provision and special consideration in VCE assessment. School processes and rules for claiming special consideration had been found to focus on identifiable absences or markers of physical incapacity. They do not deal adequately with the experience of a chronic condition as an uneven and continuing process over time. For example, even if not away from school due to a hospital admission, a student living with chronic illness may have to take time off school to attend lengthy outpatient appointments. Alternatively the students make the effort to attend school even if they are not well enough to be able to concentrate well in class. They then may be unable to follow through with homework tasks that day because they have medical regimes and appointments they need to spend time on, or they need to rest and recuperate at home after the effort of attending school. These illness-related limitations are not always visible outside the family context, and are also difficult to articulate within current procedures assessing entitlement to special consideration.

Of significant concern to the research team was that most case study participants and their parents were unaware of students' options, and rights, to complete VCE over three years rather than the standard two-year period. In the case of one young man who was completing VCE via the three-year option, his school had begun putting pressure on him to conclude school more quickly as the third year began to approach. An additional

concern was that few parents reported any clear understanding of the role and purpose of the RCH Education Institute.

Lillie, for example, was in Year 12 and was endeavouring to complete her final VCE assessment in spite of missing significant amounts of school since primary school, and in spite of being hospitalized during the last year of VCE. Lillie lived in rural Victoria and generally visited the RCH as an outpatient rather than an inpatient. She had been attending the hospital regularly from the age of 4 years. Her mother reported that it was only when Lillie was in Year 12 and in hospital, and through a conversation with one of the teachers from the RCH Education Institute that they realized this was an option.

> There had been no discussion that Lillie could actually withdraw…from VCE and repeat the next year or any number of other gradations in between. We had no idea about that until she ended up in hospital in the middle of Year 12. Had no idea at all and I think as someone who's been going to RCH for so many years we should have known that.

She commented further that the scheduling of hospital appointments did not take into account her daughter's schooling. She pointed to practical difficulties related to special consideration in the final year of schooling and offered sensible suggestions:

> I don't know how often they [the doctors] actually sat down and said 'Well how's Lillie going at school, how is this impacting on her, what's going on?' I think it would be really useful for there to be someone who oversees it …being a mediator between the hospital and the schools because that doesn't happen… In terms of getting an effective outcome [through] …VTAC…you need ongoing help. They were happy to let her do internal exams at other times and do exams at different venues but sometimes if you went to another venue nobody knew she was coming for example. I just don't think those guidelines are anyway near strong enough for kids who are ill…She lost lots of time just because of the sheer number of visits [to outpatient appointments].

Education: Recommendations and suggestions from parents

The importance of communication and a single contact person was repeatedly emphasized by the parents. Millie's mother explained how well it worked in her current school:

> We're having regular…meetings. They're following up. Her aide will ring me… and say 'What's going on?' and I'll just look at the phone and go, 'I don't know. Can't see it. There's something going on that I don't know exactly what it is,' I said, 'This is the impression I get…that's what we're trying to do, but it's just not working.' Just recently Millie's had two months off, she [the aide] rang me and said 'da de da' and I said, 'I've tried.' I'm balling my eyes out to this woman and she goes, 'Alright, we'll deal with this. Leave it with me.' Got back to me – probably only a couple of hours later and said, 'Don't you worry about that. I'll deal with this. I've spoken to the appropriate people. I have the go ahead to

do this, this and this, and we're working on it, don't you worry about it.' That's how fantastic it is.

In meeting the young person's emotional needs parents worked hard to find a balance between having the young person feeling alone because people didn't know about their health issues, and making the young person feel singled out and different because of their ill health.

A core strategy for success reported by many parents was to have a clear chain of contact, communication and responsibilities between hospitals, families and schools so that the young person's educational and social needs were frequently considered and adequately met. Parents reported that prolonged or repeated absence from school whether through hospitalization, lengthy outpatient visits or time spent unwell at home, had a significant effect on the breakdown of young people's relationships with their teachers and peers. They felt that this could be mediated to some extent through electronic communication such as email, instant messaging and social networking websites. Several parents felt strongly that it was problematic for the hospital to have taken the step to 'ban' access to these instant messaging for young people in the RCH.

In the midst of all these communication difficulties, many parents faced a constant dilemma in terms of acting to promote the interests of their child while avoiding being seen as someone who is 'making a fuss', or being unreasonable, which they understood as likely to put health and education professionals offside.

At a time when rhetoric suggests that education and health institutions are collaborating well to promote the life chances of young people with chronic health conditions, parents in our study frequently reported taking on the role of strong advocate for their child's interests and needs, in both school and health care arenas. Indeed the parents we encountered commonly embodied the so-called 'health education interface' themselves, with varying rates of success and difficulty. While seeming to rely on parents to advocate on their son or daughter's behalf, these same education and health institutions also appeared to expect parents to trust in professional expertise and leave teachers and health care professional to get on with the 'education' or 'treatment' of the young person. Parents thought that their expertise was often not readily acknowledged in these institutional contexts and they felt pressure to behave in ways that would not be interpreted as meddlesome or 'difficult'.

In this study it was predominantly mother's who undertook the overt primary 'management' role in terms of facilitating and driving action to ensure their son or daughter's physical health, emotional wellbeing, social and educational needs were being met as much as possible. The parenting role seemed to be characterized by a combination of watchfulness, supporting, encouraging, pushing and advocating. Within that role parents expressed a range of challenges in relation to promoting their child's overall wellbeing and participation in regular aspects of adolescent life. They were acutely aware that for their children, family, social and educational connections were continually strained because their children were living with a chronic health condition. Parents were concerned about both immediate and ongoing consequences of these disconnections and about the sense of vulnerability they had in relation to their child. The young people in this study were not necessarily fully aware of the lengths to which their parents were

working 'behind the scenes' to promote their interests, their wellbeing and participation in regular aspects of life relating to education and social interactions. Mothers in particular, commonly had particularly close and productive partnerships with their sons or daughters, which served to proactively facilitate the young people's connections to schooling and peers. The capacity of families to sustain the high levels of support required to manage entitlements to education and allied support services over the long term varied. While parental connection to avenues of social support and assistance were highlighted as valuable, personal resourcefulness and resilience stood out as a key quality of these parents:

> *We didn't know about Arthritis Australia, we stumbled on that one on the internet, we didn't know about visiting school teachers, we didn't know about advocates, we didn't have any help with the disability payment, you know the carer payment, I missed out on all of that, yeah basically nobody tells you anything about anything. (Mother)*

Kim's mother lived with the same condition as her daughter, and offered a different perspective. She had learned how to manage systems through her own history of navigating schools and health services. She acknowledged the right of the individual to determine a successful life as her benchmark. Her daughter's goals of leaving a small rural town, attending university and becoming a successful professional are embedded in family values.

> *You know you only fail if you don't try sort of thing and I encourage them strongly to try things that they probably know they've got no hope at because they just don't know and it also teachers then that 'No' won't hurt them and there's always a tomorrow so even if Kim's goals for VCE they're high in a sense but everything else she does, she, if she doesn't get them she knows it's not the end of the world. She only has to go on her trip to England for two years and then come back and she's mature age [entry], so that's all I sort of do with Kim and she's mature enough to accept that sort of thing… so that's our family.*

Parents illustrated that they were highly attuned to the emotional as well as informational aspects of supporting their child and were concerned that health and education professionals were often not sufficiently sensitive to that. In relation to health care one mother said:

> *People…wouldn't have read [my daughter's] history … she really got distressed having to regurgitate all of her problems from the years and go through it all and drag it all up.*

And another commented:

> *When [my son's] specialist retired that was a very emotional time for [him] and it was a very big thing for us when we said goodbye to Professor X…I didn't realize the depth of [my son's] sadness when he had to say goodbye to him… so when [my son] did this speech this time to say goodbye in front of everyone I was just so proud of him. He got in the car and he cried all the way home. He was just devastated. It was really heartfelt – so you don't, don't underestimate the importance of health professionals in these people's lives.*

Many of the young people involved in our case studies were experiencing parallel issues of physical ill health and challenges with mental health such as depression or low mood. Several young people were involved in psychological counseling. A key problem raised in this area related to the 'moving on' and changing of counselors while young people are still involved in ongoing counseling. This raised problems with young people having to tell their 'story' again and again to different health professionals, as well as young people and families encountering new counselors who they do not see as such a 'good fit' as the previous counselor, and whom they do not feel as comfortable with.

Several young people and parents reported that counselors found the closeness of parent-child relationships between the parent and the child with chronic illness not to be developmentally appropriate. That is, the counselors gave the impression that they felt teenagers should be beginning to decrease close ties with parents but what they saw between parents and young people in this study were ongoing, often very close and supportive relationships. Parents and young people indicated that they felt counselors were ignoring the positive and facilitating nature of these close ties for young people who were dealing with significant adversity and were likely to be experiencing some degree of social isolation. For example the young woman in our study who lived with her grandmother expressed dissatisfaction with her counseling experiences. Her grandmother commented that the counselor seemed to judge the closeness of their relationship as inappropriate and gave the following account:

> *And I can see [my grandaughter's] mood drop when we go in there because when we went yesterday she said 'I'm going to tell her today I don't want to come any more because it's not beneficial to me and I really don't like her'. She had a great woman there ages ago but she left and no one is going to replace her you're just not going to get another …And [the counselor] said 'Well why don't you want to come here anymore?' and 'X' said 'Because look if I've got a problem I can talk to Nan about it, I don't need you.' She said 'No offence', she was nice [about it]. She said 'I don't mean to be rude to you but I don't need a person to air my issues with because I'd rather do it with Nan'. And the counselor can't see that either, it's like 'But this is why kids go to counseling because they don't want to talk to their parents or they can't talk to their parents'. Well we can so we don't need to be here…*

3.2 Hospital: What parents reported works well

Most of the parents reported on the strengths of the hospital and the adolescent ward in particular. Parents reported several examples of events and processes where they felt that things had gone particularly well in terms of people and institutions supporting and accommodating the needs of their son or daughter. One mother said:

> *So many people complain about our health system. I'm always the one thinking 'Oh actually it's pretty good'. You may have to wait a little while in emergency but at least you'll get seen, and you'll get seen by a very good doctor. The Children's Hospital is phenomenal in what they do.*

And another commented that her daughter was frequently in hospital and the adolescent ward provided a particularly positive experience:

> Having a relationship or rapport with the nurses who knew her and used to joke with her and they were just really lovely and she enjoyed going in...It was pretty rare for her to find somebody who rubbed her the wrong way...and then with the kids there were frequent flyers ... so at least she had some sort of social interaction and I think that was really important ...I think most kids would like that but they also need to have that social structure as well that they're missing out because they're sick.

In relation to education, a clear message from parents was the importance of one consistent and well-informed contact person at the school who could liaise with the young person, teachers, parents and health care professionals as necessary. For example, one mother outlined a combined approach her son had experienced at school involving staff from the Ronald MacDonald Learning Centre, school staff, the mother and the young person:

> [This funding] meant that one of the teachers had to then put their hand up and take responsibility. So she would do it within school hours when her timetable allowed and the school gave permission for her to do that ...and that was great because it just gave the one central point that I could then have to go to and she would be totally available if ever I needed her. We communicated via email, phone call or whatever. ...And she would say 'Well let's prioritize what's important here and not let Ben feel overwhelmed by how much he's missed'. So that was a really important thing for us, that really helped that year, got him back on his feet.

She continued:

> I know they've got welfare officers [in schools] that are there to deal with issues – but if you've got a child with a chronic ...if they're missing long periods of school it would be great if someone within the school – the system – [could take] on that responsibility... I think it might have been a social worker [who organized this support] ...I had been talking to the hospital about the issues and asking for advice about what was out there ...Otherwise we wouldn't have known about that.

Hospital: What parents reported is of concern

Parents expressed a range of concerns in relation to promoting their child's overall wellbeing and participation in regular aspects of adolescent life. These related to interacting with schools as illustrated above and in the scheduling of health care appointments at the hospital. Parents and young people were concerned about the repeated scheduling of appointments during school time. They were also concerned about insensitive scheduling of appointments early in the morning, which failed to take into consideration the length of time that it would take families to travel from home. In particular, early morning appointments often meant that families living outside the city had to travel to Melbourne the day before the appointment so that they could arrive on time, meaning that they had

to incur additional accommodation costs. Extended times away from regular life, especially during periods when there was not an acute health crisis was seen as unnecessarily damaging for school and peer connections.

Conclusion

A major concern that emerged from the interviews with parents is that support for young people with ongoing health issues tends to occur because of parent effort or good luck rather than systematic design or specific planning on the part of health and education institutions and their representatives. Parents often reported expending large amounts of time and energy trying at different times to enhance the educational and social circumstances of their unwell child. As one mother said, 'it used to make me absolutely furious. Why did I have to fight so hard for my kid?'

Health and education professionals are better positioned than the average parent to understand the systemic features that can aid or detract from these young people maintaining positive educational and social connections, and yet from the parents' perspectives the systems are found wanting. There appears to be a significant absence of enabling and systematic institutional processes that work to attend to their varying and changing social and educational needs overtime. The goal of ameliorating the potential impact of chronic illness on the overall life chances of young people living with chronic health conditions is visibly high on the agenda of parents, but they feel it is often less high on the agendas of education and health care professionals. This can be readily reframed so that young people with ongoing health conditions, however invisible, have the right to inclusive and supportive practices that overrides the poor communication and scheduling priorities of hospitals and schools.

4. Education and Health Professionals

Throughout the Keeping Connected project, many stories have emerged about how young people negotiate relationships with their teachers and the health professionals who work with them in hospital. This section focuses on how these professionals view young people's experiences and their relationships to school and other forms of social connectivity. It also examines the priorities that professionals set in their respective roles and successful and unsuccessful practices they report have emerged in both the hospital and school settings.

Health professionals interviewed included senior doctors, nurses and other clinicians from The Royal Children's Hospital. We sought views from two groups of education professionals: (1) teachers in schools who had experience with caring for students with chronic illness; and (2) Royal Children's Hospital Education Institute personnel who early in the study (at the time we conducted the focus group interviews) were known as Education Advisors. Although the role of education professionals employed within the RCH Education Institute has subsequently changed to focus on teaching and learning, the views expressed by education professionals in the focus groups do provide insights into challenges that face young people in managing schooling as well as support provision.

4.1 Health Professionals

The health professionals who participated in the focus groups were recruited from a list of names provided by the RCH Education Institute team of teacher consultants in February/March 2009. All participants had worked at the RCH for many years and had long standing connections with teacher consultants, and formerly education advisors, from the RCH Education Institute.

How they see young people in their care

Health Professionals observed the young person's desire to be 'normal'. One focus group participant explained:

> What I've learnt from them is they don't want to be treated any differently than anyone else and get quite upset if people do… they just really don't want it to be highlighted because it's not a big part of their identity.

This is particularly evident, after a sudden change in a young person's health condition:

> Young people don't see themselves as sick so it's just part of who they are. The transition in the kids' heads to call themselves disabled doesn't exist. It's not part of their identity at all. They're just thinking: 'bloody stupid stroke', and not 'this is who I am now'. They also think they'll be back 100%: 'I had the stroke but I'll get better and I'll be the way I was before'.

According to the health professionals, the realization of living with an ongoing health condition is gradual. But foremost, *'It's about living; it's not about the disease. Kids don't want to talk about their disease when they introduce themselves; they don't say: 'Hello, I'm cystic fibrosis'.* This focus on the identity of the person rather than disease is discussed as a changed discourse in the health profession. Participants spoke unanimously about a paradigm shift *'from looking at a particular condition to looking at the person and their circumstances. There has been a better recognition over the years of the identity of the person rather than the person being a disease process with legs.'* They acknowledged that this is *'really difficult when issues of their body are involved because it's personalized and to not become objectified is really very important.'* Not surprisingly, it is especially difficult during adolescence. Corrective devices such as wheelchairs or spinal frames *'are not attractive. They are cumbersome, they're big, they stand out, you don't just blend in; you can't just sit and hide.'* Thus, these health professional participants told us their interactions with young people focus on educating about the illness, *'…helping them to understand more about their illness and their body and why we're asking them to do what they need to do'* and empowering the child *'not to become a disease but to become themselves with a problem that they have some say over and control over.'*

How health professionals see their role in supporting young people

Health professionals defined their role as providing for the acute care needs of hospital in-patients and the regular reviewing of out-patients' progress. They distinguished between medical conditions based on the causes (i.e. congenital diseases or accident/trauma-based conditions) and level of involvement (i.e. a short treatable illness or a life long medical alignment). The many variables and different combinations affect a young person's health state and have implications for treatment and recovery. Regardless of the young person's medical condition, their overall goal is to return them to a 'normal' life as quickly as possible.

Health professionals suggested that the issue of the young person's control is particularly important in securing their commitment to, and active participation in their treatment to ensure a positive outcome: *'It's a big commitment from a physiotherapy point of view that they need to be doing it daily, two or three times a day. If they don't, it's going to fail.'* A lot of encouragement and reminders are required to ensure their ongoing co-operation, particularly for girls. One health professional explained that: *'young girls [are] a bit more quiet, a little bit more reserved and you really have to push them, be on their backs a little bit and encourage and really talk about the outcome, talk about what we're aiming for at the end and why they're needing to do it.'*

Social and school connections

Given the prolonged and repeated times that young people spent in hospital, health professionals recognized the need for recreational and educational facilities and socio-emotional contact. Young people who spent a sustained amount of time in the hospital sought out contact with their peers and from friendships: *'Some of the young people have flat moments and some of them actually appreciate when they leave the medical area and go down to the adolescent ward because they find that's a bit of an older friendship group to be with. It's age appropriate.'* But the opportunity to socialize is limited, as is the opportunity to engage with

academic work: *'Kids are sitting in a noisy room everyone running in and out so it's not really conducive to do anything educational. A lot of them say they can't study in this environment.'*

All the participant health professionals saw maintenance of school connections as important in a young person's recovery and many reported engaging with schools directly:

> *The school can ring me any time if they want to discuss something or need. If they're at a special school and have an OT then I do a handover to the OT at school. (Occupational Therapist)*

> *We don't have as much access to the Education Institute so I find the rest of the team are kind of trying to step in and do that but we still, where we really feel that it's vital that someone is involved, we refer to the Education Institute and we do have someone on the ward for a restricted period of time to speak to the families and then liaise with the school just to help with the transition back to school. (Transplant Coordinator)*

Otherwise they liaise with a nurse from the Royal District Nursing Service or one of the education consultants from the RCH Education Institute. One health professional summarized her efforts to support young people as *'developing a curriculum of recovery.'*

For young people with trauma or accident-based chronic illness focusing on the young person's pre-injury state was highlighted as important in getting the school's support:

> *When a school knows a child a couple of years pre-injury they're more able to engage in that because they know what the child's strengths are. If they have an injury early in Year 7 at a brand new school when no one has got a handle on them, that's tricky. (Senior Clinician)*

In any case, individual differences in a young person's ability to perform academically were understood as covering the full range of the continuum and as being influenced by many variables:

> *Some are really great students pre-injury and some of them are average and some of them are poor students. Some have strong family support and some have less family support and I think everybody is very individual. We've never really had two students go back to two schools that were exactly the same. (Senior Clinician)*

School re-entry was also noted as a time when many young people are anxious about disclosure about reasons for their absence from school and thus their health condition:

> *Often, when [young people] are in [hospital] for a long time they're terrified of going back to school and 'what I'm going to say'? Once they're back at school for a few days it's all over but it's just that, 'Oh, everyone's going to ask what's wrong with me'. That's a bit intimidating for them. (Clinical Nurse)*

According to the health professionals, some young people may refuse school altogether or experience a lack of motivation in returning to school when they have had lengthy absences. Consequently, they need a lot of encouragement. School re-entry may be an especially stressful time when young people experience a change in physical appearance

(for example hair loss because of cancer treatment). This may leave the young person self-conscious about the way they look and anxious about whether they will be accepted. Health professionals claimed that one of the critical factors in a successful return to school is the young person's self-confidence:

> *Getting their confidence back after going back to school and it depends what their illness was. They mightn't remember all their work like they did before so there's going to be a lot of extra support for them to get back where they were. (Clinical Nurse)*

However, concern was expressed about return to school frequently being marked by *'a lot of unrealistic expectations as to what the kids can and can't do.'* A frequent cause of tension was the *'clash of expectations between schools, families and hospital for the right intentions. Sometimes it's not clear who's responsible for change.'* A factor might be that *'a school may not have had a student with a cancer illness before, they may not know what is involved in treatment and so on.'*

Thus, in establishing what these health professionals call a service plan to support young people returning to school, the issue of potential discrepancy between the child's needs and their school progression was raised, that is, the chronological age of the child determines service plan provisions and working relationships with teachers or teacher aides rather than age and developmentally appropriate strategies that are matched more closely to the young person's immediate circumstances and needs. One health professional explained that some children need the same person as a key relationship for two or more consecutive years that is, *'using an attachment model and a developmental model not a service plan.'*

Health professionals observed a great range of responses from schools. As one focus group participant explained:

> *Some schools are really well resourced and have really good education units so they can pick up the slack between when the child comes back without having specific funding. There are other schools who are pretty unwilling to do anything until there's a formal integration package. (Clinical Nurse)*

Another health professional acknowledged that: *'The resourcing in schools becomes really problematic because teachers are asked to do something that isn't their core business.'* This might explain why some schools *'show little flexibility in terms of school work or don't have contact so families can feel schools don't care.'* School fees were also raised as an issue. That is, what length of absence is required to justify schools waiving or reducing fees?

In contrast some schools were implementing modified school programs. This might be as simple as *'the children coming a little bit later or finishing earlier …shorter programs, particularly in those earlier stages after they get back to school'.* Young people may not be able to go to school full time, or *'they need ways of working around sport.'* However, there is a fine line between good supportive care and being too easy on the young person. A speech pathologist claimed:

> *It happens a lot that children get looked after too well, which is deskilling. They are actually being deskilled by this nurturing environment. There should be an expectation of not 'Oh, poor you' but 'Come on, you are expected to participate'.*

One of the most problematic issues was highlighted as the impact of a health condition on the young person's behaviour and consequential negative reactions from teaching staff and the wider school community. As one health professional explained:

When kids' behaviour has deteriorated and they have behavioural difficulties, they do get labeled as a difficult child even when the behaviour has changed. It changes people's take on them from being a positive support into a negative, waiting for them to do wrong rather than expecting them to do right. (Occupational Therapist)

Negative reactions from other children in the school were also reported to health professionals by parents during consultations: *'Parents often report that the children have been teased because of their shoe raise and their short leg and things like that.'* Health professionals also heard stories from parents about pressures on teachers and schools from other parents within the school community who have a child in the same classroom as a child with a chronic health issue: *'People will think about it as distraction in the class. Someone else's learning will drop off and that doesn't happen, that's nonsense.'*

Another issue concerned siblings who may not have regular contact with their ill brother or sister, while they are in hospital. This distress in the family and the emotional impact may affect the sibling's concentration levels at school. It was pointed out that advocacy or negotiation with the school is needed so that they are 'mindful of what the sibling is going through'. One health professional captured the problem succinctly: 'Siblings are often involved and get worried. It can work in two ways: their sibling gets teased or they may become a bit of a celebrity.' Celebrity status was exemplified by a sibling pushing the wheelchair of their ill brother or sister, which raised both curiosity and admiration in the school community.

A further concern was parents' interaction with schools where wrong or incomplete medical information caused confusion in schools:

The parents only give the school their version of the story that's not going to be very helpful. It can be quite negative, quite strong and gives the wrong impressions. I have calls from Principals, Vice Principals: 'What about this?' I'm happy to do that if the Ed Advisor is not sure about the medical side of things. (Clinical Nurse)

A related issue for health professionals is the challenge of coordinating various support service providers:

There's DHS there's SCOPE, there's Yooralla, private organizations, all sorts of agencies that you're dealing with constantly. The biggest difficulty that I have in trying to deal with agencies is that I do know they're involved. (Senior Clinician)

The families will tell you [that there is a support service provided at school] but they will have only a first name. They are not able to tell you which organization and how to get in contact with them or whether they're an OT or physio or speech therapist, or counselor. (Senior Clinician)

All health professionals spoke highly of The Royal Children's Hospital Education Institute. They saw the Education Institute as the interface between the hospital and the family and school. This is illustrated in the words of one health professional who explained:

> *The Ed Institute helps the schools understand what this young person's condition is because at various stages there's communication issues, particularly with the acquired brain injured group of kids. They may look normal but do not act normal. (Occupational Therapist)*

The additional support through volunteers at the RCH Education Institute was also very welcome:

> *They [the Education Institute] send the volunteers up; there are volunteer education people as well so they'll come up and help out as well. (Clinical Nurse)*

However, at the time the focus groups were conducted in May/June 2009, there was confusion about the shift in service provision provided by the Education Institute, for example:

> *I'm not quite sure with the new focus on providing learning opportunities for in-patients, those things that we've worked on in the past, whether they can still be provided. (Clinical Nurse)*

There was also some concern about potential insufficient support for the large group of out-patients:

They come into hospital and we're still discussing how we can best meet their needs and refer to the Ed Institute, and what their role will be and what we're willing to pick up. (Clinical Nurse)

4.2 Education Professionals

The 12 education professionals who participated in focus groups or were interviewed were those already well connected with the RCH Education Institute. Some were student welfare coordinators and most others were principals or assistant principals in primary and secondary schools. Their experiences and their perceptions were mediated by their role of facilitating student support.

A most striking feature of the interviews was the constant use of stories of particular young people. This was beyond the use of occasional anecdotes about one young person or another. The education professionals would use the opportunity of a question or prompt from the interviewer to tell the whole story of a young person and then distinguish this story from another:

> *Each young person comes with different issues and a different set of circumstances. And then it's different for each age. So I make decisions according to each child and it also depends on the particular teachers they have and the classes they are in. (Student Welfare Coordinator, Secondary School)*

They recognised and accentuated the individual nature of the schooling journey. They also highlighted the complexity of dealing with the range of people who were involved with each young person - their families, their teachers, peers, health workers and the school community. This process, they said, needed to be constantly monitored as it was rarely static.

How they see young people in their care

The education professionals spoke of the young people by name: 'There was Jonah'. While they recognised these young people were seen as 'the sick kids', they were very aware of how important it was for young people to fit in and not be labelled as a 'sick kid'. The stories they told of these young people emphasized themes of resilience. For some the struggle with medical conditions was seen to engender the development of resilience:

> *Some of them are just, you just wonder where the strength comes from that they are very, very determined to keep up their connections but also very resilient. (Student Welfare Coordinator, Secondary School)*

Some education professionals spoke of young people who had become ill or had medical conditions related to an accident while they had known them. Having known them 'before' and 'after' they acknowledged the young people were whoever they were 'before'.

For these young people (like all young people), relationships with peers at school were thought to be particularly important:

> *Look most kids come to school to see their mates, they don't come because they love maths, they come to socialise and it's the same for the sick kids. They want to be here because they want to see their friends and they want to be seen as normal and school is part of normal life. (Student Welfare Coordinator, Secondary School)*

Thus education professionals saw their work as centrally concerned with supporting that relationship:

> *They can repeat a year or they can catch up on the work and some of them you know who've been in hospital we can supply the work and they do the work in hospital or at home with the help of a visiting teacher and sometimes they can keep up academically, but the academic side of things can always be revisited the next year, but the social side of things is really difficult.*
>
> *Usually the really close mates, friends stay connected fairly well, others in the class will be you know all concerned and all want to have a piece of this person when they come back and then drift off very quickly yeah so they want their five minutes of fame. (Student Welfare Coordinator, Secondary School)*

However, supporting social relationships and inclusion was difficult. Absence can break the pattern of relationships. Education professionals recognized that even a short absence could be highly significant in breaking connections:

> *I think in the day to day classroom situation if you're not in the class you just disappear. (Principal, Secondary School)*

And prolonged absences reduced connections even further:

> *If someone is away for a long time the teacher might start off with good intentions but then forget or it slips their mind. (Student Welfare Coordinator, Secondary School)*

While technologies such as email and Skype support a continuing presence, this is at times an 'artificial' experience. Nevertheless, it was thought that these technologies hold some promise for the maintenance or re-establishment of relationships at school:

> Now with Russell last year I know the general studies teacher set up a couple of Skype things and there was one boy who did keep contact for some time but the majority of students didn't and it's interesting to see Russell back now and other students too. Once they come back after a few days of awkwardness they're back in the cut and thrust of classroom life and its fine again. (Principal, Secondary School)

And although teachers monitor the process of reconnection: 'I noticed yesterday in the playground he was sitting with some friends just watching them play down ball', the path to reconnection is sometimes difficult, particularly when some young people try new behaviours:

> He was trying to re-establish himself over and over again within the student group, so he'd come in and he'd be that sort of 'look at me, look at me' behaviour that was his way of developing his position in the social structure and it was a nightmare .That was his way of staying connected with the kids or re-establishing really himself with the kids. (Secondary School Teacher)

However, as one Student Welfare Coordinator reported, schools are not always able to prevent young people disconnecting:

> We had one girl who was … in Year 9 I think when she was injured, and she was unable to reconnect at all. Academically or socially, we tried, and we had visiting teachers and we tried to get her back in, but she ended up doing distance education because she couldn't. Now that may have been the nature of the girl, the nature of the injury. When she came back she had a halo and she was not meaning to be mean but she … was an attractive girl who was concerned about her looks before she had the accident. She was very, you know, the hair was always done and the makeup, she was a very girly girl yeah. And I think the whole halo scars thing was just too much for her. And she wasn't strong academically anyway so she struggled at school and because she'd missed so much she just couldn't, and that was really sad you know, she had a visiting teacher and we'd supply the work…. (Student Welfare Coordinator, Secondary School)

In instances such as this, the disconnection was immediate:

> She came one day and she just couldn't face it, it was just too much for her I think. I think it was the nature of the [injury], what was wrong.

How education professionals see their role in supporting young people

The most significant issue raised by the participants was around ownership of the knowledge about the illness. Education professionals had strong concerns about how desires for privacy impacted on good support by the school. Some felt constrained to

follow the lead of the young person or parents in regard to sharing or keeping private knowledge of the illness, its progress, its implications for the future of the young person and the treatments the young person must undergo. They view this as not necessarily generative:

> I think all staff should know, I think that's paramount for the success of the child being connected to the school and everywhere else but some parents, and this is from my experience only, just don't want people to know. And look even on the program that I run now we have some parents that we offer them the tutoring and they don't want the school to know that that child is getting anything extra. (Learning Program Manager)

In one particular case a primary teacher reported that in a case where the parents of a child with leukemia were open to disclosure, it was important to discuss the child's condition with his class to calm fears amongst classmates:

> there were times where I could feel that they were frightened and we'd spent a lot of time talking, … you know, they wanted to know what bone marrow was and what it meant so … the big book of the body came out and all that sort of thing so that … it took away, obviously you had to be careful what you said but it connected them. (Primary Teacher)

In another case, an assistant principal felt discussing the young person's health condition with the class was a proactive way of addressing potential rumours, teasing and bullying:

> One student that we have at our school at the moment and with her physical appearance … it's a clear indication that she's not 100% healthy and so students can make hurtful comments and it's important that we inform them, obviously with the student's and the parent's permission, on exactly what is happening there so that students are much more sensitive and understanding of that particular student. …It was a matter of just sitting down with the students and explaining the situation to them and … talking with [the student] as well in terms of just clarifying with her what she wanted us to say and how it was going to be said and who would be explaining this to the students. (Assistant Principal, Secondary School)

Teachers also recognized the importance of sharing knowledge with other teachers as young people make the transitions between classes, year levels, and sectors (primary to secondary). This varies region to region and relies heavily on the Year 6 and Year 7 staff and across a variety of schools.

School personnel and school culture

Teachers were aware of the complexity of the needs of these young people. This sometimes resulted in teachers feeling frustrated with processes, lack of knowledge and time constraints, 'we get frustrated but there's never, I've never seen anyone resent what they're doing for her'. In one case, a primary school assistant principal commented that supporting a young person effectively relied on placing them with the right teacher:

The strength of the classroom teacher … has a lot to do with it and it's really critical where you place your children with medical needs …You know those teachers that will just run with it and you know it will just be an absolute success before it even starts. (Assistant Principal, Primary School)

In another case, a school had sought and gained disability funding (under the deteriorating physical condition category) for an integration aide to be the link person between the young person and teachers:

I mean just having one key person even for them to link up with every morning, you know, when they do come to school; someone that they meet who knows them really well, who helps them with organizational skills and … just provides that link is really critical, and so we found that applying for funding and getting someone who's to work with the student when they're at school has been really valuable. (Assistant Principal, Secondary School)

According to these participants schools often have particular processes (eg. developing personal learning plans and associated information and staff development sessions) for addressing the needs of young people with chronic illness and most often this is based on the involvement of a welfare coordinator who oversees school connection and communication. All teachers who were interviewed mentioned the importance of this role and the success of the young person's connection being reliant on the quality of the work done by the person in that role. One Student Welfare Coordinator gave details of the work she does:

I will go in and visit the kids pretty early on if that is possible from their health point of view. If it's not I would start emailing if they can't have visitors and I always make a definite effort to meet with the parents and get to know the parents so that the whole school connection thing stays. If someone is away I remind the teachers. (Student Welfare Coordinator, Secondary School)

Links with family

It was reported that student welfare coordinators relied heavily on parents, particularly mothers, for updates on health progress. Some teachers were in regular email and phone contact with mothers. This sometimes occurred on a daily basis and involved home visits for keeping connected and for tutoring. Student welfare coordinators were also very aware of the family situations and additional responsibilities placed on parents of a young person with an ongoing health condition:

So what school should be about is supporting the family as well… it's not just about the academic support of a child any more…depending on what the needs of the child are, we support the whole family. (Student Welfare Coordinator, Primary School)

Links between school and hospital

For teachers, communication with health professionals is important and many reported receiving helpful information through briefings at the hospital or contacts with hospital staff. They assert they need to know how the condition will affect the young person, what might occur in the future:

> *I think the connection between the hospital and the school is really important so that you know what's going on and the student themselves know that you know what's happening. (Student Welfare Coordinator, Secondary School)*

This transmission of information from hospital to school and from school to hospital is often carried out by parents. But this can be problematic when the school does not have a complete picture of the child's health and because of privacy are waiting *'until the parent comes forward to let [them] know how sick the child is'* and how they can best support the family and the child.

Education professionals recognized that a whole school culture of inclusion is significant in supporting the social connection of these young people. They particularly appreciated health professionals who also recognized the importance of social issues:

> *I think it's great when the hospital facilitates the social side of things. When we took those kids in for the birthday they gave us a room. They did all that they could. (Student Welfare Coordinator, Secondary School)*

However, some education professionals felt that the link between social wellbeing and academic progress is not always well understood or appreciated by others outside the education profession and that this could lead to tensions between parents, health professionals and teachers:

> *They [hospital staff and parents] were worried he might stay down and that would not be good for his progress. I felt all the time the focus should be more on just keeping him hooked up with his friends and I think it's important they actually see that. We didn't get caught up in it we just did what we wanted basically from this end and while I did make sure he did do maths and so on it wasn't a priority. (Principal, Secondary School)*

Some education professionals reported that such tensions could be avoided by regular meetings between the parent, health professional, student welfare coordinator (and other key staff such as the integration coordinator, school nurse and visiting teacher) as illustrated in the following example:

> *… the Back On Track case worker made it a fairly clear road for us and for the parents and it was great support for the parent to see that we were all working together for her child … so if there's any questions or any understandings that need to be clarified, they're actually there to be able to assist … as well obviously things that they aren't able to disclose as well … and it also sort of clarifies some of the processes that they take in the hospital that we're not always clear on in the school setting and vice versa. They need to see what we've got in place, where there is a learning plan or whether or not we can access other resources or*

assistance for the child through the referral, whether it's language or speech or what other avenues we can tap into as well for the child or the child in the school setting. (Student Welfare Coordinator, Primary School)

Many teachers reported experiences of helpful contacts with health professionals, and in acknowledging the value of the exchange of information and knowledge that came from this communication, they advocated for further development of communication between health and education professionals that is inclusive of young people and their families.

4.3 Education Advisors

How education advisors saw young people in their care

The education advisors saw the young people in their care as having little control over their lives: *'the treatment is imposed, their procedures are imposed, their food is imposed, and their visitors are imposed' (EA 07)*. In hospital they are physically constrained, have limited privacy and they may feel socially isolated: *'We often hear of 'kids' who just aren't supported anywhere, they don't have parental contact, they don't have hospital contact, they don't have school contact and so they're kind of isolated' (EA 10)*. Young people from rural areas may have few networks available for them and also for their family. For young people in isolation rooms *'cabin fever sets in'*. For many young people with chronic illnesses hospitalization can be a way of life. As a consequence ongoing support and attention from families and friends may fall away in terms of regularity in contrast to the more intense support typically provided to young people who have shorter stays in hospital.

Education advisors also felt that young people experienced loss of control through busy treatment schedules in hospital that involves contact with numerous clinicians:

> *A gastro student was in the hospital last week and the surgeon was there, the doctor was there, the gastroenterologist, three nurses, myself, parent, grandmother, all around the bed and they were examining his stoma bag and shirt right up to there, undies down there. It was…, I just wonder what he was feeling at the time. And that's the first thought that struck me, I'm setting up a lap top and all of a sudden people converged, and I just wondered… (EA 10)*

Their schedules expand beyond the hospital as other health and education professionals establish contact with them:

> *And then when they go home they might have visiting teacher service, some of our guys might also have, through Red Kyte, have a tutor so they've got people at them everywhere… it was all these people sort of coming in and almost wanting a piece of him. (EA 08)*

> *Because there are that many people, plus with TAC, there are that many people in his life trying to keep this young boy connected it was just so overwhelming for the family. I don't need to be an extra person in their life at the moment so it was handed over to someone else. (EA 02)*

For some young people, their lives become very disjointed moving back and forth between home and hospital:

> *Even those ones who might come in for three weeks, they might have their blocks of treatment and they're in here for a couple of weeks at a time, they're often too sick. They're often too sick and then by the time they're better they go back home, and then they can go to school and then they come back and so they just have this very disjointed [life], so if you try and do any teaching with them they're just not up to it. (EA 08)*

Education advisors felt that fear becomes part of young people's lives. The fears may be about what is ahead of them. There are fears to be addressed at school such as what people will think when they look at them:

> *I work with 'kids' with external fixators, so a major frame on their leg going back to school, it's got the fear factor, it's got the look at me factor and the [young person] might not be ready for the look at me factor. (EA 07)*

However, one area in which young people were thought to have 'some sense of control' is their school work through access to laptops in hospital and at home as well as MSN. However, it was recognized that this control also extends to the young people's readiness to participate:

> *It's interesting, I've got one patient who is back in again and she refuses to have any contact with outside people when she's in hospital, including doing school work. And I worked really hard to get that connection with school and to get them on side in terms of sending school work through, and once they sent work through, she refused to do it. So you know you can facilitate all the connections and you can do all that but ultimately, if the student's not in emotionally the right place or not willing …. (EA 10)*

Nevertheless, for the education advisors, connection to school was seen as critical in terms of social networks and the young people's sense of worth and their identity: 'Kids don't want to drop out of school because it's their rock, it's their social network' (EA 07). They also believed that the young people recognized this need:

> *Most of the time they're busting to go back to school. (EA 08)*

> *It was a little preppie who brought it home to me who was really angry about being in hospital because 'I should be at school'. (EA 08)*

> *The 'kids' are defined by their picture of their classmates. (EA 07)*

Because school was central to social networks, education advisors reported that young people regard contact from the school as an indicator of the care of the school and also of the valuing of themselves. However they did recognize that some young people have never been connected to school regardless of their illness, and some refused to go to school. As one education advisor explained:

And we see a lot of risk takers, especially on the adolescent ward, and Four Main, we see a lot of risk taking behaviour. And that's an opportunity for us to get back in there because the risk taking behaviour is representing what's happening in their life. And we have an opportunity to bring education back to life for them, and support them to either go back in, or find a new school or whatever it takes. And I think that's just another important part of our role, that we can capture those 'kids' that are about to fall through the cracks and give them a second chance. And they're quite often the ones that say, I don't want to be at school, I've been wagging, I've been jumping on the train lines and all of that. But once they've had an accident, they sometimes have that wake up call; they'd like to be back with their peers. (EA 07)

They also reported that some young people were refused by schools. They reported instances where it was difficult to reconnect the young people to schools because the school blocked that reconnection.

The education advisors claimed that reconnection to school could also be inadvertently made difficult by families themselves. Some young people had families who made it too comfortable at home or families who did not want to let go. For other young people there can be problems at home: they can be very angry with their families or there may be problems with parents with mental health issues. The education advisors were very aware that the young people live in families with all the issues that any families might have. The difference for these young people and their families who are facing multiple other issues as well as chronic illness is that for those young people there are more layers to manage in the reconnection/connection process.

The education advisors recognized that young people may face teasing and bullying in schools and needed strategies to address this and to assume a degree of control. One education advisor provided specific instances of what happens in a young person's world that demands resilience and empowerment:

The clearest example … I have is the kids who are having limb lengthening and external fixators that I see in pre-admission clinic. So I see them as the school sees them, you know, they come in with their parents, they're told all this information about they're going to have this major surgery. So I see the capacity there but I can also talk to them about some strategies that they can use when they go back to school, whereas if you've got an acute cancer or something, you can't give a kid strategies prior to cancer. But with some of our kids we can build their resilience and talk to them about their surgery and what it means and how to be, what's the word, empowered going back to school and be in control of their frame, rather than the frame being in control of them, … and I think with a lot of our kids, when you see them individually, it's about building that resilience within them. We talk about teasing and bullying and we can go out and do the big meeting at school about teasing and bullying, but my firm belief is that we've got to work with those kids here to help them go back [with] some strategies and feeling good about themselves. (EA 07)

Views about support in schools

The education advisors had a strong sense of the fear that they believed was present among many school staff in regard to working with these young people; fear about doing the wrong thing or not knowing what to do. They claimed that fear has several manifestations. Sometimes it prevents the school from using inclusive practices: *'Sometimes those schools who don't do it [work with student] that … are the ones who are scared' (EA 08)*. Schools will sometimes say they are fine and do not need advice: *'Or they have said, 'no we're fine' and then things go a bit pear shaped, but it's often not for lack of wanting to do the right thing, it's often for fear of doing the wrong thing and [they have] probably been misinformed' (EA 07)*. At other times the school may suggest the young person stays home until they fully recover. Teachers in schools may also be requested to learn challenging procedures, for example, changing the inner tube of a tracheotomy for a young person in Year 7. Such procedures involve teachers in taking on new roles with new responsibilities. Also, parents may sometimes have unreasonable expectations of what the school can do, such as *'testing and the ability to inject insulin and that sort of thing particularly with lower primary kids' (EA 10)*. For the school there are also issues of legal ramifications of having the young person in the school:

> *Certainly one of my experiences, where a school didn't want a student back in a wheelchair, because they were really concerned about other kids pushing the chair. They didn't know, and I think some schools just really struggle with that concept. (EA 06)*

According to the education advisors, schools may have financial and resource demands as well. Finance may be available for long term initiatives but not for short term issues such as *'an extra pair of hands, someone to wheel a child backwards and forwards in between classes, take them in and out of the toilets, make sure they're safe in the playground. (EA 05)*

Despite these challenges, the education advisors were generally very positive about the ways in which schools supported young people with chronic illnesses and their comments were often were framed within understandings and practices of inclusivity:

> *I'd say 95% of the schools we deal with have [supported young people well], and it's 5% that really struggle to keep a young person in mind who doesn't fit into the structures that they already have in place. So if the school has got a fantastic student welfare program and is inclusive, see kids as individuals, have individual differences programs etc. etc., for our kids we can find a pathway in. (EA 07)*

Another education advisor's comments about a successful school offered insights into the ways education advisors gauge that success:

> *Sometimes you walk into schools and it's a no-brainer, it just happens. … it's the fourth time I've been to that school in two years for four different kids, four different conditions and they are just like yep, no worries. I had a list of things to talk about with physios and they just said, 'yeah, yeah', ticking off their list, no worries, 'yeah we can do that and oh we can open this gate so he can get to*

his car park and da de da and it just happened. And I think that it is a culture thing. (EA 03)

The education advisors were also able to point to signs when schools were unlikely to be successful in supporting a young person with chronic illness: *'When schools say to you, out of sight out of mind, about their kids' (EA 03)*, that resistance is sometimes due to lack of ability and knowledge such as *'a secondary school, where they kind of wiped their hands of it, just like I'm not quite sure what to do it's a bit too hard' (EA 11)*. Also, the failure of a school may not be consistent across the school:

> *But it's easy to generalize about schools because I found just over the last week that I'm working with two different kids from the same school, two different year levels, Year 8 and 9 – very different experiences for both families. Year 8 completely unsupported whereas the Year 9 family were much supported. So it's hard to generalize. (EA 10)*

One of the education advisors questioned why schools were able to work well with students with disabilities but struggled with students with chronic illness. It was thought that sometimes schools may be more successful with different diagnoses as noted in this comment:

> *And I think when you say out of sight out of mind, particularly with certain diagnostic areas, you get a variety of responses. I know cancer has got a high profile and that does give you an automatic … entrée in, but … I work in rehab so we've got students with ABI and it's an invisible illness in itself so often the schools are dealing with an illness they can't see. And we get more requests about behaviour and naughty children, naughty boys in particular, we get the "naughty adolescent" that schools struggle with without them looking at that's an illness connected with that behaviour. And some of the professional development that I've done in schools, when I go to whole staff and do that, it's because the student has had nuisance value, and nuisance value gets much more attention than illness value, which is a particular problem in the other diagnostic area that I work in, which is cardiac. That's also more recognized and so it depends out in the school community how they view the different diagnostic areas of illness and therefore how they treat those students. (EA 05)*

For the education advisors, success was sometimes attributed to finding the right person which suggests that if that person is not found the connection may fail. This raises the issue of school responsibility:

> *But as someone who is, I suppose, not that long out of schools, I just say that if you haven't got that person there you keep going up. Because I was always that person who got that phone call who said, your teacher isn't doing blah, blah and the schools just have to take responsibility for that. And at the end of the day, the passing the buck and not returning phone calls is just unacceptable and there is no reason why they shouldn't be doing the right thing. (EA 08)*

The question of school accountability generated extensive discussion in the focus groups. The issue arose as the education advisors discussed schools' resistance to having a young person at the school:

> The case of the school that wouldn't want the young girl back, because she had a scary appearance, there were lots of supports in place to say that student must be included and their school policy supported that, but then how do you actually administrate that? (EA 04)

The education advisors used various approaches to address accountability. They sought policy documents: *'but if you try and find that written somewhere i.e. a school is accountable for their students whether they're in school or out of school as a legal statement it's very, very difficult to find,'(EA 06)*. They also advised educational authorities or asserted their own authority to insist on compliance.

Effective support in schools

The education advisors identified three factors for effective support in schools: (1) the school culture; (2) finding the right person to work with; and (3) consistency in maintaining connections. A school culture that *'[has] a simple inclusiveness and openness to challenges that were taken on board in a very, very positive way' (EA 01)*, is what the education advisors tried to identify at a systemic level. However, they regarded the identification of the right person to contact at a school as an essential first step in the process. One advisor identified the critical and telling moment:

> When you contact a school you know from the person that you speak to, the kind of response you're often going to get. For instance, where I have seen the capacity built in school and where it has worked really well is because the head of student welfare is absolutely outstanding and really does take her job very seriously and does put all the supports and strategies in place so that when the next student did come along, she new exactly what to do. (EA 11)

> This key contact person is particularly important in the secondary school: 'It's really important and just having the right person [who is] actually wanting to do something could make or break it because they are the key, for six or seven other people'. (EA 11)

The education advisors also identified the consistency of the connection between school and the young person as a factor in success. They argued that the young person associates consistency with caring:

> And it's interesting because kids sometimes associate the school work element and getting their school work from the school as in how much the school cares for them. So for example, I've got a student from Mildura who had trouble getting work from school and it took a long time for it to come down. And so the school chose to send it by snail mail over fax. This girl was in tears because she felt the school didn't care about her, she was emailing teachers and all the rest and so it's that sort of connection. (EA 10)

They also made the point that it is not just a matter of consistency with school work: 'It sends a very clear message that they're actually valued and part of the school'. (EA 11)

Views on health professionals

The education advisors recognized the value of multi disciplinary teams in the hospital where it is possible to have 'conversations with so many different professionals where everybody is heard. So the school feels supported because they know who to go to' (EA 03). However, it was also a challenge for the education advisors to help medical staff see the educational needs of the young people and their identities as students:

It's interesting the other day when someone mentioned how changing the language in a medical forum from patient to student really changed their mindset. You know, because I guess they just see them as this patient, this thing that they need to treat but as soon as you say student you're personalizing it, and it's like, yeah, well they do have a life outside of the hospital. (EA 02)

A further challenge reported by education advisors was that they felt that some hospital staff do not appreciate their expertise in communicating with schools, nor do they understand the long term nature of the connection that education advisors have with the young people:

I think at times there's not that sense probably from the hospital perspective, about how long term our connection is. That it's not, and we don't like being reactive and just fixing and saying well off you go, because we know that's not the way it is. (EA 08)

Conclusions

From the health professionals' perspective, shifts in their practice have occurred as medical knowledge and technology has extended life expectancy and enabled many young people with chronic illnesses to look forward to social and educational activities in which their peers are engaged. Where the health professionals once saw the health condition first and the young person second, they now see them as resilient young people with capacity to self-manage their lives of which the chronic condition is only a part. This is reflected in the structure of health care at the hospital, that is, multidisciplinary clinical teams who see building relationships with families and schools as part of their role and the RCH Education Institute as an important link in this respect. However, they were uncertain about the new role of the Institute.

While some education professionals spoke of these young people as students whose needs they tried to meet like any other student, thus taking an inclusive stance, they were, nevertheless concerned about school connection and specific issues coming out of the young person's health condition. These included areas such as advocacy, funding for teacher aides and modifying the school environment; challenges of finding time to modify the curriculum, organize homework and home visits; communicating with health agencies;

and ethical considerations such as how much information to disclose to school staff and students about a young person's health condition.

Because participants interviewed for this project were health care professionals and education staff with particular personal commitments to working well to support young people with chronic health conditions it is reasonable to presume that their descriptions represent particularly positive situations where professionals providing advice and assistance are aware of key issues, skilled in responding to such issues, and invested in making things happen to the benefit of the young person. Indeed, their descriptions do contain a seemingly positive slant that does not always gel well with those issues highlighted earlier in the report through discussion of comments from the young people and parent participants in the study. Nevertheless, in spite of possibly being at the heart of current 'best-practice' around these issues, the comments from the health and education professionals involved in the study point to findings that still suggest that, for health and education professionals collectively, there is a need for better communication within and across sectors about how to best support individual young people in achieving their broader life and educational goals. There are also implications from the findings of this component of the study for policy and practice in both sectors such as how this knowledge might be diffused into broader professional communities.

5. Key themes and issues for attention

The Keeping Connected project was a collaborative project between university-based researchers and The Royal Children's Hospital Education Institute. Its primary aim was to contribute to better understanding of young people whose lives have been disrupted by chronic illness or accident as well as their ongoing relationship to education. It investigated, using qualitative longitudinal case studies, how these young people saw themselves, their hopes, their needs, their supports and the difficulties and challenges they faced, especially in relation to education, school, social connections, and their own future directions. The study also used interviews and focus groups to investigate how various other interested parties – health and education professionals of various kinds, parents – saw these young people and their needs. The project was longitudinal and qualitative, using ethnographic, visual and narrative methods. The approach taken aimed to: i) give a central role to the young people themselves and what they wanted to say and show others; and ii) show the diversity in the situations and personalities of the individuals involved, as well as drawing from these close-up studies a better understanding of issues for improving the support and engagement available to young people and their families.

Previous sections of the report have discussed project findings through each of the main components of the study. In this final section we consider several of the main themes that this project has highlighted: *1) Being normal, being vulnerable; 2) Support via a continuing process not a checklist; 3) Giving voice to diversity, and: 4) Advocacy, rights and communication*. Within our discussion of these themes we also draw out some implications and issues in relation to the work of the RCH Education Institute, and the broader mission of providing better support for young people across the education health interface.

5.1 Being normal, being vulnerable.

One of the major themes that has emerged from this research is a better understanding of the way the desire to be normal and the situation and awareness of being vulnerable are intertwined in the identity and practices of the young people, and that institutional policy and practices can fail by being too focused on only one end of this dynamic.

In our first encounters across the 31 case studies, and when we first viewed the sets of photographs produced by the participants as the story of who they were, we were struck by the extent to which these were images and conversations that might be expected of any teenagers of similar age. Friends, appearance, leisure activities, making statements about tastes - for example in the ways they decorated their room - and the ways they set up photographs of themselves were all important. Like others of this age, they were often trying out personas of who they were, and wanting to control how they appeared, and indeed the use of photographs in this project was one of its attractions to them. They largely chose to show themselves in activities and situations not related to their illness. This interest in being seen as normal was also evident to many of the health professionals

and education advisors whom we interviewed, and is reflected in comments many outsiders make about the apparent 'resilience' of these young people.

At the same time, this is a group of young people who have to cope with physical and psychological disruptions, needs and conditions that most of their peers do not. They may be out of school for extended periods, or for frequent shorter periods; they may not be able to participate in certain kinds of activities; they may be living with uncertainty about the nature of their illness (a number, especially with Crohn's disease, had initial long periods of mis-diagnosis); there may be continuing uncertainty about how their illness will impact on their lives in the future. At times their physical condition may produce low mood - even depression - or difficulties managing a full day of school, or planned activities with friends. Their mothers usually have the closest ongoing view of these changes. They tend to worry about their son or daughter, and try to mediate with schools and with professionals as needed, try to protect their child where this seems needed and advocate and facilitate their support and participation where they consider too much 'protection' is happening elsewhere (for example where a school response is to separate the child from their peers, or where academic expectations are lowered).

While the presence of these characteristics in this group of young people (wanting to be normal, being vulnerable) is not in itself a surprising finding, the project shows that the combination and interaction of these dual characteristics is an important dynamic in the young people's thinking about themselves and their future, and that schooling practices and policies often tend to emphasize one or other side of the dynamic at the expense of the other.

First, in terms of identity-making and hopes and planning for the future, the work involved in passing 'as normal' and the appreciation that they may lose this public status, is one source of the drive and determination (or 'resilience') many note for this group. Young people often go to great lengths to manage their continued education participation and to revise and reconstruct thinking about future careers that will work for them. But it is often at a cost: in public spaces such as school they can appear to be managing everything and maintaining the impression that they are coping as well as everyone else. Their vulnerability may be hidden from the view of their teachers and fellow students. At home their exhaustion and fears may be more apparent.

But another strand of the stories by the young participants is that many are frustrated in their wish to be seen as normal by peers and a school culture which takes any signs of difference as cause for bullying. The school bus was frequently reported as a site for problems. For some in our study the visible differences (catheters, scars, weight gain or loss, bloating, jaundice, collapsing at school) were sources of self-conscious concern in their school environment; for a few others, there were problems to be managed in having no external visible physical difference while having a significant condition that affected their wellbeing and behaviour (especially for those with acquired brain injury; but also for those with psychological conditions (eg. eating disorders) or greatly reduced stamina at particular points).

In the hospital setting the concern of the young people (and their families) was to maintain the status of 'being normal' as much as possible. Being denied access to their normal internet social networking sites, or to mobile phones, was experienced as adding to their sense of being taken out of their world; of potentially cutting ties with friends that

would require work to rebuild. Mothers often went to enormous lengths of daily travel, and juggling work, to bring preferred foods and be a familiar presence during periods of hospitalization.

In the school setting, a significant problem is that accessing support (including special consideration in examinations) often requires a very overt effort to build a case about what is 'not normal' about the young person. In the early interviews with the 'education advisors' located at the RCH Education Institute, this is one of the tensions they mentioned that was an issue for them. On the one hand they saw themselves as part of a drive to support the young person's re-engagement with their existing relationships and pre-established ways of being in the world as much as possible; on the other hand, they found that actually accessing support in the education sphere and in schools involved much form-filling and detailing of disability. In other words, the default position for some schools appears to be to treat young people as if they have no special needs, and the alternative appears to be to swing to the treatment of them as a highly visible category that emphasizes their difference. A key theme that emerged from the project was that we need to find ways of seeing these young people as both normal and vulnerable, not as either/or.

Schools and school programs that genuinely encourage and value diversity do make it much easier for young people in this situation to be able to talk about any of their needs rather than feeling a need to hide these. In the study we had three cases of young people who in the course of the study entered a Year 9 program that actually focused on personal and social matters – not on them specifically, not singling them out, but on diversity and different kinds of issues more generally. In each case they and their mothers reported a major positive transformation of their experiences, self-confidence and relationships with peers. Conversely, schools which are highly concerned about removing anyone who might threaten a particular pattern of high results or where teachers are not flexible in curriculum can be difficult places for these young people to be.

This research highlights an important question about 'Who should the school tell about the young person's condition?' The answer is that staff need to ask the young person and their family how they wish to proceed and discuss with them the pros and cons of various people having a deeper understanding of the young person's health-related circumstances. Those who do not want details made public may be signaling that the school is not a place where they trust such information to be used to promote the young person's interests.

Finally here, it seems possible that a focus by health professionals on returning to normal life and a curriculum of recovery (as reported in Section 4) may unwittingly reinforce some of the young people's desires and efforts to be perceived as 'normal'. Health care professionals have also expressed the view that parents, particularly mothers, have a strong influence on their children's attitudes to living with illness. However, there has not been a large focus amongst the parent participants in this study on a return to normal life, more so their emphasis has been on accommodating and adapting to new circumstances and supporting their son or daughter to move forward. Nevertheless, a heightened awareness amongst parents and health practitioners (as well as teachers) of the normal/different, visible/invisible dilemmas faced by young people could enhance collective efforts and attitudes towards supporting this group and help avoid interested parties unwittingly

contributing to and heightening young people's vulnerability and consequently complicating their access to support services which might otherwise be of benefit to them.

5.2 Support via a continuing process not a checklist

A strength of qualitative longitudinal research is that it enables researchers to see continuities and changes over time. It gives opportunities for young people to comment retrospectively on matters they were less willing to comment on at the initial time, or to talk about hopes for the future which we later see have had to be recast. In terms of 'education connectedness' and relationships with school, this is an important issue.

This study has drawn considerable attention to the fact that young people often experience their chronic health condition as a series of ups and downs, not something that is uniform in its effect or a simple trajectory over time. If we simply took at face value our first encounters with each person, the photographs they produced for us about 'who they were'; what they told us about themselves; we would have had a relatively simple picture: they want to be seen as 'normal' teenagers, and what they need is to be treated that way, with a bit of specific back-up if they are forced to miss school, or have trouble with mobility, etc. But over time we saw them and their families at different times: when they were down, or recovering from a period of depression or a physical set-back; when something had changed at school, with positive or negative consequences. What a young person may be able to do (or face) one week, they may not be able to do (or face) at another time. One of the reasons many mothers felt such a burden in managing the medical and education interactions concerning their child, was that they feel responsible for taking account of these shifting states, and of mediating and being an advocate in relation to them. In the case of school or other support mechanisms, a one-off assessment is insufficient to identify and respond to the variability/changeability of living with a chronic illness.

This study has also highlighted that 'disadvantage' in relation to schooling and examinations is not simply about amount of time missed. We had examples of young people (eg Sophie) who felt well-supported by school, who indicated that they had received positive feedback about how they were going, and yet whose actual VCE result came as a considerable surprise, much worse than expected. It seemed to the researcher when probing this further, that in part the problem may have been that although she managed to pass Year 11 (a year when she spent nearly 10 months in hospital), she may have missed some key units that re-appeared in the Year 12 examination, and may have received less than optimal guidance about Year 12 subjects. As well, she has a disease which saps her stamina. She now receives a disability pension, and in Year 12 there had been an application for special consideration for VCE, but neither she nor her mother knew exactly what that entailed or what benefits it brought. In a number of stories we heard that the kind of support the young person received from school was focused on the immediate situation, and the people they dealt with to arrange support changed as they moved to different year levels. Both these types of arrangement do little to promote the long-term interests of young people living and learning with an ongoing health condition.

Matters raised in different ways by all of those we talked to involved the need for attention both at the policy level and at the level of the practices and human interactions.

Because disruption and effects of chronic illness are a continuing process, when a hospital-related health condition of a young person is identified, schools need a process that can review support needs for the individual that project forward (eg to VCE pre-requisites, or special consideration) into future years, and that review and recalibrate as needed. At the policy level too, ways of getting better communication and review both across institutions and over time in schools in relation to an individual are needed, so that all the responsibility does not fall to the family to manage. There needs to be a good and confidential point of contact at each school with whom the ups and downs can be discussed.

In terms of individual practices and relationships, the study showed that the young people do not all want the same approach to whether the school makes their needs visible to others, so it is important that someone talks to and listens to the young person themselves in relation to such matters. Whatever the policies put in place, the very diversity of the situations and needs we revealed in this study indicates a need for points where these can be directly negotiated, and where this is not left to the urging of the mother to initiate.

5.3 Giving voice to diversity

It is tempting to treat our search for 'connection' or communication problems in education systems as if they were analogous to some medical problems – as if our research will provide for the one correct treatment and perhaps even cure of the condition.

However, in articulating conclusions to be drawn from this study, we are acutely mindful of the challenges to clarity that are posed by both the kind of data we have gathered and the way we have gathered it. We were searching for ways of understanding and appreciating how chronic illness impacts upon identity and the way schools respond to this. We have tried to see this relationship through a diversity of approaches and we have been conscious from the outset that there is not likely to be a clear or simple list of recommendations to be derived from stories and experiences which are as different and complex as identity itself. For example, there is little uniformity in what our young people or their families want made known to teachers, or fellow students, concerning even the most basic 'facts' of their condition. We encountered situations where individuals with the same condition had entirely different attitudes about revealing this information to fellow students, depending on their individual assessment of the culture of the school, and it was only our interviews which elicited understanding of the factors which make up this culture for each student. We also had cases where the same young person had different attitudes, over time, to their condition. When you extend this assortment of attitudes to the range of factors which includes school, family and friends it becomes a dauntingly complex area for the recommendation of practice or policy.

On the other hand, we do not want to make a virtue of complexity. From the conceptualization of this study we have been looking for ways to ensure that sometimes deeply affecting stories and images should not obscure the need for practical advice that might help young people other than those who have generously shared with us their own distressing experiences.

There are some distinct possibilities for better practice among teachers and health care practitioners, including the prospect of using stories of this kind in professional development, and for fine tuning current approaches to understanding key issues such as diversity and identity in teacher education. But the major thrust of our advice for achieving happier and more equitable outcomes for young people like our participants is essentially a matter of voice – but not theirs alone. We mean the voice of an effective advocate, above and beyond the advocacy already enacted by parents.

5.4 Advocacy, rights and communication

The young people and their families in the case studies exhibited stoical determination in their interactions with both health and education worlds. Parents commonly reported that they had worked persistently over many years to find their way through both systems with varying degrees of success. Both hospitals and schools appeared as complex mazes to most of the parents. In the absence of formal communication channels, it was usually the mothers who embodied any interface between health and education. And yet, some parents reported that they were often perceived to be nuisances in both sectors while trying to meet their son or daughter's health and education needs. What has emerged as a clear and pressing need is a system of advocacy on the part of the young people and families within both health and education systems—and between schools and the hospital.

Young people and parents often felt that the scheduling of clinic appointments at RCH takes little account of the young person's education commitments, so they continue to miss classes – even when they are well. The timing of appointments was also felt not to adequately acknowledge the significant disruption to the lives of families, particularly those from outside the metropolitan Melbourne area. In the health care services used by these families there does not appear to be a systematic approach to advocacy and overall management. As one father pointed out:

> My solution is the social workers should be from the point when you join the hospital – they should be with you continuously. Whereas the medical system works on departments, so in ICU, intensive care – and you have social workers there – and then you change social workers…you can't [raise all issues] with your medical experts like your surgeon [who] you'll see…more intensively around surgery…so from then on, the nursing staff from intensive care [become the main health staff you talk with]…but you can [raise issues and concerns] with the social worker and they are the ones that can lead to all [sorts of solutions], but there didn't even seem to be a check list of 'This is what you can do,' or 'You go there'.

This points to a significant discontinuity of support within the health setting, but even if that were rectified, these social workers do not appear to commonly work with staff in regular educational settings so further discontinuity is therefore inevitable.

Similarly, many schools have rigid and impenetrable systems and processes and many of the young people in this study seemed to escape being noticed by their teachers. Young people with chronic illness tend to slip easily under teachers' radars in classes with 20 to 30 others—especially when they are trying hard to blend in with the other

students. Information that parents carefully provide to schools, related to their daughter or son's absence, health events or the need for support is often not relayed to classroom teachers. And in secondary schools, young people typically have a dozen teachers in a single year, so communication—or lack of it—has emerged as a major concern for parents and young people.

Health professionals and teachers who participated in the study also acknowledged that communication within the school and between the hospital and school could be better. Those health professionals who spoke to us were adamant that any discussions about managing health conditions in schools should involve the young person in discussing their circumstances and identifying their needs. Education professionals did not raise this type of collaborative interaction as a key concern.

Each student with a chronic health condition in any school sorely needs one consistent, long-term contact person to take formal responsibility for advocacy and communication within the school, with the young person, parents and with health professionals. This could be a role where one individual has time and resources to support multiple young people within a school, or where a range of individuals are each given responsibility for supporting just one such student each.

Many of the young people consulted in this study have been overlooked in education, and their rights—in terms of access as well as success and achievement in education—have often been ignored. Rather than be accommodated by schools, these students have more commonly been expected to accommodate inflexible school regimes. Additionally, many have not been informed about options for part-time study or undertaking high-stakes final year programs, such as VCE, over longer periods of time.

Our study indicates that lowered educational expectations of young people with significant health issues is common, but does them no favours. The question that needs to be asked at this point is, 'How can these young people best be supported in their formal education?' The answer lies in the development of systematic and formal approaches that i) interact effectively across the boundaries of the health and education sectors, and ii) involve advocates from both the school and the hospital working together to monitor and support the progress of these young people. While different aspects of the study unearthed kind and supportive individuals in both sectors who stepped in and helped (sometimes proactively but more often at times of crisis), this does not constitute appropriate systemic or systematic support. While this inadequate situation is compounded by the desire of many of the young people consulted in the study to quietly fit in, they do have particular requirements that, if met, would enable them to achieve in education and consequently improve their overall life chances. These requirements differ enormously between individuals and do not automatically relate to extensive, or expensive, resources.

In summary, hospitals need to acknowledge and support the young person's pursuit of education as a vital part of their overall health and wellbeing, while schools need to acknowledge and support the young person with health-related issues to develop their social connections and maximize and maintain their potential in educational achievement. It is clear that parents carry a heavy burden of promoting their child's interests each day and whilst some are savvy in navigating their way through the health/education interface, many are not so fortunate. Like young people, parents have need to be supported institutionally in dealing with the complexities that accompany having a child with a

chronic health condition, and to have someone other than them to advocate on behalf of their son or daughter in both systems.

Through its awareness of the key issues, as well as its connections to health professionals and the education sector, its research and support model, the Royal Children's Hospital Education Institute is well positioned to influence policy and practice across these sectors. However responsibility also belongs in hospital teams and schools to find better ways to support young people in achieving their life goals. Government policy and resources need to support education and health professionals to take up this responsibility and focus on enabling young people with long term health challenges to engage and achieve in education.

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Appendices

Appendix A: Publications and conference presentations from the project to date

Journal Articles

Yates, L. (2010) The story they want to tell, and the visual story as evidence: young people, research authority and research purposes in the education and health domains. Special issue: Visual Research Methods and Issues of Voice. Visual Studies (in press).

Guillemin, M. & Drew, S. (2009) Questions of process in participant-generated visual methodologies. Visual Studies. (in press).

White, J., Drew, S. and Hay, T. (2009) Ethnography Versus Case Study: Positioning Research and Researchers Qualitative Research Journal Vol. 9, No. 1, pp. 18-24.

Conference Presentations 2007-2010

AARE symposium 2009: Adolescents living and learning with chronic illness: Resilience, goals and life trajectories. Canberra, 29 Nov – 3 Dec 2009

- Ferguson, P., Drew, S., and Walker, H. 'Chronic illness and resilience: Personal strengths, material resources and social supports that help young people remain engaged with education and social life'

- Moss, J. 'Growing up with a chronic illness: A story of a girl'

- Hanewald, R., St Leger, P. and Dixon, M. 'Health and Educational Professionals Perspective of Young People who have a Chronic Health Condition'

White, J. (2009) The 'Keeping Connected' Project: Negotiating Methodology, Ethics and Findings in a Performative Context, paper in the Australian Association of Educational Research (AARE) Symposium 'Shaping Australian Education Research: By Whom, For Whom, In Whose Interests? British Educational Research Association (BERA) Annual Conference, University of Manchester 2nd - 5th September.

White, J., Drew, S. and Yates, L. (2009) Creativity and going beyond: investigating identity, connection and ethics The Fifth International Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign, May 20th – 22nd.

Drew, S. White, J. Ferguson, P. and Hay, T. Teenagers and chronic condition self-management: Much more than medical aspects of self-care. (Poster), Society for Adolescent Medicine Annual Scientific Meeting, Los Angeles, US, March 2009.

AARE symposium 2008: Schooling, identity and social connectivity: Sustainable futures for young people with chronic health conditions. Queensland University of Technology, 30 Nov – 4 Dec 2008

- Yates, L. 'Research design and the Keeping Connected Project'

- Potas, T., Green, J., St Leger, P., Robertson, M. 'Negotiating partnerships to build strategy for supporting young people with chronic illness in schooling'

- Ferguson, P., White, J., Hay, T., Drew, S. 'Voicing Identity'

- Moss, J 'Schooling, identity and social connectivity'

Drew, S. White, J. Ferguson, P. and Hay, T. Teenagers and chronic condition self-management: Much more than medical aspects of self-care. International congress on chronic disease self-management, Melbourne, Australia, 26-28 November, 2008.

Guillemin, M. and Drew, S. Ways of seeing, ways of knowing: Visual methodologies and questions of process. Re-imagining Sociology: The Annual Conference of the Australian Sociological Association, Melbourne, Australia, 2-5 December, 2008.

Ferguson, P., White, J. and Hay, T. (2008) 'Perspectives from the Inside: The Voice of the Student' Keeping Connected: Young People, Identity and Schooling Conference Royal Children's Hospital, Melbourne, 21st July.

White, J. and Hay, T. (2008) Friendship, schooling and chronic illness: connecting with young people or collection of data? The Fourth International Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign, May 15th– 18th.

Yates, L. (2007) 'Connectedness' and the hospital/schooling interface: evidentiary and ethical issues in a collaborative research project using visual and narrative methods Panel on "Methodological issues in study of urban youth", American Education Research Association Conference, Chicago, April 2007.

Professional Non-refereed Journals

'Keeping Connected', Australian Teacher Magazine, June 2010, Vol 6, No. 5, p.40. Available online: www.ozteacher.com.au

Walker, H. (2010) Keeping Connected: Young people living and learning with ongoing health conditions. Curriculum Leadership, Vol. 8, Issue 14. Available online: http://cmslive.curriculum.edu.au/leader/keeping_connected,31245.html?issueID=12129

O Keeffe, D. (2010) Down but not out, Education Review, pp. 8-9, February 2010

Wright, K. and Robertson, M. (2007) Keeping Connected: Young people, identity and schooling, Curriculum Leadership, Vol. 5, Issue 22.

Project Reports

'Keeping Connected: Young people's stories of living and learning with an ongoing health condition'. Available online: http://www.education.unimelb.edu.au/keepingconnected/publications/yp_report.html

This report was written in December 2009 for the 31 young people who participated in the longitudinal case study component of the Keeping Connected project. Their stories and photos form the central focus of the report.

The RCH Education Institute Client Database Audit: Technical Report, March 2009.

Media Reports

'Exposing the Damage', Genevieve Costigan, The Voice, Vol. 4, No. 2, p. 7, March 2009

'New School of Thought on Ill Kids', Margaret Cook, The Age, 19 March 2007

'Study into how adolescent illness disrupts schooling', UniNews, Vol. 16, No. 3, 5-19 March 2007

Appendix B: Participant demographics

1. Case study participants:

Gender	Age at start of project 2007	Age at onset	Health Condition
F	18	5	Addison's Disease B12 Deficiency
F	17	11	Ulcerative colitis, primary sclerosing cholangitis
M	17	7	Bronchiectasis
F	16	16	Crohn's disease
F	16	8	Juvenile Rheumatoid Systemic Chronic Arthritis
F	16	16	Stroke
F	16	16	Lupus
F	16	16	Fractured skull and other injuries
M	16	15	Common Variable Immunodeficiency (CVID)
F	16	birth	Familial Mediterranean fever
M	16	3mths	Stickler Syndrome, Neuronal Intestinal Dysphasia
M	15	14	Crohn's disease
F	15	9	Crohn's disease
F	15	12 or 13	Chronic Fatigue
F	15	14	Head injuries after bike accident
F	14	10	Mitral heart valve prolapse
F	14	14	Anorexia
F	14	11	Bronciolitis obliterans & avascular necrosis
F	14	10weeks	Cystic Fibrosis
M	14	13	Stroke avm
M	14	9mths	Haemophilia
M	14	14	Eating Disorder
F	13	9	Myasthenia Gravis - autoimmune neuromuscular disease
F	13	6weeks	Cystic Fibrosis
M	13	12	Craniopharyngioma/Hypopituitarism
F	13	12	Acquired brain injury
F	12	12	Chronic Pain Syndrome
M	12	11	Crohn's disease
F	11	11	Scoliosis
M	11	7mths	Haemophilia
F	10	18mths	Hereditary Angioedema

2. Past clients of the RCH Education Institute - retrospective interview participants:

Gender	Age	Health Condition
F	27	Cerebal Palsy
M	26	Spina Bifida
F	23	Diabetes
M	23	Brain injury
F	23	Cancer
F	22	Cancer
M	20	Cancer

Appendix C: Example information statements and consent forms

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Young person starting in 2007

HREC Project Number: 26203

Research Project Title: Keeping Connected

Thank you for taking the time to read this Information Statement. This Information Statement and Consent Form is 4 pages long. Please make sure you have all the pages.

For people who speak languages other than English: If you would also like information about the research and Consent Form in your language, please ask the person explaining this project to you.

You are invited to participate in a research project that is explained below. This research project is a project of the University of Melbourne (Faculty of Education) together with the Centre for Adolescent Health and has been funded by the Australian Research Council in association with the Education Institute of the Royal Children's Hospital.

What is an Information Statement?

These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you would like to take part in the research.

Please read this Information Statement carefully. You can ask us questions about anything in it. You may want to talk about the project with your family, friends or health care worker.

Participation in this research project is voluntary. If you don't want to take part, you don't have to. You can withdraw from the project at any time without explanation.

Once you have understood what the project is about, if you would like to take part please sign the consent form at the end of this information statement. You will be given a copy of this information and consent form to keep.

1. What is the research project about?

This research project is looking at how having an ongoing health condition or accident trauma can have an impact on young people's experiences of school and education. Many young people with health conditions or trauma can have long absences from school that can make it harder to stay in touch with friends, other students, teachers and the broader school community. There has been little research on the education experiences and relationships of young people in this situation and we want to learn more about it. We are interested in hearing more about how young people's experiences of education and school-based relationships are shaped by significant health problems. The focus of the project is on young people's connection to school when they have an ongoing health condition, it is not specifically about your health condition.

The main focus of the project is getting information about these issues from young people themselves. We are asking around 3000 young people to take part in our project. All of the young people participating are patients of the Royal Children's Hospital and clients at the RCH Education Institute.

We are also interested to get the opinions of some other groups of people. We will be talking to:

• Around 20 parents of young people with a chronic illness.

• About 30 educational professionals and around 15 health care professionals who work with young people with a chronic illness.

• About 20 young adults who were clients of the RCH Education Institute in the past.

All the information that we are gathering from different participants will help us to highlight key issues that will help guide schools and health professionals in developing further programs and approaches for supporting young people with chronic illness or accident trauma in the future.

2. Who are the researchers?

• Professor Lyn Yates is the Associate Dean of Research and Research Training in the Faculty of Education at the University of Melbourne.

• Dr Lyndal Bond is a senior researcher at the Centre for Adolescent Health at the Royal Children's Hospital.

• Dr Julianne Moss is a senior lecturer in the Faculty of Education at the University of Melbourne.

• Dr Julie White is a lecturer in the School of Educational Studies at La Trobe University.

- Dr Pamela St Leger is a senior lecturer in the Faculty of Education at the University of Melbourne.

- Dr Trevor Hay is a senior lecturer in the Faculty of Education at the University of Melbourne.

- Dr Peter Ferguson is a senior lecturer in the Faculty of Education at the University of Melbourne.

- Dr Sarah Drew is a researcher at the Centre for Adolescent Health at the Royal Children's Hospital.

- Dr Mary Dixon is a lecturer in the Faculty of Education at the University of Education.

3. Why am I being asked to be in this research project?

We are asking you to take part because:

- You are aged between 10 years and 18 years of age.

- You have an ongoing health condition or have been involved in accident trauma that is being treated at the Royal Children's Hospital.

4. What do I need to do to be in this research project?

We would like you to:

Part 1: Complete a survey.

We will ask you to complete one survey during 2007 and one survey during 2008. The survey will take around one hour to complete. It will ask questions about how you feel about your school, family, friends, and about yourself. The survey can be completed in a number of ways:

- Using an online web-based survey while you are at the Royal Children's Hospital or at home.

- Over the phone with one of our researchers asking you the questions and writing down the answers.

- Using the old-fashioned paper and pen survey.

Part 2: Be involved in an in-depth case study

At the end of the 2007 survey, we will ask you if you want to be involved in a case study.

If you are involved in this part of the project, you will be matched up with one member of the research team. We will ask you to:

- Be involved in four in-depth interviews. Two interviews will take place during 2007 and two will take place during 2008. Each interview will take about one hour to complete and will focus on questions about school, friends, social activities, your health etc.

- Be involved in taking some photographs and/or video footage that will help tell a visual story of your experiences. This will help us to understand more about the issues that are important to young people.

Being involved in Part 2 of the project means a time commitment of around 10 hours over 2 years. We will support you to complete the tasks so that they are as easy as possible.

Because of the nature of the second part of the project, it is possible that even if you say you are interested in taking part, you will not be selected to take part.

If you are selected for the case study part of the project, we will give you further information, and you and your parent/guardian will be asked to complete another consent form at a later date.

5. What are the possible benefits for me?

There is no direct benefit to you for taking part in our research project. However, we hope that you will enjoy talking to us about your experiences.

6. What are the benefits to other people in the future?

We hope to use the information we get to learn more about the experiences of young people with a chronic illness or accident trauma. We hope to understand ways that we can best support young people with chronic conditions to stay connected with school and friends and to develop new programs and approaches to help them do this.

7. What are the possible risks, side-effects and/or discomforts?

We understand that talking about a health condition and personal aspects of your life might sometimes be difficult. There is a slight possibility that you may become unhappy or distressed by some of the topics that are covered in the survey and case study discussions. We have done our best to make sure that the questions will not cause you to feel upset. If you do feel unhappy at any stage during the project and would like to talk to a counsellor at the Centre for Adolescent Health, we can help arrange this for you at no cost.

8. What are the possible inconveniences?

The main inconvenience to you is the time that it will take to participate in the project. This includes the time it will take to fill out the surveys and be involved in the case study. We will do our best to make this as easy for you as possible.

9. What will be done to make sure my information is confidential?

All the information we collect from the surveys and case studies will be kept private. We will not use your name on any of the information we collect. If necessary we will use a false name. The information will be stored in either a locked filing cabinet that only the researchers on this project have access to, or on a computer that is password protected. Researchers who are not directly involved in this project, but who are interested in the project, may also look at the information we have gathered.

Any information that can identify you will be kept private unless the law requires us to share it. The Ethics Committee at the Royal Children's Hospital will also be able to access this information if they need to. All the information will be kept for at least 7 years after your 18th birthday and then destroyed once we have stopped using it.

If we write or talk about the results of the project, or produce educational manuals or videos, we will not use any real names in order to protect your privacy.

10. Will I be informed of the results when the research project is finished?

We will send you a short report of some of the results at the end of the project. This information will not be about individual people but it will be about the group information as a whole.

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name: Dr Lyndal Bond

Contact telephone: 9345 6674

If you have any concerns about the project or the way it is being conducted, and would like to speak to someone independent of the project, please contact:

Dr Catherine Lees
Manager, Ethics and Research Office
Human Research Ethics Committee
Telephone: (03) 9345 5044

CONSENT FORM FOR PARTICIPANT TO GIVE INFORMED CONSENT TO TAKE PART IN A RESEARCH PROJECT

Young person: Starting in 2007

HREC Project Number: 26203

Research Project Title: Keeping Connected

Researcher(s):   Prof. Lyn Yates, Dr Lyndal Bond, Dr Juilanne Moss, Dr Julie White, Dr Trevor Hay, Dr Peter Ferguson, Dr Mary Dixon, Dr Sarah Drew, Dr Pamela St Leger

I (Participant name) _____

voluntarily consent to take part in the above research project explained to me by

Mr/Ms/Dr/Professor _____

I believe I understand the purpose, extent and possible effects of my involvement in this project.

I have been asked if I would like to have a family member or friend with me while the project was explained.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that the researcher has agreed not to reveal results of any information involving me or my medical history, subject to legal requirements.

If information about this project is published or presented in any public form, I understand that the researcher will not reveal my identity.

It has been explained that my involvement in this project may not be of any benefit to me.

I understand that if I refuse to consent, or if I withdraw from the project at any time without explanation, this will not affect my access to the best available treatment options and care from The Royal Children's Hospital.

I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (1999).

I understand that this project has been approved by the Royal Children's Hospital Ethics in Human Research Committee on behalf of the Royal Children's Hospital Board.

I understand I will receive a copy of this consent form and Participant Information Statement.

Signature _____ Date _____

Name of witness to participant's signature (printed) _____

Witness signature _____ Date _____

I have explained the project to the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this project.

Researcher's Signature _____ Date _____

Note: All parties signing the Consent Form must date their own signature.