An Australian and New Zealand review of education support for children with chronic health conditions.
April 2015

This report was prepared by Dr Liza Hopkins on behalf of The Royal Children’s Hospital Education Institute.

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Executive summary

Introduction
Education support for students who miss school due to a health condition is an essential component of a holistic or child- and family-centred model of care. Yet the provision of education to children absent from school both during hospitalisation and during periods of recovery at home has been characterised by lack of policy direction, fragmented services and disconnection between education systems and health care systems. As medical care improves and rates of some chronic illnesses also increase, ever increasing numbers of children and young people are living with chronic health conditions which may necessitate frequent, regular or long term absence from school. Ensuring these students are not disadvantaged educationally is a challenge for both the education and health care sectors.

The project
This report describes the findings of a recent research project into the nature of education support to students with health conditions across Australia and New Zealand. Due to the diversity of settings in which such support is delivered, the nature of the education support system and the paucity of relevant policy across the jurisdictions in this region, the research focussed on the provision of education support to students in hospital. In some jurisdictions the hospital based education support extends to home and community care settings as well, while in other states hospital schools and education services are restricted to the hospital setting. For these reasons the findings of the project are presented on a national and state by state basis.

The project explores primary data obtained through interviews with key personnel in health-care and hospital-based education settings across Australia and New Zealand, as well as presenting preliminary findings of a web-search for relevant policy documents and details. The report takes a descriptive approach to the data collected, in order to explore the similarities and differences in the models employed across different jurisdictions. The project also involved a brief review of the relevant literature, to help identify the elements of good practice in education in health care settings.

Key findings
The project identified a number of elements which were common to education support services for students in hospital across Australia and New Zealand, including:

- Education support for long stay hospital inpatients either in classrooms or ward based services for students confined to bed
- Support for siblings of inpatients as needed, including referrals to enrolment in local schools
- Liaison with home schools for long stay patients for curriculum, assessment and reporting purposes
- Provision of support to school aged students regardless of whether they are enrolled in government or non-government schools.
In addition to these common features the following issues were commonly identified as pertinent, although managed in different ways in different settings:

- Provision of education support during periods of recovery at home
- Implementation of the national curriculum in Australia
- Distinguishing between students with mental health and medical health conditions
- Eligibility criteria for service
- Use of digital technology to connect students with their regular school
- Liaison between the hospital and the regular school.

In conclusion, the report draws together the findings of the primary research with the published evidence from the literature review to present the elements of a model of good practice which best supports the educational needs of students living with chronic health conditions.
Introduction

Inclusion and education are key determinants for the healthy functioning of contemporary democratic societies across the globe, and improving the systems which promote participation in education and increased social, economic and political participation are critical for governments at all levels. Yet despite public, media and government rhetoric about improving educational outcomes for all students, increasing inequality across a range of social indicators is producing a growing gap between those able to achieve their full educational potential and those at risk of being left behind (Cobbold, 2014). One group, in particular, at high risk of not reaching their full potential in the education system are those students living with chronic health conditions which affect their ability to attend school regularly, or which have other effects on student learning, even when the student is able to attend school.

As medical science advances, and understanding of genetic conditions improves, increasing numbers of children and young people are living with chronic health conditions which might once have been fatal or severely debilitating. At the same time, health care systems are continuously seeking ways to reduce costs and decrease length of hospital stays, while improved medications and treatments which prolong life may also have hidden side effects and long term consequences. While accurate numbers are hard to come by, reliable estimates suggest that up to 30% of school aged children in developed countries may have a chronic health condition (Halfon et al. 2012). Some of these students, such as those with mild asthma or managed diabetes will have their health conditions largely managed in the community and at home, while others, including those with childhood cancers, genetic conditions such as cystic fibrosis and those who experience severe trauma or head injuries may face long periods in hospital or repeated admissions and greater or lesser periods of time recuperating at home.

Ensuring that the educational needs of these children and young people continue to be met in conjunction with their ongoing need for high level health care remains a challenge at the level of both policy and practice. Diversities in approach between health bureaucracies and educational bureaucracies, differences in funding models, varying outcome measures, different institutional responsibilities, existing models of care and service delivery and the range of individual and family circumstances make the development of an integrated education service challenging. It is clear, however, that education support for students made vulnerable due to their health condition must be a priority for governments serious about meeting their obligations to all students under international conventions on the child’s right to education.

This should not be taken to imply that education support does not currently exist for students with health conditions. Across Australia and New Zealand a range of services and supports exist to ensure children and young people do not prematurely disengage from education due to illness, accident or injury. Such services are provided by government education bureaucracies, by health services, by private and not-for-profit organisations and by philanthropic agencies. They vary in the eligibility of students to receive help or enrol in the service, in the age of students catered for, in the locations in which education may be delivered (including in hospital, in schools, at home and
in community settings) and the educational sector covered (pre-school, school, post-compulsory education and flexible learning providers).

Our approach

Aims of study

In order to obtain a better picture of the similarities and differences in education support services available to children and young people across Australia and New Zealand, this research project was developed and undertaken in late 2013 - 2014. The project took a descriptive approach, gathering information about the nature, extent and policy underpinnings in this domain of the education system, to compare and contrast the various models which currently exist. The explicit aims of the project were to:

- Identify best practice in education for children and young people with health conditions through undertaking a review of the relevant literature;
- Examine legislation, policy and programs on a national and state/territory basis across the two countries;
- Identify successful strategies and models of good practice in providing education for children and young people with health conditions;
- Explore the existing factors within schools and services that promote effective service provision, and;
- Consider where the gaps exist between evidence for best practice, existing policy and existing practice.

Methodology

The project aimed to develop a descriptive account of the education support models available to students in hospital across Australia and New Zealand. Two different approaches were made to the data collection:

- A web based search for the relevant legislation, policies and programs in each jurisdiction, including the Australian Commonwealth, and;
- Primary research with senior staff members from a selection of schools and services which support the educational needs of children and young people with health conditions.

The project also included a brief literature review examining current published knowledge on the nature and effectiveness of education support programs for students with health conditions. The project was approved by the Office of Research Development and Ethics at The Royal Children’s Hospital in accordance with the Australian National Statement on Ethical Conduct in Human Research.
Web search

The search for policy documents was conducted on a national and then state by state basis, looking at the public websites of education departments and ministries in each jurisdiction across Australia and New Zealand. This was then followed up by direct email contact with each state/territory to request more detailed information. While not all jurisdictions responded, those that did sent through links back to their websites, suggesting that this is the most reliable source of public information on educational policy. In nearly all cases, information referred to programs in place to support the education of children and young people with health conditions, rather than actual policy documents. While legislation exists to enshrine the right of children and young people to receive education, little explicit policy exists to articulate the services which are or ought to be available to students absent from regular school due to their health condition. These policies and programs operate in widely divergent ways in different jurisdictions (and sometimes even within jurisdictions), varying across domains such as:

- Location of service
- Eligibility criteria
- Age of students
- Source of funding
- Administrative requirements
- Who they are delivered by, and how they are accessed.

For this reason it is almost impossible to group provision across jurisdictions and therefore each state/territory will be considered separately in this report.

Primary research

As well as conducting a web search for relevant policy and programs information, a preliminary search was also undertaken to gather information specifically about provision of education support to students in hospital across each jurisdiction, since this provides the clearest parameters around education support for children and young people with health conditions, as distinct from other groups of educationally vulnerable students such as students with disabilities and students with learning difficulties. Assistance was also sought from the HELP Alliance (Health, Educators, Learners, Practitioners), an association of educators working with students with health conditions across Australia and New Zealand.

Selection of respondents

Once the main providers of education support to children and young people in hospital were identified, a sample of providers were approached directly and asked to participate in either a face to face or telephone interview. The sample was chosen using the following criteria:

- Statewide or regional provider of education support across whole jurisdiction (WA, SA, Tas, New Zealand)
• Hospital school in specialist paediatric hospital or largest state/territory general hospital (NSW, Qld, ACT, Vic, NT)
• Selection of education providers in smaller/regional settings such as hospital classrooms or seconded teachers (Qld, Vic).

In all, the following schools and services provided primary research information:

<table>
<thead>
<tr>
<th>ACT</th>
<th>The Hospital School, Canberra Hospital</th>
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<tbody>
<tr>
<td>NSW</td>
<td>Sydney Children’s Hospital School</td>
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<td>Hospital School at Westmead</td>
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<td>John Hunter Children’s Hospital School</td>
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<td>NT</td>
<td>The Royal Darwin Hospital School</td>
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<td>Qld</td>
<td>Mater Hospital School</td>
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<td>RCH Hospital School</td>
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<td></td>
<td>Cairns Hospital Class</td>
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<td>SA</td>
<td>Hospital Education Services</td>
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<td>Tas</td>
<td>Tasmanian eSchool</td>
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<tr>
<td>Vic</td>
<td>RCH Education Institute</td>
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<td></td>
<td>Monash Medical Centre Paediatric ward</td>
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<tr>
<td>WA</td>
<td>SSEN:MMH</td>
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<tr>
<td>NZ</td>
<td>Northern Regional Health School</td>
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</table>

In addition to interview responses, information available publicly through documents such as School Annual Reports, conference presentations and hospital and school websites was used to support the primary research findings. A full list of hospital education services is included at Appendix One.

**Data collection**

Data collection took place in the latter part of 2013 and early in 2014. Face to face interviews were either conducted in Melbourne, or at the HELP conference on the Gold Coast, which was attended by many hospital educators from across Australia and New Zealand. The remaining participants were recruited through email contact and interviewed by telephone, except for two respondents, who responded by email. Both face to face and telephone interviews were recorded with the permission of respondents, and the recordings were professionally transcribed.

**Data analysis**

Since the aim of the research was to provide descriptive data, the majority of data is reported directly as uncovered through interview or document analysis. Some further analysis of the qualitative data captured both from interviews and from secondary documents was carried out using standard thematic analysis techniques, to identify underlying themes in the data and to draw
out parallels between services in different jurisdictions, as well as to identify some of the differences in services.

**Scope of the report**

This report includes the findings of each of the research steps outlined above. It begins with a review of the literature on education support for students with health conditions. It then goes on to outline the findings of the web-based search for existing policy in this area across the range of jurisdictions under examination. The third section describes the results of the empirical research with a range of providers of education support to students with health conditions, the majority of them based in major paediatric hospitals in each state/territory. The final section brings together the findings of the literature review with the evidence from each service/setting and considers the implications for policy and practice across Australia and New Zealand.

Initial searches of existing literature and service provider documentation revealed a significant diversity in the ways in which education support is provided to children and young people with a health condition, based on:

- The location in which the student is receiving health care
- The nature of the student’s health condition (including significant variation between provision for students with medical conditions and those with mental health conditions)
- The type of the organisation providing the support (schools, government services, private and not-for-profit organisations).

Because of this diversity, both in the nature of paediatric chronic health conditions and the models of education support, a decision was made to focus in this research on the support provided to students during hospitalisation. Significant differences in hospital-based education support were also uncovered during the research, however there were also many similarities, particularly in the issues which hospital-based education staff identified as impacting on their educational services. While the report touches on other kinds of education support available to this cohort of students, particularly in relation to the policy underpinnings of such support, in the main the report focuses on education in hospital and the diverse ways in which it is provided in large and small hospital settings across Australia and New Zealand.
**Evidence of best practice – literature review**

**Effects of chronic health conditions on students’ educational performance**

Evidence suggests that students with chronic health conditions are at higher risk than their healthy peers of educational underachievement (Quach and Barnett (forthcoming), Crump et al, 2013; Forrest et al, 2011; Martinez and Erican, 2009). Many research papers note that the nature of the interrelationship between health and education is not clearly known (Needham et al, 2004). For example, some health conditions are more strongly associated with poor school achievement than others, however it is not clear whether it is the condition itself which affects educational performance (Kadan-Lottick et al, 2010), emotional and behavioural issues associated with the condition and its treatment (Mukherjee et al, 2000) or the fact that more time is missed from school by students which such conditions (Bethall et al, 2012; Diette, 2000; Hancock et al, 2013).

As Feeley and Skilling note “The problems experienced by sick children are known to families, hospital teachers and home tutors. Less known is what actually constitutes quality educational provision for sick children.” (2000: 140).

There is little rigorous research published in English into the effects of different educational interventions for students with chronic health conditions. As part of this current research project we conducted a literature review of such interventions, using the University of Melbourne’s "Discovery" search tool, which searches the library catalogue, the digital repository and major academic databases, using the search terms “chronic health”, “school” and "student". The vast majority of the papers found by this search addressed schools’ efforts to manage students’ health conditions. Less than 10% addressed efforts to ameliorate educational outcomes for these students. A recent large study in the United States reports on some of the complexity involved in understanding the effects of chronic health conditions on educational performance. The study’s authors, Crump and Rivera, report that:

Chronic health conditions were independently associated with low ELA and math performance, irrespective of ethnicity, socioeconomic status, or grade level. Adjusted odds ratios for the association between any chronic health condition and low (“basic or below”) performance were 1.25 (95% confidence interval [CI], 1.16–1.36; \( P < .001 \)) for ELA and 1.28 (95% CI, 1.18–1.38; \( P < .001 \)) for math, relative to students without reported health conditions. Further adjustment for absenteeism had little effect on these results. The strongest associations were found for ADHD, autism, and seizure disorders, whereas a weak association was found for asthma before but not after adjusting for absenteeism, and no associations were found for cardiovascular disorders or diabetes.

All conditions except autism were associated with increased absenteeism. After adjusting for covariates, the absentee rate among students with any chronic health condition was 1.30 times larger (95% CI, 1.26–1.35; \( P < .001 \)) than among those without reported health conditions. Students with mental health disorders had the highest absentee rate (adjusted
incidence rate ratio, 1.88; 95% CI, 1.59–2.23; \(P < .001\). In addition, the number of absences was inversely associated with ELA and math performance.

Recent Australian work, while examining absence more broadly than just in the context of health conditions, nonetheless found that:

In all analyses, average academic achievement on NAPLAN tests declined with any absence from school and continued to decline as absence rates increased. The nature of the relationship between absence from school and achievement, across all sub-groups of students strongly suggests that every day of attendance in school contributes towards a child’s learning, and that academic outcomes are enhanced by maximising attendance in school. There is no “safe” threshold.

Hancock et al, 2013: v

Closs, however, found that for students with health conditions, factors other than unavoidable absence from school were equally as important in students’ educational outcomes. Such factors include pupil motivation and ability, parental support, alternative educational inputs and support for learning on return to school (Closs, 2000b: 98). She goes on to report on American research which found that educational outcomes for students with health conditions was more strongly influenced by socio-economic status than by amount of days absence from school. Forrest et al, in 2011, found that children with special healthcare needs were more likely to have lower motivation to achieve at school, more behavioural problems, lower academic achievement and were more likely than other students to have experienced bullying (p. 307). This held true for students whose special health care need involved a functional limitation or behavioural issue, but not for those whose special health care need only involved taking prescription medication, or a diagnosis of asthma or obesity. (p. 307). Having a Special Health Care Need (SHCN) “was associated with more days absent, poorer student engagement, more behavioral threats to achievement, and lower academic achievement” (p. 307), however the authors go on to report that, again, the causal pathways for these findings are not well established.

Means to address these differentials in educational performance vary in different educational systems. Much of the work coming from the United States focuses on school re-integration programs and the efforts of schools to accommodate students with health conditions. Work in the United Kingdom has tended to focus more on the students themselves and their individual needs, developing student-centred models which meet students’ needs across a range of settings including hospital, school and home. In Australia, education support in hospitals and schools is well-established, while support for students during recovery at home has been under-researched and under-developed (Barnett et al, 2014). For clarity, this review will look at the published evidence addressing education support in each of the three settings (hospital, home and school), while also recognising that many examples of good practice cut across all three settings.
We recognise that it is very often left up to the parents of a student with a chronic health condition to navigate the maze of educational services, and that parents very often struggle with issues such as: the roles of communicating between health care and education services; schools which are not equipped to deal with their child’s complex needs; being the expert on their child's condition; navigating the two systems and coordinating the care (Anderson, 2009; 347). We have looked elsewhere at the role which parents play in supporting the educational needs of their sick child (Barnett and Hopkins, forthcoming).

Research by Closs in the UK neatly sums up the educational needs of children with chronic health conditions:

The United Nations Convention on the Rights of the Child posits that education is an absolute right of each and every child. In the case of absent children with medical conditions there is perhaps a special imperative because of their own and their parents' very evident wish for them to be educated. Thus, children unavoidably absent on the grounds of health - who are too vulnerable to infection or too physically fragile or immobilised by surgery or other treatment but who are still well enough to benefit from education - should have education taken or transmitted in some way to them wherever they happen to be, in hospital, hospice, respite care unit or, most commonly, at home.

Closs, 2000a: 8

This responsibility to meet every child at their point of educational need falls squarely within the remit of statutory state education authorities across all jurisdictions.

**Education support in hospital**

Despite almost a century of hospital schooling in Australia (Pearn, 2009; Yule, 1999) and elsewhere, our review found no published reports of research into the effectiveness of education support in hospital, either through hospital schools or other models of education support. Unpublished data from New Zealand (Winder, 2013) indicates senior secondary students who complete their school education through the Northern Health School (see below for more details) are twice as likely to achieve Merit (the highest grade) and half as likely to receive a Not Achieved grade as compared to the national average (Winder, nd).

Payne and Valentine offer a rare perspective from the medical team on the importance of education for adolescents during hospitalisation:

Access to support from teaching staff experienced in working with adolescents with chronic illness and disability is invaluable in optimizing a young person’s educational opportunities during school years and beyond. Education may be a low priority when a student is very unwell, but school programs linked to hospital programs play an important role in promoting socialization and interaction with peers, providing routine, and offering role models and vocational guidance. A positive educational outcome is more likely when a partnership exists among education and health services and the student and their family. Current models of
interdisciplinary care therefore should attempt to incorporate education staff into their teams as a matter of course.

However, as Poursanidou et al point out: "Collaboration between health and education staff – as a key aspect of educational provision for children with chronic illnesses – represents a relatively under-researched area." (2008: 255). Closs and Burnett’s work on the educational needs of students with a poor health prognosis demonstrates the importance of flexibility in provision for this cohort of students, whether in hospital or at home. They report that the National Curriculum "should provide a baseline for children being educated other than in school. However, full implementation is not required so teachers working outside schools are liberated to consider the curriculum and children's programmes purely in terms of their appropriateness to each pupil in hospital or receiving home tuition." (1995: 390). This work also demonstrates the importance of education even for students who may not ever be going to return to a normal school setting, where education becomes the key to ‘flexible normalization’ (Closs and Burnett, 1995: 390), where education is valued for it’s own sake and not merely as a means of connecting the absent child to an ongoing educational pathway.

Searle et al found that education for adolescents with cancer provided the best support for those less academically able students when it was provided by the hospital school and further, that some students experienced their first sense of academic success there, perhaps due to small class sizes and individualised teaching, especially with a focus on learning through creative arts (2003: 382). Education support at home was less effective for this cohort.

Increasingly, information and communications technology is being utilised to connect students in hospital with their regular classrooms (Ellis et al, 2013; Fels and Weiss, 2001; Fels et al, 2001; fels et al, 2003; Janssens et al, 2010; Nicholas et al, 2011; Niselle et al, 2012; Parsapour et al, 2011; Vetere et al, 2012; Wadley et al, 2014; Wilkie and Jones, 2008). Again few evaluations of such initiatives have been conducted to examine their effectiveness in keeping students engaged with education.

**Education support at home**

The nature of health care is changing rapidly, with improved medical care resulting in lowered mortality rates and increasing numbers of patients living for longer with chronic conditions. Rates of common chronic childhood conditions such as asthma, allergy and diabetes are currently rising, while length of hospital stays continue to fall (Wilkie, 2012). Increasingly, this means more children and young people spending time being treated and recovering at home. The traditional model of the hospital school, which caters to students only during their inpatient stay, needs to be replaced by a model which also meets students’ educational needs during periods of care at home (Bessell, 2001; St Leger & Campbell, 2008; Wilkie, 2012).
Research by Searle et al (2003) with adolescent cancer students investigated perceptions of education support across hospital, home and school settings. They found that:

High achieving students engaged in extracurricular activities prior to diagnosis performed well academically in all three schooling situations. Those less engaged in school prior to diagnosis did poorly in homebound schools, better in their community [regular] schools, and best in the hospital school.

The researchers conclude from this that “homebound education may serve best only as a very short transition period between the other two types of schooling” and they “conclude that healthcare professionals involved with school placement of this population should strongly encourage students to attend their community [regular] school despite their physical appearance.” (Searle et al, 2003: 382).

**Education support in school**

Advances in modern medicine have increased the chances that children who become critically ill or injured will survive. These children are likely to return to school and the community and are expected to reintegrate into their predisease-onset lives. Although their immediate illness may be resolved or their injury healed, there are often lasting effects of these bouts with chronic illness or injury. Since going to school is a primary task of childhood, re-entry into the school system can be a major undertaking for children with chronic health conditions.

Canter and Roberts, 2012: 1

The majority of research work examining education support for students with health conditions has focused around the return to school and ongoing care of students within the mainstream schooling system. As Canter and Roberts report, in the United States much of the work of supporting students with health conditions educationally centres on school re-entry programs. Such programs may “take the form of school personnel workshops, peer education programs, or comprehensive programs” (Canter and Roberts, 2012: 2). Evaluation of a comprehensive school re-entry program for students after a burn injury in Cincinnati, involving phone calls, written correspondence, individualised videos or on site visits to school, found that school re entry programs did not statistically improve a child’s adjustment to school, as measured across a range of indicators including classroom behaviour, academic achievement and participation in special classes. In addition, this hospital-administered program focussed on the social aspects of the student’s re-integration, rather than their academic outcomes (Staley et al, 1999).

It has also been suggested that although education for a child with a chronic health condition “is mandated by law, the amount, type, and quality of care they receive in school is not well defined, despite evidence that the quality of care .... [the child] receives in school may affect school attendance and performance” (Anderson, 2009: 343). Lahteenmäki, et al (2002) found that despite
the presence of a well-organised hospital-school in their setting, students with cancer still often expressed a need for more private tutoring on their return to school. The work by Closs (2000a) also addresses the complexity of untangling the various forms of education support which are available through schools, and of the need for definitions of health condition, disability and special educational need, as well as definitive diagnoses. The range of different supports for which the child may be eligible depends very often on which definition is being used. Mukherjee et al suggest that the "variability in the support teachers offer seems to reflect ambiguity in their roles and responsibilities in relation to this group of pupils.” (2000: 68).

Understanding good practice

The most comprehensive piece of work regarding improving access to education for students with chronic health conditions is the review carried out by Farrell and Harris for the University of Manchester in 2003. This review was carried out in order to improve the evidence available to Local Education Authorities across the United Kingdom in developing inclusive education models for students with medical needs. The review found five overarching themes which emerged from the data as the most important in ensuring education authorities were meeting the statutory requirements of quality education provision. The five themes were:

- **Mainstream Ownership**, the student’s enrolled [mainstream] school continuing to take responsibility for the students’ overall educational journey,
- **Partnership and Collaboration**, establishing collaborative working relationships between hospital, school and other relevant agencies,
- **Flexibility**, the ability of the service to adapt to individual’s changing needs and circumstances,
- **Responsiveness**, the ability of the hospital and home schools to respond to the changing needs of key stakeholders, including students, parents, teachers and healthcare staff, and
- **Clarity**, having written policies and procedures to guide all practices and outline important roles and responsibilities

Farrell and Harris, 2003: 8-11

As well as identifying the key themes, the authors also include practical examples of good practice as well as recommendations for implementation of improved practices across diverse services. Interestingly, a similar report published fifty years earlier (Connor, 1964) examining best practice in provision of education to homebound or hospitalized children listed a very similar set of requirements and recommendations (p. 25), suggesting that while best practice is quite well understood in theory, in practice implementation remains fragmented.

Also in the UK, work by Feeley and Skilling in 2000, through NAESC, the National Association for the Education of Sick Children, identified ten principles which underpin high quality educational services for children with health conditions. A high quality service is one which:

1. values the child as an individual with a full entitlement to a broad, balanced, differentiated curriculum;
2. aims to develop the skills and abilities that underpin effective learning for the child in the contexts of home, school and hospital;
3. aims to design, deliver and assess a learning programme which is based on the unique needs of each individual (IEP);
4. aims to help the individual child use a variety of services and resources available in the community to support their individual learning programme, e.g. the media, health, social, library, careers, recreational and welfare services;
5. aims to meet special needs arising from disabilities by means of locally coordinated, multidisciplinary specialist services delivered in the home, school or community by appropriately trained staff;
6. is easily accessible ... and delivered conveniently when the child can make most effective use of it;
7. plans actively for young people to return from a period of hospitalisation to timely and appropriate provision at home or at school;
8. is delivered to a child's home or school as required by the IEP and with account taken of the medical needs of the child;
9. uses modern information and communications technology and encourages sharing of curriculum information with the child, the family and the hospital and mainstream school;
10. is staffed by locally-based teachers who are available to visit children and young people in their own home, in hospital or at school

Feeley and Skilling, 2000: 140-141

In the Australian context, Shiu’s work similarly identifies a set of nine recommendations to address the concerns of parents and teachers in relation to students with chronic health conditions at school:

- Schools need a specific, documented and implemented medical management plan.
- Schools need to ensure students have access to academic support.
- Parents, hospitals and schools must communicate to share information.
- Students with chronic illness need greater access to educational resources to ensure they keep up academically.
- Services within and between the home, school and hospital school need to be coordinated by a member of the school staff (not the parent)
- Emotional support for the student must be available
- Peer support is important
- Safe physical access to school must be provided.

Shiu, 2004: 249-251

Despite mounting evidence, however, for best practice in education support for students with chronic health conditions, this research project demonstrates that both policy and practice continue to be fragmented, unco-ordinated, provided by a range of services and following different models in each of the states and territories.
Current policies in each state/territory - web search findings

Commonwealth of Australia

The administration of both education and health care are regarded as the responsibility of state governments in Australia. Nonetheless at the federal level, Australia is a signatory to the United Nations Convention on the Right of the Child (UN, 1989) which enshrines the right of all children under the age of 18 to receive education, and further requires that that education should allow the child to reach their fullest potential. The federal government has also passed the Australian Education Act of 2013 (Australian Government, 2013), which specifically states that:

All students in all schools are entitled to an excellent education, allowing each student to reach his or her full potential so that he or she can succeed, achieve his or her aspirations, and contribute fully to his or her community, now and in the future.

And:

The quality of a student’s education should not be limited by where the student lives, the income of his or her family, the school he or she attends, or his or her personal circumstances.

While not specifically mentioning a student’s health condition it is clear that health status must be considered to be part of a student’s personal circumstances and thus cannot be used to discriminate against their receipt of quality education.

In addition to the Education Act, the federal government has also passed the Commonwealth Disability Discrimination Act of 1992 (Australian Government, 1992), which defines disability across seven measures.

“Disability”, in relation to a person, means:

(a) total or partial loss of the person’s bodily or mental functions; or
(b) total or partial loss of a part of the body; or
(c) the presence in the body of organisms causing disease or illness; or
(d) the presence in the body of organisms capable of causing disease or illness; or
(e) the malfunction, malformation or disfigurement of a part of the person’s body; or
(f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
(g) a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

(h) presently exists; or
(i) previously existed but no longer exists; or
(j) may exist in the future (including because of a genetic predisposition to that disability); or
(k) is imputed to a person.

It is clear from this definition that students with chronic health conditions fit the definition of disability under legislation, however it is also clear that in practice students with health conditions are not identified or regarded in the same way as other students with disabilities within the education system.

The federal government also funds some specific initiatives in student health across schools nationally, including the More Support for Students with Disabilities program and the National Safe Schools Framework.

New Zealand

In New Zealand education is administered by the Ministry of Education, within the framework of the Education Act of 1989 (New Zealand Government, 2014). Provision of education support for children and young people with a health condition (mental or medical) is provided through a series of three Regional Health Schools, which cover the entire country and which are organised according a set of Regional Health School Guidelines, developed by the Ministry of Education in 2000, when the health schools were first established. The New Zealand Health Schools provide a seamless service in the education of students in hospital, at home and in community settings, providing a service similar to those available in Australia through a range of providers, including hospital schools, distance education providers, private tutoring services and open access educators.

Australian Capital Territory

At the state level, all Australian states and territories have specific legislation regarding the provision of education within their jurisdiction. While varying slightly in detail, in essence every state makes it a requirement for all children within prescribed ages to attend a registered school or other place of learning unless they have an exemption. Each state also has specific policies on issues which impact on student health such as anaphylaxis management, student wellbeing, disability and bullying.

In the ACT education is governed by the Education and Training Directorate (ETD), through the Education Act of 2004. ACT schools offer a range of services for students with disabilities, including the Student Centred Appraisal of Need, which also applies to students with medical conditions affecting their ability to participate fully while at school. Students in hospital are educated by The Hospital School, which is administered under the disability area of the ETD. The ACT ETD also offers a distance education program for students unable to attend school due to a range of circumstances which include medical and mental health conditions.
The ETD also provides a range of policies which cover student’s health care needs whilst they are at school. These policies include:

- Administration of Prescribed Medication, Catheters and Injections to Students (1997)
- Management of Eating and Drinking Support in ACT Public Schools (2010)
- Students with a Disability: Meeting their Educational Needs (2008)

We were unable to find any explicit policy addressing students’ educational needs during absence from school for health care.

ETD also offers a school program for students aged 12-17 who are patients of Child and Adolescent Mental Health Services (CAMHS), in conjunction with other therapeutic and rehabilitative programs.

**New South Wales**

The Education Act of 1990 (NSW Government, 2014) governs the delivery of education in New South Wales through the Department of Education and Communities (DEC), to students of compulsory school age, that is between 6 and 17 years. In addition, NSW DEC has a comprehensive initiative called “Every Student, Every School”, which addresses learning and support for students with a disability, learning difficulties or behaviour support needs in government schools. The department also has a “Disability Action Plan 2011-2015” to ensure schools and other education services are compliant with state and federal disability legislation. Special education in NSW is provided through the Schools for a Specific Purpose, of which ten are Hospital Schools, located in major paediatric hospitals and on paediatric wards in general hospitals. NSW also has a distance education option for students unable to attend regular school due to their health condition.

Support for students with health conditions who are attending regular school is addressed through the comprehensive “Student Health in NSW Public Schools: A summary and consolidation of policy” document (NSW Government, 2005), as well as the “Physical as Anything” resource to support students with medical, developmental and psychological conditions.

**Northern Territory**

School education in the Northern Territory is administered by the Department of Education and Children’s Services (DECS) within the requirements of the Education Act (NT Government, nd). The Education Act as been in existence for 35 years, and is currently undergoing a consultation process in order to assist in the development of a new Act. In addition the DECS has a very detailed Medical Policy which covers the administration of medications to students with notified medical conditions, as well as the development of Student’s Health Care Plans. The NT DECS supports the national framework for Health Promoting Schools and provides policy advice in four areas of curriculum and wellbeing:

- Health (nutrition and sexuality) education
- Physical education
- Drug education
- School sport coordinators.

The Northern Territory Open Education Centre (NTOEC), offers distance education to students in the senior years (years 10-12) with long hospitalisations. Other education support for students in hospital is provided by two hospital schools, however we were unable to find any explicit policy rationale for this arrangement. Nonetheless, Darwin Hospital School is one of the few settings which reported the existence of a formal document (a Memorandum of Understanding) between the health and education sectors governing the delivery of education services in the hospital.

**Queensland**

In Queensland the delivery of school education is administered by the Department of Education, Training and Employment (DETE), under the auspices of the *Education (General Provisions) Act 2006 (Qld)* (Qld Government, 2014). The DETE have a number of explicit policies to support students with health conditions whilst at school, including:

- Inclusive Education Policy
- Management of Students with Specialised Health Needs
- Students with Disabilities Program
- Supporting Student Health and Wellbeing in Queensland State Schools

In addition, Qld DETE offers students the option to enrol in one of seven schools of distance education if they are home bound and feel that it would be appropriate for them. Student fees are waived for students who have limited choice of schooling due to location or a medical condition. In the case of medical conditions, the student must be expected to miss at least 80 consecutive days of school. Education support is also offered to some patients associated with Child and Youth Mental Health Services (CYMHS).

**South Australia**

School education in South Australia falls under the Education Act of 1972 (SA Government, 2012), administered by the Department for Education and Child Development (DECD). The act is supplemented by departmental policies regarding the health of students in schools, such as:

- Student Health Support Planning (including the Medications Management Policy), and
- Students with Disabilities Policy

In addition the DECD has a new developed service model for Integrated Support Services for five categories of students one of which is students with health or mental health conditions.

SA DECD offers an option for students with either medical or mental health conditions (or both) to enrol in the Open Access College. Enrolment on medical grounds requires a comprehensive written medical report from a health professional testifying that the student has either a short-term or
long-term health condition which prevents them from attending their regular school on a full-time basis. Enrolment on mental health grounds requires consideration of a documented health support plan from the student’s previous school and the involvement of regional support staff in efforts to maintain regular face-to-face schooling. Initial enrolment for students with mental health conditions is for one term, with efforts made to assist part-time attendance at the student’s regular school. Further education support for students with mental health conditions is offered through Hospital School Services which is discussed below.

**Tasmania**

The Tasmanian Education Act 1994 (Tas Government, 1994), is administered by the Department of Education Tasmania. The department provides a range of policies, procedures and guidelines to cover the health care of students in schools including:

- Learner Health Care and Safety Policy
- Learner Wellbeing and Behaviour Policy
- Meal Management in Schools Policy and Guidelines
- Guidelines for Administration of Medication
- Professional Support Staff in Schools
- Register of Students with Severe Disabilities (including physical disability or health impairment).

Distance education is provided to students unable to attend school (including due to hospitalisation) through the Tasmanian e-School. This will be discussed further below.

**Victoria**

Education in Victoria is governed by the Education and Training Reform Act of 2006 (Victorian Government, 2014), administered by the Department of Education and Early Childhood Development (DEECD). While the Act sets out the requirement for all children and young people between prescribed ages to attend school or another learning institution, it also states explicitly (section 2.1.3) that illness is an acceptable reason for non-attendance. There is no other specific mention of provision of education support to students with health conditions within this Act.

There are numerous policies which exist to support students with health conditions and/or disabilities within the Victorian school system, such as:

- Program for Students with Disabilities
- School Care program
- Medical Intervention Support
- Accessible Buildings program
- Equipment Grants
- Student Support Service Officers.
Schools are also required to develop their own health and well being policies regarding issues such as administration of medication to students at school, as well as having policies to address chronic issues such as Asthma and Anaphylaxis.

There is also provision for education in the student’s home through the Home-based Education Support program and through Distance Education. Education support in health care settings is addressed through the four residential and non-residential schools which enrol students with serious mental health conditions, through a contract between DEEC and the RCH Education Institute to provide education support at the Royal Children’s Hospital and through the provision of a part-time teacher at Monash Children’s Hospital. We have been unable to find any comprehensive policy addressing the rationale for the provision of these services in their current forms.

**Western Australia**

Western Australia’s School Education Act 1999 (WA Government, 1999) is administered by the Department of Education. Departmental policies addressing student health needs include:

- Healthy Food and Drink Policy
- Student Health Care Policy
- Student Health Care Documentation and Guidelines
- Students at Education Risk policy (where students at educational risk are defined, among other things, as those whose achievement level, rate of progress or behaviour differs noticeably from past performances and/or that of his/her peers, which could include students with health conditions)

The Department also offers Guidelines for Implementing Documented Plans in Public Schools, which refers to student plans that address individual needs, such as individual education plans (IEPs), and Schools Plus, a model of informed practice which underpins the Department’s support for students with disabilities on the basis of their educational need.
Current practice in each state/territory – primary research findings

Education support in practice – what does each jurisdiction do?

Despite the patchy nature of explicit policy attention given to the issue of education support to students in hospital, in practice every state in Australia as well as New Zealand has programs in place to address these specific educational needs. The programs vary widely in each jurisdiction across domains such as age of eligibility for students, location of service delivery, bureaucratic reporting and accountability structures, types of programs offered and degree of liaison with students’ home schools. Because of this diversity of approaches the programs offered to hospitalised students in each state are described here on a state by state basis. Final concluding sections will bring together the main similarities and differences in the services and attempt to identify the features of good practice which are highlighted by the findings.

It should also be remembered that a number of states are undergoing or have recently undergone major redevelopments of their paediatric hospital services and for this reason some of the findings of this research may not be applicable as new settings and services come into operation. The situation is not static. But what is important is the extent to which evidence is used to inform decision making about changes to policy and practice in the provision of education support for children and young people with chronic illnesses.

**Australian Capital Territory**

Education support for students treated at the Canberra Hospital is provided by the Canberra Hospital School. The Canberra Hospital School is a registered Specialist School, which is administered through the Disability Education Section of the ACT Education and Training Directorate. The school has one classroom on the paediatric ward which sees students from pre-school to year 12, as well as seeing students bedside on the ward. It has 1.5 FTE teachers and 1 Learning Support Assistant (LSA).

Nursing staff on the ward identify students who are medically able to participate in education and permission from parents for students to participate is sought where possible, but not required. Where students are in hospital for up to a week, appropriate school work is provided by hospital teachers, while if a student’s hospital stay is expected to be longer than a week, contact is made with the student’s home school to ensure continuity of education. A Transition Action Plan is completed for each student returning to school after an admission of more than one week.

**New South Wales**

Education support for hospitalised students in New South Wales is provided by ten hospital schools located in urban and regional hospitals across the state. Three of these schools are located in the three specialist paediatric hospitals, two in Sydney (Sydney Children’s and the Children’s Hospital at Westmead) and one in the John Hunter Children’s Hospital in Newcastle. The other seven are
located in the paediatric wards of large general hospitals. Hospital schools in NSW are registered schools of the Department of Education and Communities, under the classification of Schools for Specific Purposes (SSPs).

While the hospital schools in specialist paediatric hospitals in Sydney have multiple classrooms and up to 14 staff members, the smaller schools generally have one classroom and one teacher or a teaching principal. Where a hospital school has more than one classroom these are usually organised by school year level (primary/secondary or early years, middle years, senior years) as well as by diagnosis (one dedicated mental health classroom). NSW hospital schools see students who are school aged (turn 5 by the 30th June in the year of first enrolment, up to 18 years). Provision may be made for pre-school students on an individual or as needs basis. Students enrolled in school (K-12) are eligible to enrol in the hospital school (shared enrolment with census school), but priority is given to students with long stays and/or frequent admissions.

Hospital schools take a personalised approach to the development of learning support plans for students, and assist with transition back to mainstream schooling as required. Hospital school staff can also facilitate the development of student health support plans to aid transition back to school in cases where a child’s health condition may have an impact on their ongoing learning.

**Northern Territory**

The Northern Territory has two hospital schools, one at the Royal Darwin Hospital and one at the Alice Springs Hospital. Each hospital school is annexed to a local primary school, which assists in the management and financial administration of the hospital school. Aside from this, however, the day to day running of the hospital classes are largely autonomously managed by the hospital teacher and one to two assistants. The hospital schools see students who are inpatients of the hospitals, who consist of a diverse range of students, approximately half of whom are indigenous. Others are flown in from Timor and other remote locations for tertiary hospital care. A high number of students have English as an Additional Language (EAL), or may speak little or no English. Students are not required to enrol in the hospital school, they are seen if they are enrolled in another school or are at pre-school. Because of the diversity in student experience and backgrounds students are only able to come to the hospital school classroom if they are able to display appropriate school behaviours (sitting at tables, listening, taking turns to speak). Other students may be seen bedside.

The programming in the school is quite flexible, to accommodate the Australian national curriculum as well as the Indigenous curriculum, which might be operating at different levels in different communities. Programming is based on early childhood principles, while school work for specific higher school and special education needs is provided by the students’ home schools. Darwin Hospital School also reported good access to technology, wireless internet and videoconferencing facilities to link the hospital school with home schools and communities. For confidentiality reasons hospital teachers are not included in medical staff meetings, however the teacher is able to liaise with the Adolescent Clinical Nurse to share pertinent health and education information.
Queensland

Education support for hospitalised students in Queensland takes two forms. The two large paediatric hospitals in Brisbane each have a hospital school, which is administered under the umbrella of Schools for a Specific Purpose. In addition to these there are another six hospital classrooms, located in regional hospitals around the state and administered by a local regular high school. Students in hospital are eligible for education support if they meet particular health criteria. These vary slightly in different settings but generally include students with an anticipated length of stay over four days and/or a chronic health condition or a sibling thereof, particularly if the family has come from a regional area for hospital care.

Teaching is provided in classrooms and on wards and follows the Australian Curriculum, but with a high degree of differentiation and personalisation. In addition, one of the Brisbane hospital schools is responsible for an education program which works off-site from the hospital, through a not-for-profit organisation called ACT for Kids, working with children who have experienced child abuse.

Teachers in hospitals see school aged children, however in Queensland children with a disability are attached to special schools from birth, so that a pre-school aged child with a disability can also be seen by the hospital school during a hospital admission. Teachers in Queensland hospital schools also reported using a lot more formal education assessment tools than teachers in other states and having a closer alignment with state and national curriculum and teaching units. While teachers in Queensland are not able to use Skype due to education department requirements, the hospital schools are incorporating technology to introduce synchronised learning, particularly within the hospital setting to connect students on wards with the learning going on in the hospital classrooms as well as for students who have left the hospital but who have not yet returned to school and are recovering at home.

South Australia

Education support for students in South Australian hospitals is centrally organised and managed through the Hospital Education Service (HES) and based at the Women’s and Children’s Hospital in Adelaide. HES is not a school, but rather a service of the Student, Aboriginal and Family Services (SAFS) Unit of the South Australian Department of Education and Child Development based at the Women’s and Children’s Hospital in Adelaide but operating at five sites across the state.

HES offers an inpatient teaching service to students in the two big public hospitals in Adelaide, as well as providing teachers for the patients associated with two Community Adolescent Mental Health Services (CAMHS) based in Enfield in the northern suburbs of the city, one of which works with primary school aged children and the other with young people of secondary school age. Education support is also provided to the child development units across three sites, providing educational needs assessments but not teaching to the children in those units. The child development units provide developmental assessment of children with two or more difficulties such as:
• slow development
• speech and language problems
• problems with their physical activities
• forming friendships with other children, and
• sensory processing.

Education support at the Women’s and Children’s Hospital is available for students from pre-school to year 12, with additional early years (pre-school) services available to indigenous students and those with a disability. There are two classrooms, one for early years and primary students and the other for secondary students, including those treated on the adolescent mental health ward. Medical staff identify which students are suitable to attend the classroom or receive bedside teaching, with parental permission required before education can be provided. Under usual circumstances the child would need to miss more than three days of school to be eligible to attend.

Education support focuses on the Australian Curriculum, with an emphasis on literacy and numeracy particularly in the primary years. A report on the student’s activities in the hospital is sent back to their home school once per term.

As the Women’s and Children’s Hospital in Adelaide is a centre for craniofacial surgery, the school sees a number of Indonesian students who are flown in to have surgery. These students are supported by an Indonesian speaking Temporary Relieving Teacher (TRT) as required.

Tasmania

The Tasmanian eSchool for online and distance learning provides education support to students unable to attend regular school for a variety of reasons, including hospitalisation at the Royal Hobart and Launceston General Hospitals. Although established in 2010 offering blended learning through online, face-to-face, community and home based learning opportunities, the eSchool arose from over 90 years of Distance Education offered across the state. Eligibility for enrolment in the eSchool includes illness, pregnancy, isolation and other special circumstances. eSchool teachers visit the paediatric wards of the two hospitals each morning to provide classroom or bedside teaching to students from K-12 (school age), who are identified as suitable by the medical staff. The majority of students have only a short stay in hospital, however when longer stay students are identified teachers are able to contact the students’ home schools and request appropriate work to be sent to the hospital. In many cases the parents manage this process. Due to the variety of students seen in the school room the teachers usually take an individualised approach to teaching and learning.

Victoria

Education support for students with health conditions in Victoria takes three different forms, depending on which hospital it is provided in. The main paediatric hospital in Melbourne, the Royal Children’s Hospital has an Education Institute, funded by the Department of Education and Early Childhood Development, but is not registered as a school. Teachers at the Education Institute work
bedside or in small activity groups with students from pre-school to year 12 and occasionally TAFE and university students. Education support is focussed around personalised learning, with an aim to work in partnership between the school, the family and the home. Every student has an Individual Learning Plan (ILP), developed in consultation with school, parents and the student. Participation in education support is not compulsory, students opt-in to the service and parents must give signed permission. The ILP is designed to allow students to spend about eighty percent of their time on their strong learning goals (learning ‘needs’) and twenty percent of their time on passion-based learning (learning ‘wants’). Teachers are assigned to work with individual students on the basis of these learning wants and needs. There is a strong focus on learning through the Arts and with the use of technology. Students may also have the opportunity to Skype in to lessons back at their home school or at a local secondary school.

The second paediatric hospital in Melbourne, Monash Children’s, which operates across three campuses, has a teacher seconded from a local secondary school to provide ward based education support to inpatients on a part-time basis at one campus. Education support to students in both the RCH and Monash Children’s is for students with medical conditions.

Students with mental health condition have a separate education service, provided by four registered schools. One of these schools works with mental health inpatients at the Royal Children’s Hospital, separate from the work of the Education Institute. The other three are based around the Melbourne metropolitan area and see both inpatients and outpatients through hospitals and community based CAMHS services.

**Western Australia**

In Western Australia education support for students with both mental and medical health conditions is provided by the School of Special Educational Needs: Mental and Medical Health (SSEN:MMH), based at the princess Margaret Hospital in Perth. The service is governed by a Memorandum of Understanding between the Education and Health Departments. The SSEN: MMH provides more than 40 teaching and liaison programs in 18 different locations across the state. The main teaching program is based at the Princess Margaret Hospital, the specialist paediatric hospital in Perth, and provides teaching and learning opportunities to inpatients. Teachers work in collaborative learning spaces on each ward, as well as offering bedside teaching. Students must have a health referral and parental consent to participate in any learning opportunities. Approximately one third of students seen across the whole school have short term medical conditions, one third have long term medical conditions and one third have a mental health condition.

As well as direct teaching and learning with students, teachers at SSEN:MMH have dedicated time allowed for liaison with students’ home schools, while the school also runs an extensive program of professional learning around common medical conditions for teachers in regular schools. SEN: MMH also provides a home-based service for students who have left hospital but have not returned to school. This service can see a student up to twice a week for a period of up to ten weeks.
Students in hospital are seen if they are pre-school or school aged (K-12), including those in the post-school cohort (over 15 years) in particular circumstances such as adult rehabilitation.

Home schools are responsible for supplying each student’s curriculum, as outlined in the school’s enrolment policy, while hospital teachers also assess student learning and report back to home schools on a five-weekly (half-term) cycle. The services provided by SSEN: MMH in hospitals are governed by a Memorandum of Understanding between the Education and Health Departments and in addition, each program within the school has its own service protocol, outlining the requirements of each service.

Also in WA, Schools of Isolated and Distance Education (SIDE) may offer enrolment to students on the basis of having a long term illness. Students with severe medical/chronic health conditions or severe mental health conditions may be eligible for enrolment at SIDE through the Referral Program, however this program is not considered to be a long term alternative to a regular school.

New Zealand

Education support for students with health conditions in New Zealand is provided through three Regional Health Schools, which cover the entire country geographically, each based in a major city of the region (Auckland, Wellington and Christchurch). Regional Health Schools are part of the Special Education System in New Zealand, and provide education to students in hospital, as well as at home, in the community (such as local schools, cafes and libraries) and at some specialist medical services. Students are eligible to enrol in a Health School if they meet one of four criteria:

- Expected 10 days absence with a hospital admission
- Expected 40 days absence in a year due to a chronic condition (without a hospital admission)
- 6 or more admissions to hospital in a year
- Admission to a CAMHS service.

Students may be aged from 5 years until the year they turn 19 (New Zealand compulsory schooling is 6 – 16, but school attendance is from the child’s 5th birthday until the end of the year he/she turns 19). Teachers take on a central role in coordinating with the child’s home school, medical staff, parents and the student, as well as any other agencies.

All students in Health Schools have an Individual Learning Plan (ILP), which also contains a ‘transition plan’ section to help with planning the student’s transition back to school, on to a different education provider, or into the workforce. These ILPs are personalised and follow the New Zealand curriculum. Standardised assessment information is collected from students’ home schools for students in years 0-10 early in the students’ enrolment. Senior students are provided with set curriculum according to national senior assessment criteria. Each ILP is reviewed every twelve weeks, or at the end of the year or the end of the student’s enrolment. This information is then communicated back to home schools.
Technology is extensively used by the health schools to connect remote students to the Health School’s regional support centre and to facilitate video conferencing of tutorial sessions.

**Summary of research findings**

Some characteristics of education support in hospital are common to all Australian and New Zealand jurisdictions. These include:

- Education support for long stay hospital inpatients either in classrooms or ward based services for students confined to bed
- Support for siblings of inpatients as needed, including referrals to enrolment in local schools
- Liaison with home schools for long stay patients for curriculum, assessment and reporting purposes
- Provision of support to school aged students (although the age varies state by state) regardless of whether they are enrolled in government or non-government schools.

Most of the hospital education services reported that their assessment of students’ level of knowledge and learning needs both at admission and during ongoing support was informal and anecdotal rather than formalised with particular assessment regimes. In most cases provision could also be made for students to undertake assessment from their home schools if required, or to sit national or state authority testing such as NAPLAN and senior school certificates.

A further issue for many hospital education services was the difficulty of balancing the competing systems of education and health bureaucracies, particularly as nearly all hospital education services operate under their state’s education department/directorate while located in a health department physical space, and in many cases in the absence of any clear policy or documentation to govern or inform the way this is managed.

As well as many issues which are common to education support in health care settings across all Australian and New Zealand jurisdictions, there are also noticeable differences in the nature and extent of services provided. In some states hospital schools and education services cater for students during their inpatient stay, whereas in other areas, integrated services provide much broader support to students with health conditions, beyond their period of hospitalisation (if any).

**Provision of education support at home during periods of recovery**

For nearly all the areas covered in this research, though not Western Australia or New Zealand, a major issue for those who work in the area of education for students with health conditions is the post-discharge period, when students leave the hospital but may be at home for a period of days or weeks (or longer), before returning to their regular school. While a patchwork of services exist to cover this gap, including support from home and hospital schools, enrolment in distance education and private tuition, such services are generally uncoordinated and offered on an ad hoc basis, usually to those students whose parents or carers are able to advocate effectively for them and then oversee their implementation in the home.
The Australian Curriculum

The development and implementation of the Australian Curriculum offers an opportunity to increase the consistency of educational or learning goals across diverse settings. For hospital schools, however, there remain discrepancies in approach between schools which carefully adhere to the national curriculum and those which offer more flexible, individual and personalised approaches, focusing on engagement in identified learning goals rather than keeping up with the national curriculum content or goals.

Mental health and medical health

The disjunction between students with mental health conditions and those with medical health conditions, and the differing level of education support available to each cohort was also highlighted in several jurisdictions. While some of the hospital schools were able to operate a separate classroom for students in mental health wards due to differing bureaucratic requirements for staff ratios and supervision, in Victoria students with mental health conditions are enrolled in an entirely separate school, which operates independently from the education support for students with medical conditions in the same hospital. In smaller settings students with medical health conditions may be in the same classroom as those with mental health conditions, despite different approaches to education for these cohorts. There are also discrepancies in the definitions used with students with mental health conditions. In some states, for example, adolescents with eating disorders are treated in the mental health unit, whilst in other states they are seen in general medical wards.

Eligibility criteria

Eligibility for service varies by state according to whether the student is enrolled in education and the education sector in which they are enrolled. At the Royal Children’s Hospital in Victoria all students are seen regardless of the sector in which they are enrolled, including pre-school, TAFE and University students on occasion. In New South Wales the student must be enrolled in a K-12 school (their census school). Pre-schoolers, TAFE and university students, as well as young people who have left school early are not enrolled and are therefore not strictly eligible for service provision during periods of hospitalisation. In Queensland, students over the age of 13 are seen in adult hospitals rather than paediatric settings, so that the hospital schools have few senior students in their classrooms. Older students may be seen by the ward teachers in the adult hospital. In Darwin many of the older students choose not to attend school during their hospital stay.

Use of digital technologies

Almost all providers of education support who operate in hospitals reported on the difficulties of using new digital technologies to connect their hospitalised students with their regular schools and peers. Keeping students who are absent from school connected to their peers and school teachers/personnel is a critical component of ensuring students do not disengage prematurely
from expected educational pathways. This can, however, be difficult to achieve in practice. Education and Health Departmental firewalls, blocked applications, lack of wireless connectivity in hospital wards, teacher comfort and competence with the technology and concerns over privacy and inappropriate content were frequently mentioned as obstacles to the more extensive use of internet enabled devices and Apps to support both learning while out of the classroom and social connections with friends, peers and classmates.

Liaison with home schools

Recent research conducted at the RCH in Melbourne has shown that the issue of hospital teachers liaising with home school teachers and keeping students engaged with the learning that is going on in their regular classroom is of high concern to parents, although less concerning to the students themselves. All the hospital-based schools and education support services in this project had some degree of connection and communication with students’ home schools, though this varied considerably. Some services required the student’s home school to provide curriculum for the student during their hospital stay (eg: Western Australia), some would liaise only for their very long stay patients while others would communicate where possible regarding the child’s educational needs and aspirations. Difficulties in communicating effectively between hospital teachers, medical staff, school teachers and families was an issue raised by many respondents working in this area.

Discussion and conclusion

A review of the literature relating to education support for students with chronic health conditions revealed that little systematic research has been undertaken into the effectiveness of different models in meeting the needs of these potentially vulnerable students. Despite little rigorous evaluation, however, qualitative findings from a range of educational settings and with students with a range of health conditions and educational needs has consistently demonstrated the key requirements for effective education support to this cohort. As Australia is a signatory to the United Nations Convention on the Rights of the Child, it is unarguable that state education departments retain primary responsibility for the education of a student with a health condition, even if the student’s health status precludes them from attending their regular school or another learning institution. Moreover, while students with chronic health conditions fit under the criteria of disability according to federal legislation, they are not consistently identified or considered to have a disability within each state’s education system, highlighting again the barriers imposed by the patchwork of services available across multiple jurisdictions.

It is clear both from the literature and from our primary research that education support must take an ecological view of the child or young person (Bronfenbrenner, 1979) as a student and learner centred within their family, classmates, school, community and society. This approach must be child-centred and flexible enough to respond to the changing needs of the child throughout their health care journey. Clear, open communication between the family, the health care professionals
and the education professionals involved with the student is essential to ensure that the child’s needs are met holistically and without hiatus or repetition. Education services which meet the child’s needs wherever they are, whether in hospital, at home, at school or in another setting, ensure that students do not fall through the cracks of service provision. The work needs a skilled and qualified coordinator to ensure that all the strands are brought together in an effective way. This work currently falls too often on parents to co-ordinate and manage, on top of their already heavy caring responsibilities. In addition, this burden falls disproportionally on those parents with fewer resources available to them to manage this role effectively. Personalised learning and the development of an Individual Learning Plan or similar written document will ensure that the child-centred focus of education is clear to the range of health and education professionals who may interact with the child over time. Effective use of technology to connect physically absent or isolated students would enhance the child’s connectedness and support engagement in learning.

In the USA, the Medical Home model goes some way at addressing these issues. In the Medical Home model medical care ideally should be comprehensive, family centred, coordinated, accessible, continuous, compassionate and culturally effective (American Academy of Pediatrics, 2002). Care, in this model, is delivered and coordinated by a physician, and the plan of care is expected to be coordinated with educational and other community organizations. However, we suggest that the child’s education and learning needs are under-recognized in this principally medical focused model, as are the roles of schools and school personnel/educators, and the home as an important site of service provision for children managing chronic illnesses. We suggest a version of the Medical Home model that has an educator as the key coordinating professional may be worth exploring, if not trialling.

In sum, both the literature, policy developments and current practice across Australia and New Zealand indicates that effective models of education support for students with health conditions must encompass the following features:

- Is child centred and focussed on the individual learning needs of the child
- Is flexible, responsive, accessible and able to be delivered in a range of settings including the hospital, school, home and in community spaces
- Provides clear communication channels between health care professionals, education professionals, the student and the family
- Provides appropriate direct and personalised academic support to the student
- Provides opportunities for social and emotional support as well as peer connectedness
- Is coordinated by a designated education professional, linked to the mainstream education system and does not rely on the parent to fulfil this role
- Utilises technology effectively to keep the student connected to learning and to peers.

Our evidence shows that education support services for students with health conditions across Australia and New Zealand encompass many of these features, but that many services also fail to provide all features, or rely on a patchwork of services and providers to meet these needs across.
different domains. Furthermore, lack of clear policy directives underpinning the development and implementation of education support services hampers the development of more comprehensive or integrated systems. All parents want the best possible educational outcomes for their children, regardless of their health status and it is essential that education systems ensure that this is achieved via evidence-informed service decision making and provision for students living with chronic health conditions.
References


Barnett, T., Hopkins, L. and S. Peters (2014). What happens when they go home? An investigation of education support for students following discharge from the RCH. A report to the Royal Children’s Hospital Education Institute and DEECD.  


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Wilkie, K. and A. Jones (2008). "Link and learn: Students connecting to their schools and studies using ICT despite chronic illness". Presentation to *Australia Association for Research in Education conference*. Canberra.


### Appendix 1 – Education support in hospitals by jurisdiction

<table>
<thead>
<tr>
<th>State</th>
<th>Type of service</th>
<th>Number of services</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital</td>
<td>School (reports under Disability umbrella to Central office)</td>
<td>1</td>
<td>Canberra Hospital paediatric ward</td>
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<tr>
<td>Territory</td>
<td></td>
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<tr>
<td>New South Wales</td>
<td>Hospital School (Special School – Schools for Specific Purposes)</td>
<td>10</td>
<td>Bankstown Hospital School</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Ilawarra Hospital School</td>
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<td></td>
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<td></td>
<td>John Hunter Children's Hospital School</td>
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<td>Liverpool Hospital School</td>
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<td></td>
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<td>Royal North Shore Hospital School</td>
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<td></td>
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<td>Royal Prince Alfred Hospital School</td>
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<td>St George Hospital School</td>
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<td>Sutherland Hospital School</td>
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<td></td>
<td>Sydney Children’s Hospital</td>
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<td></td>
<td></td>
<td></td>
<td>The Children’s Hospital School (Westmead)</td>
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<tr>
<td>Northern Territory</td>
<td>Hospital school (annexed to closest primary school)</td>
<td>2</td>
<td>Royal Darwin Hospital</td>
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<td></td>
<td></td>
<td></td>
<td>Alice Springs Hospital</td>
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<tr>
<td>Queensland</td>
<td>School for specific purpose</td>
<td>2</td>
<td>Royal Children's Hospital School (Brisbane)</td>
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<td></td>
<td></td>
<td></td>
<td>Mater Hospital School</td>
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<td></td>
<td>Hospital class (administered by local high school)</td>
<td>6</td>
<td>Cairns</td>
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<td>Townsville</td>
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<td>Robina</td>
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<td>Toowoomba</td>
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<tr>
<td>South Australia</td>
<td>Hospital Education Service (government education department service)</td>
<td>1</td>
<td>Adolescent Services Enfield Campus - Enfield</td>
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<td></td>
<td></td>
<td>Behavioural Intervention Services - Campbelltown</td>
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<td></td>
<td>Flinders Medical Centre – Bedford Park</td>
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<td>Lyell McEwin Hospital – Elizabeth Vale</td>
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<td></td>
<td>Women’s and Children’s Hospital – North Adelaide</td>
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<tr>
<td>Country</td>
<td>Program Name</td>
<td>Count</td>
<td>Description</td>
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<td>-----------------------------------------------------------------------------</td>
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<tr>
<td>Tasmania</td>
<td>e-school</td>
<td>1</td>
<td>Statewide</td>
</tr>
<tr>
<td>Victoria</td>
<td>Education Institute</td>
<td>1</td>
<td>RCH (Melbourne)</td>
</tr>
</tbody>
</table>
|                  | Schools which work in association with mental health care providers | 5     | Austin Hospital  
Banksia Unit, RCH [Travancore]  
Avenues Education centre [Alfred health]  
Baltara School [4 campuses] |
|                  | Teacher secondment                  | 1     | Monash Children’s Hospital                                                 |
| Western Australia| School of Special Educational Needs | 1     | Statewide                                                                   |
| New Zealand      | Regional Health School              | 3     | Northern Region [Auckland]  
Central Region [Wellington]  
Southern Region [Christchurch] |
Appendix 2 – questionnaire for education support staff in hospitals

Part one: the nature of the education support offered
Please describe the nature of your service (prompt: school, classroom, integrated service)
How is your service organised (prompt: primary/secondary classroom; ward based)
How many teachers do you have? How many support staff? Volunteers?
How many students do you see on average?
How many sessions do you have with students?
How do you engage with parents/carers (if appropriate)?
What liaison is provided to the student’s home school (if appropriate?)
What role, if any, does your service play in facilitating students’ return to school?

Part two: eligibility criteria for education support
How are students referred/enrolled in your service?
How are students assessed for eligibility? By whom?
Is there a specified age range (prompt: school-age only, pre-school, post-compulsory)?
Are siblings provided for (prompt: enrolled, referred to local school)?
What referral processes exist to allow students to access external supports (eg: Ronald McDonald Learning Service)?

Part three: pedagogical models employed
Please describe the pedagogical model used in your service (prompt: individualised learning, project-based learning, curriculum-aligned learning, tutoring)
Why have you chosen this approach?
How is student learning assessed (on initial enrolment, and during/at conclusion of enrolment)?
How do practices ensure continuity of education for students?
How do you work with other professionals? Other agencies?

Part four: school/educational governance arrangements
What is your school/organisation’s governance structure (prompt: state registered school, hospital department, teacher secondment, independent organisation)?
How is this managed between the educational sector and the health care sector?
What state/federal government policies (if any) govern the way your service is delivered?
How is your service assessed/reviewed?

Part five: settings covered by the service (hospital, clinic, home).
Where is your service located (prompt: in a school, in hospital, in community)?
Where are students seen (prompt: hospital, school, home)?
What provision is made to use technology to keep remote/home bound/isolated students engaged in learning?