



Full report

School connection for seriously sick kids

Who are they, how do we know what works, and whose job is it?

MISSINGSCHOOL
KEEPING SERIOUSLY SICK KIDS CONNECTED

 **ARACY**
Australian Research Alliance for Children & Youth
Collaboration • Evidence • Prevention

MissingSchool 2015 – Full report: School connection for seriously sick kids: who are they, how do we know what works, and whose job is it?

Neil Stafford, *ARACY*

Megan Gilmour, Gina Meyers, Cathy Nell, *MissingSchool*

Liza Hopkins, *The Royal Children's Hospital Education Institute* (co-author *Whose job is it?*)

© 2015 *MissingSchool*

Missing School Inc. owns copyright of all material in this report. You may reproduce this material in unaltered form only (acknowledging the source) for your personal, non-commercial use or use within your organisation. Commercial use of material in this report is prohibited. Except as permitted above you must not copy, adapt, publish, distribute or commercialise any material contained in this publication without ***MissingSchool's* permission.**

ISBN: 978-1-921352-75-1

[Suggested citation](#)


Australian Research Alliance for Children and Youth (ARACY). (2015). *Full report: School connection for seriously sick kids: who are they, how do we know what works, and whose job is it?*. Canberra, ACT.

[Contact us](#)

If you have any queries about this report, please contact ARACY:

Mail: PO Box 5070, Braddon, ACT 2612 Email: enquiries@aracy.org.au Website: aracy.org.au

Phone: +61 2 6248 2400

 @ARACYAustralia

ABN 68 100 902 921

Acknowledgements

This work was commissioned from ARACY by Missing School Inc. and supported by a generous grant from the St George Foundation, St George Bank.

The authors thank the many individuals and organisations who contributed to the work, including Barb Donnan (Ronald McDonald Learning Program) for insight into the RMLP collection of statistics around students with significant illness or injury, Megan Jackson (University of Canberra) for discussion of the use of technology to support the learning of students who miss school because of significant illness or injury, and Jenny Lavoipierre for thoughtful general comments.

In particular, the authors thank Liza Hopkins (The Royal Children's Hospital Education Institute) for significant contributions to the companion report *Whose job is it?* on research around current practice, and to Tony Barnett (The Royal Children's Hospital Education Institute) for providing valuable editorial comment.

Table of Contents

Suggested citation.....	2
Acknowledgements	3
Executive summary	5
Missing School report – Part 1: School connection for seriously sick kids - who are they?	13
Missing School report – Part 2: School connection for seriously sick kids - how do we know what works?	61
Missing School report – Part 3: School connection for seriously sick kids - whose job is it?.....	111

Executive summary

This series of three reports is intended as a starting point in a national conversation. The reports were developed as part of a program of work undertaken by the Australian Research Alliance for Children and Youth and Missing School Inc. The program has sought to examine current evidence, policies and approaches for supporting the education of students who experience non-negligible school absences because of significant illness or injury.

Students who miss school because of significant illness or injury face a variety of challenges in their education and may experience a range of adverse short-term and long-term consequences. Academic achievement may be affected, school relationships can be disrupted, motivation and engagement diminished, and isolation from the school community and peer group can have a profound effect on the student's social and emotional wellbeing.

The aim of this research is to understand the situation in which these students find themselves and whether it is adequately addressed. Each report addresses a separate question around how – and whether – these students are supported in their education.

Who are they?

An obvious first question is how many students are involved. The first report focused on the availability and quality of relevant data, and found that, although there is a substantial collection of data relating to school attendance and another collection relating to health and illness, there is very little to link the two.

Data from the Australian Bureau of Statistics can be used to estimate that around 1.6 per cent of students in Australia experience non-negligible school absence as a consequence of significant illness or injury. This equates to roughly 60,000 students, and is consistent with a figure of 1.5 per cent calculated in research data from the US school system. Data from not-for-profit organisations tend to focus on small and self-selecting groups of students, data from healthcare organisations do not count the many students who may be convalescing outside the medical setting, and school

attendance records appear to include only sketchy detail of students' reasons for non-attendance at school.

Illnesses commonly identified as leading to non-negligible school absence include, but are not limited to: asthma, cancer, cystic fibrosis, diabetes, digestive disorders and epilepsy. Different patterns of absenteeism accompany different illnesses, and the variability in patterns of absenteeism make it impossible to estimate an 'average' number of days missed by students with significant illness. It is possible that students with different patterns of absenteeism also have entirely different educational support needs.

How do we know what works?

Without knowing how many students are missing school because of significant illness or injury, it is very difficult to ascertain whether their needs are being met. However, the purpose of the second report was to examine evidence for practices and approaches that are demonstrated or considered to be promising in relation to supporting these students. It found a paucity of research, and no strongly evidence-based 'ideal model' or 'best practice' approaches to continuing the education participation and connection of students with significant illness or injury. However, it is possible to identify some emerging evidence and commonalities in strategies and approaches.

The concept of inclusion and equity in education offers a sound underpinning, and implies that students with significant illness or injury should be able to continuously participate in, or remain connected to, their regular school. Practices which facilitate continuing education participation and connection when absent from school focus predominantly on hospital and home-based education. Aspects of these that may be more conducive to enhanced participation and connection include: continuing formal provision in multiple locations and environments; personalised needs-based learning, and flexibility to account for the nature of illness; communication between families, schools and health care practitioners; and alignment with education authority curriculum requirements.

New information and communication technologies (ICT) are one of the most promising prospects for continuing education participation and connection of students with significant illness or injury – particularly in a real-time, virtual environment. Small-scale trials of ICT in the classroom suggest that this can be beneficial for students, although some challenges need to be overcome (such as teacher confidence, privacy issues, technology capability etc).

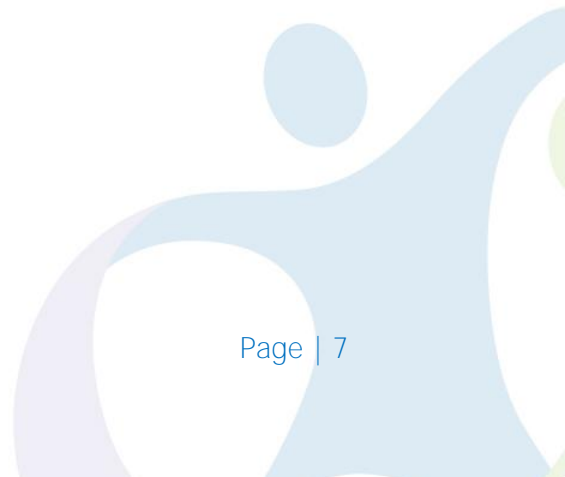
Because of the limited evidence regarding 'best practice' and 'ideal models', a draft theoretical framework has been proposed, informed by the strategies used for educational inclusion and equity, as well as by some of the particular challenges for the ongoing participation of students with significant illness or injury.

The framework is based on an overarching desired outcome of educational inclusion and equity for students with significant illness or injury. It outlines the pre-conditions for this outcome to be achieved, including: early intervention and planning; individualised and flexible approaches; integrated and consistent provision of education across environments; collaboration between healthcare and education services; and steps to ensure that social and emotional needs are met. Finally, it suggests approaches and strategies to produce the desired outcome and its pre-conditions, including: developing awareness and knowledge of significant illnesses and injuries (including breaking down stigma); formalised and actionable documentation to plan and implement strategies for individual students; greater integration and alignment of health, education and social support provision; and methods to ensure students have continuing connection with their regular school when absent from it.

Whose job is it?

The third report surveyed the legal and policy provisions already in place in Australian schools and school systems, and attempted to compare them to the draft theoretical framework.

Current policy and philosophy in Australia strongly supports the inclusion and equitable participation of all children in education, implicitly embedding the rights of



students with significant illness or injury to be given additional support to continue learning and to remain connected to their regular school.

However, the policies and processes covering the education of students with significant illness or injury are often subsumed into a disability and/or special needs area that may not directly relate or easily apply to such students. This may hamper awareness, recognition and clarity around the rights of these students to receive support.

State and territory education policies and processes show a number of commonalities relating to the education of students with significant illness or injury. There is a focus on individualisation of approaches and flexibility according to student need, although whether these are effectively implemented is unclear.

Alternative education programs and services provide a source of support for some, but not all, students with significant illness or injury. Hospital schooling varies considerably from state to state in terms of accessibility, eligibility, extent of tuition, **and attachment to the student's regular school. The result is uneven and sporadic** provision, which is likely to differ depending on where a student lives and goes to school.

One of the biggest limitations in current policy, process and provision appears to be the continuing formal learning out of school and out of hospital, i.e. while at home. Such learning appears to be ad hoc and reliant on individual parties and localised approaches that may be in place.

Conclusions and key recommendations

The list of key recommendations is lengthy, and is indicative of the extent of work still to be done in order to ensure that students with significant illness or injury have equitable access to education despite missing school.

In order to ensure an evidence-base for intervention, more reliable data is needed. Key recommendations from the first report focus on exploration of primary data sources, and modification of data collection methods as appropriate to address any identified gaps. These include:

- working with data collection agencies and organisations to draw on any unpublished data;
- engaging schools and state and territory education departments to obtain access to any detailed school-level records of attendance and causes of absenteeism;
- conducting a more detailed audit of international statistics which might be applied to the Australian context;
- changing recording mechanisms, so that reasons for absence are more specific and can be cross-correlated with duration of absence;
- advocating for specific measures to be included in current national surveys, so that better estimates of rates of absenteeism can be obtained; and
- carrying out new primary research, including development of new surveys and school data collection processes.

The theoretical framework, which currently stands in for a 'best practice' model, should be developed using a collaborative process which allows for pathways to be identified, practices to be tested, impacts to be measured, and outcomes to be evaluated. Specifically, this includes:

- development of 'joined-up' education and health services which work across a variety of settings;
- greater collaboration and formalised links between all parties involved in the education and care of students with significant illness or injury;
- engagement of parents and students as equals in the planning, implementing and review of education and care arrangements;
- development of a culture of inclusion in schools which improves knowledge of the needs of students with significant illness or injury;
- practitioner support and 'up-skilling' for both medical and teaching professionals;

- implementation and integration of ICT into the school and home environments to allow students to maintain connection with school; and
- ensuring that provision is consistent across jurisdictions so that students do not face discrimination based on where they live.

Despite the good intentions and efforts of some individual educators, parents, policymakers and others in the field, there is a gap in current policy and provision for students with significant illness or injury. Potential means of addressing the gaps and limitations emerging could include:

- development of national legislation specific to the needs of students with significant illness and injury, mirrored by policies and procedures developed at the state and territory level to explicate the processes to support such students. These should be clearly communicated to educators, parents, students and other stakeholders, and their implementation monitored through regular review and reporting;
- development of specific policy for students with significant illness or injury, and not merely subsuming this into disability;
- formalising health and education data linkage and collection processes to allow for improved monitoring and research into the numbers of students with significant illness or injury, and the extent of their absence, and to determine support needs and resources accordingly;
- ensuring that funding, infrastructure, resources and staff development opportunities are available to support the additional needs of students with significant illness or injury as a legislated entitlement. This should recognise that there may be a continuing need for educational and learning support across the **student's school life whether the illness is ongoing, or whether the student has recovered from the illness or injury leading to the absence;**
- advancing health initiatives and health services within school settings to support awareness and management of illness, managing environmental barriers to attendance, and enhancing integration of education and health services;

- advancing educational initiatives within medical settings to promote understanding amongst medical staff of the importance of the child's education and learning needs, and wellbeing and identity as a student or learner;
- formalising linkages between the healthcare and education sectors in order to develop a cohesive, integrated education model that maintains **students'** connections with their regular schools, and making explicit the legislated responsibility of schools to support the education of all their students;
- incorporating and facilitating the use of information and communication technology as an integral part of learning, allowing for remote education and **'virtual' presence in school; and**
- formalising the roles and responsibilities of all parties, including parents and carers, in supporting students with significant illness or injury.

Tens of thousands of students every year face disadvantage because they miss school as a result of significant illness or injury. Principles of inclusivity and equity, as well as legislation, support their right to maintain their participation in education despite their illness. In order to inform practice and to mitigate the disadvantage, much more work is needed. This includes continued development of data collection systems, research into effective practice, and formal explication of the roles and responsibilities of all parties.

Most importantly, all such development, research and explication needs to have its origin in a collaborative process which engages all stakeholders from the beginning, including policymakers, professionals from the medical and education sectors, and – critically – the students and their families.

So - who are they?



School connection for seriously sick kids
Part 1: Who are they?

MISSINGSCHOOL
KEEPING SERIOUSLY SICK KIDS CONNECTED

 **ARACY**
Australian Research Alliance for Children & Youth
Collaboration • Evidence • Prevention

Missing School 2015 – Part 1: School connection for seriously sick kids: who are they?

Neil Stafford, *ARACY*

Megan Gilmour, Gina Meyers, Cathy Nell, *MissingSchool*

© 2015 *MissingSchool*

Missing School Inc. owns copyright of all material in this report. You may reproduce this material in unaltered form only (acknowledging the source) for your personal, non-commercial use or use within your organisation. Commercial use of material in this report is prohibited. Except as permitted above you must not copy, adapt, publish, distribute or commercialise any material contained in this publication without *MissingSchool's* permission.

ISBN: 978-1-921352-76-8

[Suggested citation](#)

Australian Research Alliance for Children and Youth (ARACY). (2015). *Missing School – Part 1: School connection for seriously sick kids : who are they?* Canberra, ACT.

[Contact us](#)

If you have any queries about this report, please contact ARACY:

Mail: PO Box 5070, Braddon, ACT 2612 Email: enquiries@aracy.org.au Website: aracy.org.au

Phone: +61 2 6248 2400

 @ARACYAustralia

ABN 68 100 902 921

Acknowledgements

This work was commissioned from ARACY by Missing School Inc. and supported by a generous grant from the St George Foundation, St George Bank.

The authors thank the many individuals and organisations who contributed to the work, including Barb Donnan (Ronald McDonald Learning Program) for insight into the RMLP collection of statistics around students with significant illness or injury, Megan Jackson (University of Canberra) for discussion of the use of technology to support the learning of students who miss school because of significant illness or injury, and Jenny Lavoipierre for thoughtful general comments.

In particular, the authors thank Liza Hopkins (The Royal Children's Hospital Education Institute) for significant contributions to the companion report *Whose job is it?* on research around current practice, and to Tony Barnett (The Royal Children's Hospital Education Institute) for providing valuable editorial comment.

Table of Contents

Suggested citation.....	14
Acknowledgements	15
Executive summary	17
Introduction	20
Definitions	25
School connection for seriously sick kids : who are they?	29
Overview of audit approach	29
Current metrics for illness and school attendance	30
How many students experience non-negligible absence from school as a result of significant illness or injury?	31
What are the significant illnesses and injuries which lead to non-negligible school absence?.....	37
For how many days are students with significant illness absent from school?.....	40
Recommendations.....	45
Appendix I: Overview of data sources and measures	47
Appendix II: Calculation of estimates made in this report.....	54
References.....	55

Executive summary

This report is one of three developed as part of a program of work undertaken by the Australian Research Alliance for Children and Youth and Missing School Inc. The program has sought to examine current evidence, policies and approaches for supporting the education of students who experience non-negligible school absences because of significant illness or injury. The aim is to understand the situation in which these students find themselves and whether it is adequately addressed. The focus of this report is on the availability and quality of metrics indicating how many students are affected by significant illness or injury which affects their school attendance.

Main findings

A survey of available sources reveals that there is a significant collection of data around school attendance, and also around health and illness, but very little to link illness and absenteeism.

A variety of national and international sources were reviewed:

- Data from the Australian Bureau of Statistics (ABS) focuses on the number of children and young people in Australia with disability and some of the limitations they experience. The ABS Profiles of Disability survey provides data on the kinds of barriers experienced in school by students with disability, including whether or not they have difficulty with school attendance, but explicitly excludes students who were not attending school at the time of data collection. The ABS Survey of Ageing, Disability and Carers uses very broad categories to describe disability types and barriers which arise for students with disability, but can be used to estimate that around 60,000 Australian students experience problems with attendance because of illness or injury. At the time of writing, this equates to around 1.6 per cent of the student population.
- In the US, research from the 1990's suggest that around 1.5% of students experience illness which has an impact on school attendance. While this data is not recent, and uses definitions which are not always consistent with current understandings of disability and illness, there is a limited body of Australian

research which suggests that this figure may be still applicable in the Australian school-aged population today. It is consistent with the figures inferred from the ABS data.

- Data from various not-for-profit organisations focus on small groups of students with specific illnesses, or who seek charitable support, and are not representative of the entire population.
- Data from hospital and health-care records can be used to estimate the number of students who are hospitalised every year, but overlook the numbers of students who are resting or convalescing at home, outside both the health and education systems.
- Records from state and territory education bodies have not been thoroughly examined, but those which are readily available suggest that there is extensive data on school attendance and absenteeism but little to explain reasons for non-attendance.

Illnesses commonly identified as leading to non-negligible school absence include: asthma, cancer, cystic fibrosis, diabetes, digestive disorders and epilepsy. Different patterns of absenteeism accompany different illnesses. Some students may miss only a few days of school at a time, but may do so at frequent intervals throughout the school year. Other students may miss months or years of school in a continuous stretch. The variability in patterns of absenteeism make it impossible to estimate an 'average' number of days missed by students with significant illness, and in fact students with different patterns of absenteeism may also have entirely different educational support needs.

Conclusions and key recommendations

This examination of available sources reveals a gap in the data which warrants further investigation. Current data collections are unable to say how many students experience non-negligible school absence because of significant illness or injury. It is thus impossible to know whether education systems are working effectively to support them. The fact that this population of students is frequently overlooked in surveys, and

is not identified in wider healthcare/education data collection, suggests that it is highly likely that they are not being equitably supported.

Key recommendations from this report focus on exploration of primary data sources, and modification of data collection methods as appropriate to address any identified gaps. These include:

- working with data collection agencies and organisations to draw on any **unpublished data**;
- engaging schools and state and territory education departments to obtain **access to any detailed school-level records** of attendance and causes of absenteeism;
- conducting a more detailed audit of **international statistics** which might be applied to the Australian context;
- **changing recording mechanisms**, so that reasons for absence are more specific and can be cross-correlated with duration of absence;
- **advocating for specific measures to be included in current national surveys**, so that better estimates of rates of absenteeism can be obtained; and
- **carrying out new primary research**, including development of new surveys and school data collection processes.

Introduction

Around Australia every day, thousands of children miss school because of illness. Some of these children will be missing a few days every year; some will be missing a few weeks every year; some will be missing months and possibly years of school.

One of the specific challenges facing students with critical or chronic illness is that they may experience frequent or extended absences from school, either because of illness or treatment. The double burden of illness and school absence has many long-term consequences which may include:

- delays in developmental skills due to missed experiences
- school refusal and absenteeism
- academic under-achievement
- behavioural problems
- increased anxiety
- attention and concentration problems
- reintegration difficulties
- specific learning needs
- low self-esteem
- disruption of friendships
- difficulties in forming and maintaining relationships
- reduced opportunities for social support
- increased vulnerability to other life stressors or secondary illnesses
- peer rejection

(Donnan and Webster, 2011; Whiteford, 2010; Shaw and McCabe, 2008; Dockett, 2004; Shiu, 2001).

This is a long list of 'possible side-effects' and not all students will experience all of these problems. However, the research is clear that school absence resulting from illness is a significant problem for many students.

Retention, or 'repeating' a year or more at school, may be appropriate for some students – depending on the anticipated absence, when it occurs in their schooling,

and their general socio-emotional environment – but is otherwise not generally recommended. In a review of educational issues faced by students with chronic illness, Irwin and Elam (2011, quoting Jimerson et al., 2006) note that retention does not improve academic outcomes, but is instead detrimental to socio-emotional and **behavioural outcomes, and has a negative impact on students' attendance and attitudes toward school. They observe also that "students perceive retention as a highly stressful life event, and retention is a strong indicator for dropping out of school."**

The importance of maintaining connection between students and their schools in mitigating these problems has been frequently highlighted in the literature (Porter, 2008; Dockett, 2004; Shiu, 2004a). However, an absent student may be largely 'invisible' in the context of a busy school, and easy to overlook when planning for **teaching and learning. The extent to which the student's needs are addressed** is heavily reliant on the disposition of individuals within the school, and there is thus widespread variability and inequity in the educational access afforded (Lavoipierre, 2012; Wilkie, 2012).

During a hospital admission, a student will generally have access to the hospital **school. The stated mission of most hospital schools is to work with the student's** regular school to maintain continuity of learning. In practice, and for a variety of reasons, this is often not successful (Wilkie, 2012).

Current advances in healthcare also mean that many children requiring medical treatment receive their treatment on an outpatient basis, and may spend significant periods of time recovering at home rather than in hospital. They may be too vulnerable or fragile to attend school, although quite capable of undertaking school work and possibly craving social interaction. During this time, they have access to neither the hospital school nor their regular school.

The school experience of many students with critical or chronic illness or injury is one of isolation and marginalisation.

While the need for increased systemic support for students is clear, the educational environment is complex and it will take time to develop appropriate solutions. Such

solutions are likely to require improved linkages between educational and health sectors, and involvement of students and their families in uncovering the issues, barriers and possibilities faced by different individuals in different contexts. For example, variations in the nature of the significant illness or injury, the student's age, and the location, resources and capabilities of families, educators, and health professionals are all relevant factors.

MissingSchool is dedicated to working with families, educators and health professionals to identify best-practice models and raise awareness; and to advocating for change at a government systems level.

This work has been commissioned by *MissingSchool* in an attempt to understand the environment in Australia for children and young people with serious illness or injury who are also engaging with education.

Consolidation and synthesis of existing data has been problematic, largely because of the wide variability in language, terminologies and definitions used by different authors for different audiences. In order to maintain the coherence and 'readability' of these reports, we adopt a set of definitions, outlined in Definitions. When reviewing the literature and other data sources, we will note as appropriate where other authors have differed.

Even with a clear set of definitions, there is a wide range of complicating factors, not all of which can be adequately addressed in this document.

Significant illness or injury is likely at some stage to involve treatment in hospital. For students in metropolitan areas, medical care is generally close at hand. However, students in rural or regional areas may need to travel to the nearest large city to a specialist paediatric hospital. In some circumstances, the nearest hospital with an appropriate specialisation may be in a different state. Regular, although routine, processes and treatments may require a substantial amount of travel and time away from home, family and school. Lengthy treatment may involve re-locating the entire family to a different city for the duration of the treatment. In this case, maintaining contact with the student's regular school becomes significantly more difficult, and communication platforms adopted by the different state education authorities may not

be compatible. Until recently, different states have also maintained differing curriculum, assessment and reporting requirements, and while many of these differences have been dispelled with the adoption of national standards, some persist.

Students whose regular school is a 'home school' are not captured in any of the data, and their situation has not been examined.

There are many parties involved in the care of a student with significant illness, and all have a unique perspective on the nature of the illness and the purpose and relevance of school and education. These parties include the students, their school-aged siblings and families, their teachers, classmates, educational leadership, and school communities, medical and allied health staff. Surveys are designed to capture the data which the surveyors believe to be relevant; legislation is designed to reflect the imperatives of government authorities; interventions are developed to meet the needs assumed by their developers. The different – and sometimes conflicting – perspectives and perceptions of the different parties make it almost impossible to draw out a coherent understanding of the challenges arising.

Privacy issues come into play at the intersection of public spaces (schools and hospitals) and private spaces (the family home). While the state bears the ultimate responsibility of ensuring that its students have access to quality education, it must respect the rights of individuals and families to privacy in the home, and confidentiality at school.

Advances in information and communication technologies theoretically make it possible to connect individuals anywhere in the country, but challenges arise from concerns around privacy in the home, at hospital and at school, access and resourcing issues, and constraints on communication platforms in different jurisdictions.

Advances in medical technology mean that more and more children and young people are surviving illnesses which were previously incurable and unmanageable. A generation ago, or even less, these children and young people, and their families and teachers, may not have had the time to consider the implications of their withdrawal from their schools and education. Today, they are likely to become adults in our communities and societies, and they will need access to quality education if they are to

have the same opportunities as other children and young people to fulfil their potential. While dealing with significant illness, they remain students.

MissingSchool began this work in the hope of building some clarity around the systemic issues facing students with significant illness, and their families, teachers and schools in Australia. It offers no answers, but instead **“rigidly defined areas of doubt and uncertainty”** (Adams, Douglas: *The Hitchhiker's Guide to the Galaxy*, 1978). Further work remains to be undertaken by the parties who bear the responsibility for addressing the challenges in the system, and we hope that they may find this document a useful starting point.

Definitions

Absence

Different patterns of absenteeism will be experienced by students with different significant illnesses, and even by different students with the same illness. Some students may be absent for months and years at a time, others may be absent for shorter and more frequent periods. Absences have been described as 'prolonged', 'extended', 'frequent' or 'recurrent'.

At this stage we do not want to put a quantitative limit on the number of days which must be missed before an absence becomes 'non-negligible'. However, we expect that such an absence would mean either multiple months in one stretch, or else smaller absences of days or weeks which added up to multiple months or even years over the course of the student's school life. A single absence even of several weeks would not necessarily constitute a non-negligible absence.

At the school level, it is possible that the needs of the student will be more closely linked to the student's pattern of absenteeism than to the student's illness.

Disability

Medical conditions and illnesses are clearly included under definitions of disability in the Commonwealth legislation. In more general usage, disability may be understood to mean vision, hearing or mobility impairment or behavioural issue, and there may be confusion amongst teachers and families about whether the provisions of the disability legislation applies to the situation of students with significant illness (Department for Education, Employment and Workplace Relations, 2012). Families who are grappling with the import of a significant illness may view disability as a stigma or unwanted label. For the purposes of this report, we accept medical conditions, illnesses and injuries as disabilities as defined under the Commonwealth Disability legislation (Attorney-**General's Department, 2005**).

Enrolment / registration / attendance / participation

Different schools, different families, and different agencies have different understandings of what it means to be enrolled in a school. Simple enrolment in a school does not mean that the student is attending. Simple attendance at a school does not mean that the student is

participating. Equally, a student who is not actually attending school may still participate in the life of the class with the help of distance communication technologies and support strategies. In this report we will use 'participation' to mean that the student is engaged in meaningful activities which support his or her social or academic development.

Illness or injury

There are connotations associated with the words 'illness', 'disease' and 'condition', and language is often chosen on the basis of the perceived impact of those words. We have chosen to use the term **illness**, understanding that it is not communicable, and may be transient or permanent.

We restrict our use of 'illness' here to somatic illnesses only. We acknowledge the need to support students with mental illness, and would not reject discussion of those needs. However, the field around mental illness is complicated, and it is possible that the needs of students with mental illness are substantially different from the needs of students with somatic illness. Deeper investigation of those needs is warranted, but is not attempted here.

None of the terms mentioned above covers the possibility of an injury which leads to school absence. We have thus chosen to refer to **illness or injury**. Use of either word should be read as including the other unless explicitly indicated.

Regular school

The school which the student ordinarily attends when not experiencing illness-related absence is referred to as the **regular** school. This is in order to avoid the misunderstandings inherent in the use of 'home school' (which may instead refer to the education of the student at home), 'mainstream school' (which raises interesting but unhelpful questions around the boundaries of inclusivity), 'origin school' (which is not commonly used, and is open to misinterpretation), and 'census school' (which is a term used by state education authorities and not familiar to the other parties who may read these reports).

School

We understand schools to include any provider of formal education up to Year 12. While students in pre-school and tertiary environments also face challenges associated with illness-related absences, the constraints in these environments are different from those in primary and secondary schools and beyond the scope of this report.

Siblings

The school-aged siblings of students with a significant illness are also at risk of missing school. They may travel with their families to accompany the ill student elsewhere for treatment, and thus be removed from their regular schools. They may miss school activities simply because their families are preoccupied with the care of the ill student. Older siblings may be expected to stay at home with their ill sibling as the family's economic circumstances require parents and carers to work outside the home. Siblings' needs are different, but also arise from the experience of living with a significant illness in the family.

Siblings are here understood as **school-aged siblings**. We acknowledge that much older or younger siblings may also be affected by the experience of living daily with a significant illness, but our focus is on their needs which arise from missing school.

Significant

Illness or injury may be variously described as 'serious', 'critical', 'chronic', or 'life-limiting'. All of these words are contestable, and different definitions are adopted by different authors and agencies to meet their own needs. Use of any of these words raises the possibility of disagreement about the nature and severity of the illness or injury.

Our focus is on neither the nature nor severity of the illness or injury but on the school absence which results from it. We have thus chosen to use the word **significant** to describe any illness or injury which has a non-negligible impact on school attendance. The definition of what is non-negligible is discussed above.

Students

In literature and casual discussion, we refer to 'children', 'adolescents', 'teenagers', 'young people', 'kids', 'students', 'learners', 'pupils', etc. We have chosen to adopt the term

students to describe all these people. This avoids categorisation by age, and also highlights the fact that we are focusing on the dimension of their lives which revolves around school. Given this whole school focus, we are concerned with students from Foundation to Year 12.

School connection for seriously sick kids: who are they?

Overview of audit approach

This report forms one component of the body of work between *MissingSchool* and ARACY, and focuses on the current available metrics related to significant illness and injuries experienced by students, and illness-related school absence. This has involved conducting a scan and audit of available data to identify measures currently recorded in Australia, along with discussion of the limitations of these data, and wider data gaps in the area.

The intent of this study was to identify the main significant illnesses faced by students, and their effect on attendance at school, including establishing time absent from school due to illness. However, this was contingent on the availability of suitable data.

The report focuses on students with significant illness or injury. Many of these students have siblings who also miss school as a result of **their family's focus on** managing the illness or injury. This report has not attempted to estimate the number of siblings involved, but it is noted that significant illness or injury disrupts the education of many more students than are represented in the report.

The approach to the audit involved reviewing a broad sweep of data and evidence sources, principally conducted online. The main source areas comprised:

- national data collections and reporting bodies, government and non-government, such as the Australian Bureau of Statistics, Australian Institute of Health and Welfare and Australian Council for Educational Research;
- state government statistics and reporting, specifically related to recording mechanisms undertaken in schools and reported by departments of education;
- peak bodies and non-government organisations for education, health and specific illnesses (e.g. asthma, diabetes, cancer); and
- international research studies and statistics, targeted to address emerging gaps in data from the three source areas above.

Sources were then reviewed for relevance, with data measures and items of relevance recorded, along with any limitations associated with the data (e.g. scope, audience, time period, applicability to a wider population, etc.). Data from these sources were subsequently used as a basis to estimate the incidence of significant illness or injury and related school absence among Australian students. A detailed overview of main sources used in this report is provided in Appendix I.

Current metrics for illness and school attendance

The Australian Bureau of Statistics report on Schools, Australia (2014) notes that there are around 3.65 million students attending school in Australia.

This audit indicates that there are currently no definitive measures of either the numbers of students in Australia missing school because of significant illness or injury, or of the extent to which their schooling is disrupted (i.e. days missed) because of their illness or injury.

A number of national data collections provide some insight into this issue, predominantly in terms of prevalence of chronic medical conditions, disability, and hospitalisations due to injury. However a frequent limitation of these data is that no link is drawn between illness and school attendance. While extensive school attendance data is recorded across Australia, detailed reasons for non-attendance, and thus data on impact of significant illness, appear to be lacking. In addition, students whose enrolment status is not clear – either because of an extremely long school absence, or because there is uncertainty over which education provider is taking responsibility for continuing their education – may be absent from the data altogether.

Establishing relevant metrics currently requires something of a 'patchwork' approach, utilising various data sources and previous academic research into the issue, and building in a number of assumptions to form best estimates possible.

How many students experience non-negligible absence from school as a result of significant illness or injury?

Australian Bureau of Statistics

The Australian Bureau of Statistics reports that, in 2004-5, four in ten children (41 per cent) under the age of 15 had a long-term health condition (ABS, 2007). More recent data (ABS, 2012a) breaks this down into specific conditions:

Table 1: Incidence of specific long-term conditions amongst children 0-14 years, 2011-12

Long-term medical condition	Number	%
Diseases of the respiratory system (<i>includes asthma</i>)	790,500	18.8
Diseases of the eye and adnexa	472,700	11.2
Mental and behavioural problems	259,300	6.2
Diseases of the skin and subcutaneous tissue	172,600	4.1
Diseases of the ear and mastoid	155,200	3.7
Diseases of the nervous system (<i>includes epilepsy</i>)	70,700	1.7
Diseases of musculoskeletal system and connective tissue	64,200	1.5
Diseases of the circulatory system	39,700	0.9
Diseases of the digestive system	39,200	0.9
Diseases of genito-urinary system	32,100	0.8
Congenital malformations, deformations and chromosomal abnormalities	31,100	0.7
Diseases of blood and blood forming organs (<i>includes diabetes</i>)	24,900	0.6
Endocrine, nutritional and metabolic diseases	10,400	0.2
Infectious and parasitic diseases	7,300	0.2

While robust, credible, and useful for establishing the extent of illness amongst children, these data give no indication of whether these illnesses result in school absence. It is possible that not all of these cases will affect school attendance. Equally, it is likely that other acute and rare illnesses and injuries that could impact attendance are not recorded.

The data describe the population of children aged between 0 and 15, which overlaps the school-aged population but does not match it exactly. Additionally, the data

enumerate incidences rather than students; co-morbidity of any conditions would mean that a simple tally of the numbers of students with each condition would not reflect the total number of students with long-term health conditions.

If it could be assumed that the figure of 41 per cent applies as well to the school-aged population as to the population of children aged 0-15, then this would put an extreme upper bound on the numbers of students with long-term illness (but not injury). It is silent on the numbers of students who miss school as a result of significant illness (of any duration) or injury.

ABS Profiles of Disability

The ABS *Profiles of Disability* (ABS, 2012b) estimates in its *Children at School with Disability* document that 292,600 children with disability attend school in Australia. The implication is that children who are not attending school are not included in this figure; and the document does indeed conclude by noting that it specifically excludes “children who did not attend school because they had finished school, were being home-schooled, or were prevented from attending school because of their condition at **the time of the survey**” (ABS, 2012b).

The *Profiles of Disability* define several broad categories of disability: sensory and speech; intellectual; physical restriction; psychological; head injury, stroke or brain damage; other. Of these categories, only the last two are likely to include significant illness or injury. Table 11 of the *Profiles* indicates that about 32 per cent of students whose disability includes injury or illness report no difficulty with schooling. Possible difficulties experienced by the remaining 68 per cent of students are diverse and variable, and although they may include ‘difficulties with attendance’, it is not clear how many students actually experience school absence as a difficulty.

Table 1 in the same file notes that there are 63,700 people aged 5-20 with a disability who do not attend school, but does not break down the numbers by disability type or by reasons for non-attendance. Since disability is defined here to include illness, it is highly likely that some of these individuals at least will be absent because of significant illness or injury; however, it cannot be assumed that this is the case for all.

The *Profiles of Disability* thus specifically excludes students who, at the time of the survey, are unable to attend school because of illness. At the same time, it fails to enumerate the students for whom attendance is interrupted as a result of disability of any kind.

ABS Survey of Disability, Ageing and Carers (SDAC)

Elsewhere, in the *Survey of Disability, Ageing and Carers* (SDAC), the ABS estimates (Table 3) that 177,300 students aged 5–14 face some level of schooling restriction due to a disability or long-term health condition (ABS, 2013).

The difficulty here **is that the SDAC definitions of 'disability or long-term health condition' and 'schooling restriction' are very broad.** However, by making some assumptions about the categories being reported, it is possible to come up with a very rough estimate of the numbers of students who miss school because of significant illness or injury.

The SDAC categorises disabilities broadly as:

- sensory, intellectual, physical, and psychological impairment;
- head injury, stroke or brain damage; and
- other disabilities, which include long-term conditions or ailments.

Table 8 of the *Profiles of Disability* indicates that approximately 25.8 per cent of reported disabilities are in the latter two categories which include injury or illness. This suggests that, of the 177,300 students aged between 5 and 14 who face a schooling restriction, perhaps 46,000 students face such a restriction because of significant illness or injury. This figure applies only to students in the first ten years of schooling, and if we can assume that it will increase by roughly 30 per cent when the final three years of formal schooling are included, then the number of students who face a schooling restriction rises to almost 60,000.

The nature of the restriction on schooling is not clear. The SDAC glossary explains that 'schooling restriction' may include: inability to attend school, attendance at a special school, attendance in a special class in an ordinary school, needing at least one day off a week on average, or other difficulty at school.

The figure of 60,000 students thus potentially includes students with disabilities other than significant illness, or who may have restrictions other than an inability to attend school. It may also 'double-count' some students who have more than one sort of disability. It is therefore an estimate only of the number of students who miss school because of significant illness or injury.

The figure of 60,000 students is approximately 1.6 per cent of the total school-student population of around 3.65 million.

Research literature

Similar figures are broadly reflected in some academic studies seeking to establish the proportion of children with significant illness.

In Australia, and drawing on ABS data from 2002, Shiu (2005) reports that 15 per cent of children have a long-term health condition and 3.5 per cent a severe chronic illness. Shiu discusses positive educational interventions for these children, but does not quantify the proportion of the student population experiencing illness-related school absence.

Though dated, the work of Newacheck and Taylor (1992) reports that 31 per cent of US children have a chronic health condition, and that 12 per cent of those children (or about 4 per cent of the total population) were absent from school for 7 or more days. They note that: **"a small segment of the chronically ill population disproportionately shoulders the burden of illness when that illness is measured in terms of bed days and school absences"** (p.366).

Shaw and McCabe (2008), report that 18 per cent of US children have chronic illness and (citing Kaffenberger, 2006) that approximately 1.5 per cent of all children are unable to regularly attend school due to chronic illness.

The Royal Children's Hospital Education Institute (Barnett, Hopkins and Peters, 2014), also citing Kaffenberger (2006), calculated that across Australia every year, more than 67,000 students miss school because of significant illness or injury. This landmark investigation identified that 30 per cent of students who had attended the Hospital's

Education Institute still had not returned to school one month after discharge. Of these students, only 43 per cent had received any educational support of any kind at home.

The variability in the estimates is exacerbated by different definitional categories of illness and school absence. Much of the research literature examines chronic conditions and/or disability, which simultaneously includes conditions other than illness and excludes acute significant illness and serious injuries resulting in hospitalisations and non-negligible absence from school.

Australian Institute of Health and Welfare

Australian data indicate that injuries – being the third leading cause of hospitalisation – are a common occurrence amongst young people, although it is problematic to establish the extent to which these disrupt schooling.

A report for the Australian Institute of Health and Welfare (Eldridge, 2008) states that 316,000 12-17 year olds sustained an injury in the previous four weeks, representing 20 per cent of all people in this age group. Of these, around one in ten (31,600, or 2 per cent of all people in the age group) reported time off school or work because of the injury. There are no details of the duration of this 'time off' and so the figure of 31,600 (2 per cent) will include both negligible and non-negligible school absences.

In terms of hospitalisations, in 2005-6 it was reported that just over 91,000 12-24 year olds were hospitalised due to injury, of whom 24,000 were hospitalised for at least one night. The mean length of stay for those hospitalised overnight (i.e. excluding the same day separations) was 5.4 days, with those involved in transport accidents likely to stay the longest (7.3 days). Since many of these patients will have spent further time convalescing at home after discharge from hospital (Barnett, Hopkins and Peters, 2014), the students among them will have experienced a school absence significantly greater than the hospital admission. Many of these cases will no doubt have a significant impact on school participation, but since the population does not match the school-aged population and there is no further breakdown of the duration of hospitalisation, it is difficult to establish clearly the actual incidence of such cases.

Table 2: Proportion of students with significant illness or injury and/or experiencing non-negligible absence from school – summary of data

Data set	Students with significant illness or injury	Students who experience non-negligible school absence as a result of significant illness or injury	Notes
ABS (Health survey)	41.0%	silent	Refers to 'long-term health conditions' and focuses on population 0-15 years
ABS (Profiles of Disability)	8.3%	silent	Survey excludes students who were absent from school and includes disabilities other than significant illness or injury
ABS (SDAC)	Not discussed	1.6%	Inferred from data
Shiu	15.0%	silent	Refers to 'long-term health condition'
Shiu	3.5%	silent	Refers to 'severe chronic illness'
Newacheck & Taylor	31.0%	4.0%	US data. Absences defined as 7 days or more
Shaw & McCabe, citing	18.0%	1.5%	US data

Kaffenberger			
The Royal Children's Hospital Education Institute, citing Kaffenberger		1.6%	Calculates this to be over 67,000 students across Australia
AIHW		< 2.0%	Refers to injuries

What are the significant illnesses and injuries which lead to non-negligible school absence?

The Australian Bureau of Statistics

Data from the ABS (ABS, 2013) shed some light on the types of significant illness which may affect school attendance and the nature of that effect. For example:

- There were 302,400 children aged between 0-14 years at school with asthma; of these, 42 per cent had time off school in the past year because of asthma.
- One third (31 per cent) of all people with cancer report absence from work or school in the past year because of their illness.
- Around 10 per cent of people with arthritis, diabetes, or circulatory disease report absence from work or school in the past year because of their illness.

Clearly, this is not an exhaustive list of all illnesses which lead to non-negligible school absence. While the data cover different age groups and different illnesses, they confirm that not all students with any specific illness will experience absence from school because of it.

Research literature

A number of academic research studies have examined the impact of specific conditions on school attendance and the likelihood and/or duration of school absence. This is summarised in

Table 3 below.

Table 3: Absence due to specific conditions – summary of relevant findings

Condition	Increased likelihood / extent of school absence
Asthma	<p>Students aged 5-14 years with asthma were around 1.6 times more likely to report having days away from study (22%) than students without asthma (14%) (ABS, 2006).</p> <p>Other research suggests a higher range of 12-36 days per year compared with 3.5 days for students without asthma. This indicates students with asthma have between 3.4 to 10.3 times as many days off as their peers without asthma (Shaw & McCabe, 2008).</p>
Cancer	<p><u>Survivors</u> of cancer had around 1.9 times more days off school in a year compared with a control group (mean of 9.6 v 5.0 days) (French et al., 2013).</p> <p><u>During treatment</u>, absence is likely much higher, ranging from 25-80 days, which equates to between 7.1 to 22.9 times as many days off as students without cancer (Shaw & McCabe, 2008).</p>
Cystic Fibrosis	<p>Students with cystic fibrosis are reported to average 19.5 days absent in the school year, which is 5.6 times more than for students without cystic fibrosis (3.5 days) (Shaw & McCabe, 2008).</p>
Diabetes	<p>In one study (Glaab, Brown, & Daneman, 2005), students with type 1 diabetes had around 1.6 times as many days off in a school year as those without diabetes (median of 8.8 v 5.5 days). Another study puts this at 4.0 times as many days off (14 vs 3.5 days) (Shaw & McCabe, 2008).</p>
Digestive disorders	<p>Students with digestive disorders had significantly greater school absence, ranging from 8.4 times as many days for those with <u>inflammatory bowel disease</u> (13.4 weeks v 1.6 weeks) to 2.8 times more for those with <u>coeliac disease</u> (4.4 weeks v 1.6 weeks) (Calsbeek et al., 2002).</p>
Epilepsy	<p>Students with epilepsy had about 1.6 times as many days absent from school in an academic year as those without this condition (mean of 15.3 days v 9.4 days) (Ibekwe & Ojinnaka, 2008).</p>

While the data are somewhat variable, they do indicate the types of illnesses more likely to lead to non-negligible absence from school.

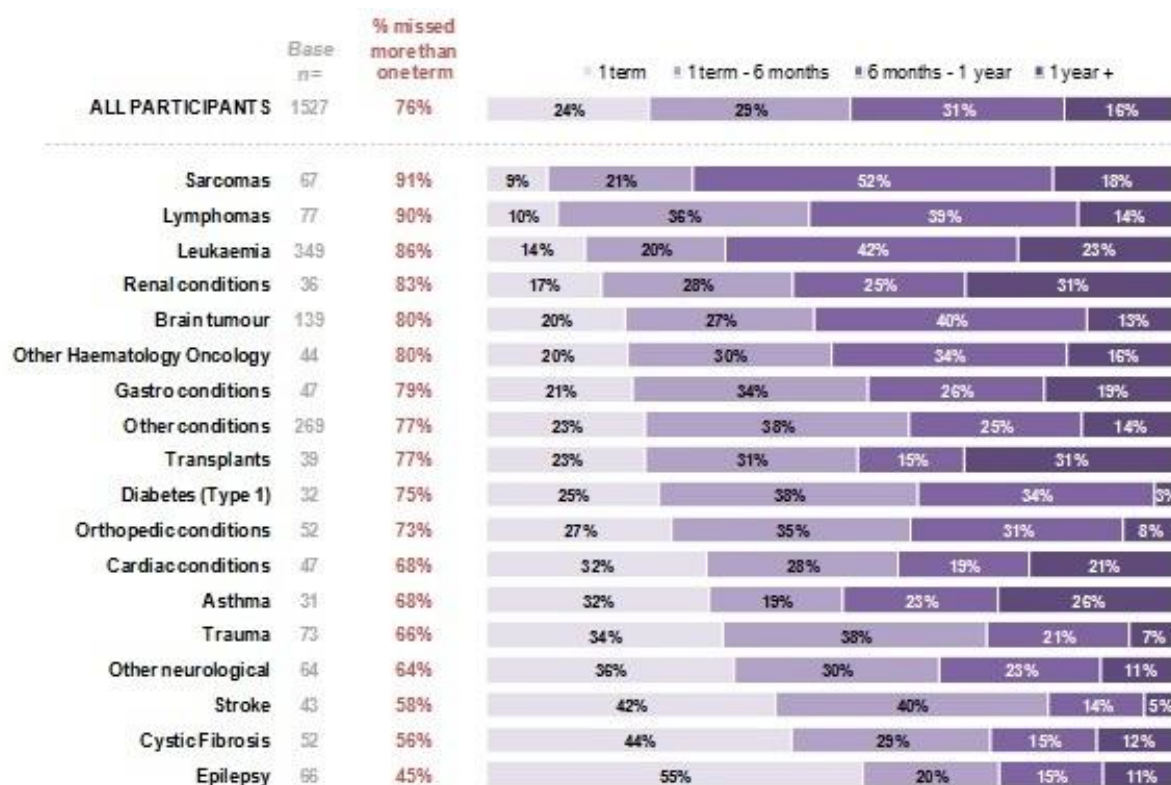
Charitable organisations

The *Ronald McDonald Learning Program* (RMLP) in Australia aims to help children recovering from serious illness to catch up on missed education, and includes an eligibility requirement that they have missed at least one term of school; this is recorded through parent (or carer) applications estimating the total amount of school missed as a result of their child's illness up to the time of application. The organisation's annual report from 2013 records over 900 students across Australia enrolled in the program, many of whom spend the full year in the program, with almost 200 more on a waiting list.

Figure 1 shows that, amongst all program participants, approximately three-quarters (76 per cent) missed significantly more than one term of school because of their illness. Absences were generally longer for students with cancer, and lower for students with epilepsy and cystic fibrosis. These data are based on absences reported at the time at which the student sought access to the program; they do not take into account ongoing absences during or after the student's involvement with the RMLP. Total absences over the student's school life may thus come to much more than the amount reported here.

Figure 1: Extent of missing schooling among RMLP participants, by illness type

Data provided by the RMLP for this report offer a rare insight into the world of



students who miss long periods of school because of illness and are the subject of a detailed analysis funded by the RMLP, Victoria University and the Victoria Institute. This report is available from the [Victoria Institute website](#).

Several other organisations in Australia play roles similar to that of the RMLP. The Fight Cancer Foundation notes in its annual report for 2012 that 115 students with cancer benefited that year from its *Back on Track* program to support them in maintaining connection with their education, and that it also assisted in supporting 515 other young people in hospital in Victoria. Redkite runs an *Education and Career Support* program, also for students with cancer.

These organisations operate independently of the state education authorities, and so their figures reflect only the population of students who seek assistance from them. They have traditionally focused largely on cancer patients, although they have begun to broaden their services to meet the needs of students with other illnesses. The data cannot be used to draw conclusions about the general population, or about the whole population of students with significant illness or injury.

Combining figures from these two programs alone, it can be seen that well over 1,000 students with significant illness seek assistance outside the education system and their regular schools in order to keep up their studies. It is impossible to establish how many other students there are who seek assistance privately elsewhere or who, for whatever reason, do not seek assistance outside the education system and must rely wholly on their regular schools for support.

For how many days are students with significant illness absent from school?

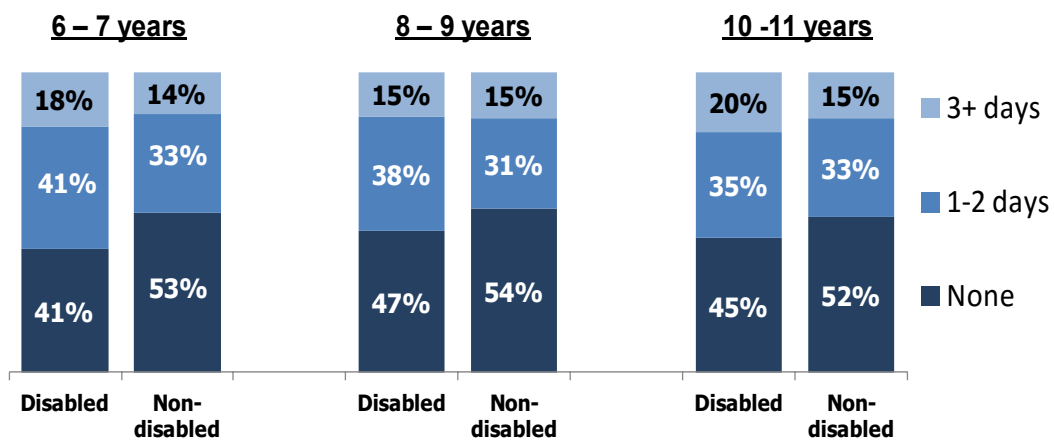
Some primary data exist which inform this research question, although a number of assumptions must be made in order to use them. While calculation of the number of days absent provides one measure of the impact of significant illness or injury, the pattern of absence is another, less easily measured indicator. Some students may be absent for a single lengthy period of weeks, months or years, while others may be absent for only a few days or weeks at a time but on a recurring basis throughout their

schooling. It is possible that the support required by students with significant illness or injury is more closely related to the pattern of their absence rather than to the duration of a single absence.

Longitudinal Study of Australian Children (LSAC)

The LSAC data are collected through interviews with families, selected at random from national databases. They include some analysis of school days absent over a four week period for primary school students with and without a long-term medical condition or disability. This shows a tendency for individuals reporting a medical condition or disability to experience more school absences, although this is noted as only being statistically significant amongst the 6-7 year old cohort (Daraganova, 2012).

Figure 2: Percentage of students who have been absent from school in the last four weeks (by age and disability status)



Over all three cohorts, a student with a long-term medical condition or disability is 20 per cent more likely than other students to have had three or more days off in the last four weeks. This has parallels with US education statistics, which indicate that students with disability in the fourth grade are approximately 25 per cent more likely to have had three or more days off in a month, while those in the eighth grade are around 40 per cent more likely (Child Trends Databank, 2012).

Here, the reasons for the days off are not given, and it might be conjectured that students with long-term medical conditions or disability would be more likely than other students to have days off because of illness rather than, for example, because of family holidays.

Once again, the reported data also include many students with other types of disability. The statistics for students who experience school absence because of significant illness or injury cannot be clearly isolated.

State data

A search for data held by state and territory education authorities yielded little of relevance to the question of illness-related school absence. It is possible that not all data collections are publicly available, and that a request to the relevant departments may have been illuminating. However, at first glance it appears that data around school absences arising from significant illness or injury are not systematically tracked. The only data set which could be identified is held by the Queensland state government. The Queensland State School data provide a breakdown of absenteeism and whether it resulted from illness (Queensland Government, 2013a). Extrapolating from this data, it can be estimated that each student was absent because of illness for an average of 4.2 days in one school year (see Appendix II).

Table 4 presents results from several research studies examining the relationship between specific illnesses and school absence, and it is possible to calculate from them **a factor for an 'increased rate of absence' for those illnesses (as previously outlined in Table 3)**. Applying these factors to the average calculated from the Queensland State Schools data, an estimate can be made of the number of days absent for certain significant illnesses.

Table 4: Estimates of school absence for selected medical conditions (days per school year)

Medical condition	Increased rate of absence	Average number of days absent
Asthma	3.4 – 10.3	14.3 – 43.3
Cancer (during treatment)	7.1 – 22.9	29.8 – 96.2
Cancer (survival / post treatment)	1.9	8.0
Cystic Fibrosis	5.6	23.5
Diabetes	1.6 – 4.0	6.7 – 16.8
Digestive disorders	2.8 – 8.4	11.8 – 35.3
Epilepsy	1.6	6.7

The wide variability in the number of days absent, even for students with the same medical condition, illustrates the difficulty in quantifying the impact of illness on school attendance.

Research literature

Some international research studies have sought to quantify the extent of school missed due to significant illness. Again, these demonstrate degrees of variability and precision, and range from a median of 2.0 days per year absent (Griffin, undated) and a mean of 3.1 days (Newacheck & Taylor, 1992), to an average of 16 days absent compared to 3.5 for 'healthy' students (McDougall et al., 2004, cited in Shaw & McCabe, 2008). A small Australian study conducted by Shiu (2005) indicated that students with 'mild' illness were absent for a mean of 10.8 days, rising to 13.9 days for those with 'moderate' illness, and, significantly, to 41.7 days for those with 'severe' illness.

Table 5: Summary table of research literature related to days absent for students with significant illness or injury

Data set	Average days absent because of illness for students without significant illness or injury	Average days absent because of illness for students with significant illness or injury	Notes
Longitudinal Study of Australian Children	5.9	6.9	Many assumptions untested
Queensland State Schools	4.2	6.3 – 96.2	Variable depending on illness
Shaw & McCabe	3.5	16	Citing McDougall
Shiu	Not given	10.8 (mild) 13.9 (moderate) 41.7 (severe)	

Recommendations

What more is needed: addressing gaps and limitations

This audit and analysis clearly shows gaps and limitations in the data collected and produced in relation to the impact of significant illness or injury on school attendance. It illustrates the challenge in producing robust and definitive estimates of school absence arising from specific illnesses or injuries.

The audit demonstrates that many agencies in Australia conduct significant research into both health and education; however, these are often treated as separate fields, and linkages between the two are less apparent. While data on both school attendance and illness are abundant, there are **few robust studies which draw a link between the two fields and quantify the impact of significant illness or injury on school attendance**. Those which do usually focus on 'children with disability', which may exclude students with acute illness or injury, and include others whose disability is neither illness nor injury.

Primary recommendations: considerations for addressing gaps

The goal of this audit has been to ascertain what data are available and where limitations and gaps exist. Further time and resources may allow closer examination of other sources of data. For instance:

- working with data collection agencies and organisations to draw on any **unpublished data** or procuring ad-hoc analyses of their data sets (e.g. LSAC, ABS);
- engaging schools and state and territory education departments to obtain **access to any detailed school-level records** of attendance and cause of absenteeism; and
- conducting a more detailed audit of **international statistics** and engaging country-specific data collection agencies to ascertain data metrics available that could be applied to the Australian context.

Supplementary recommendations

It may well be that the approaches outlined above still result in data gaps and limitations. In this case, the way forward could entail **changes or additions to primary research collections**, for example:

- **Changing recording mechanisms**, so that reasons for absence are more specific and can be cross-correlated with duration of absence. This will rely on schools' understanding of the nature of significant illness and injury and their student populations; Shiu (2004) observes that many schools fail to maintain adequate data on their students' health needs. The ongoing development of the Nationally Consistent Collection of Data for Students with Disability (NCCD) is a notable opportunity to address the gap. Currently the NCCD focuses on adjustments made in school to accommodate students with disability rather than on the number of students with disability. Similarly, while it does not preclude collection of data for students who are absent from school, they are not explicitly included. Students who are attending hospital schools or who have spent lengthy periods recovering at home may be overlooked as their enrolment status at their regular school may not be clear. Ideally, the NCCD would incorporate a means to capture data on students who experience non-negligible school absence related to significant illness or injury.
- **Advocating for specific measures to be included in current national surveys** which will better enable estimation of absence as a result of significant illness or injury.
- **Carrying out new primary research**: this could range from a simple population omnibus survey to establish key metrics of incidence, to working with individual schools / school areas to administer additional data collections that can be used for analysis.

Appendix I: Overview of data sources and measures

The following provides an outline of the more relevant sources of data examined through this study. While every effort was made to be inclusive of the range of collections and studies in the field of health and school participation, there remains the possibility that some studies may not be mentioned here. It should also be noted that some data sources and releases may have been superseded since the initial review process for this report was conducted.

National data collections and reporting bodies

Australian Bureau of Statistics (ABS) data

The ABS is the government's central agency for the design, collection, analysis and dissemination of studies of Australian society. Data from the ABS is highly credible and robust and many studies are repeated on a regular basis. The following presents an overview of the key studies and publications relevant to health and school attendance.

Source	Details
Australian Health Survey	Last conducted in 2011-12, the Australian Health Survey provides population-wide data on the health of all Australians. This includes incidence of specific medical conditions, broken down by age groups, and some reporting of absences from work or school caused by health. Additional analysis of specific conditions, such as asthma, shed further light on their impact (ABS, 2006; 2007; 2009; 2012a; 2013).
Survey of Disability, Ageing and Carers	Last completed in 2012, this survey provides details on the long-term health conditions of people and relative severity of their 'disability' (defined as ' <i>having a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities</i> '). Some data examines the impact of disability on school participation and the types of restrictions that people with these conditions face (including non-attendance) (ABS, 2013b).
Profiles of disability	This 2009 analysis offers further detail on the situations and actions of those with disability and their relationship with school. In particular, the data shows information on whether someone has a disability and is attending school, the type of school attended, difficulties encountered at school and the type of support received. One measure ascertains the level of schooling restriction (mild to profound) faced by young people

	aged between 5 and 20 with disability (ABS, 2012b).
Disability, Vocation and Education Training	This 2009 analysis is focused on young people aged between 15 and 24 and examines current participation in school and completion of Year 12. In this regard, data are presented which indicate the reasons for non-completion of Year 12, including because of ill health (ABS, 2011).
Australian Social Trends series	This series based on a range of data sources and surveys includes some specific work on health and education participation. Updating a similar publication from 2000, a 2012 release reports data on school attendance and the level of schooling restriction for children with disability aged between 5 and 17, and the type of difficulty experienced and support provided for them (ABS, 2000; 2012c).
Schools, Australia	The main output of the National Schools Statistics Collection (NSSC), this census of schools conducted every year records, among other things, school and student numbers, participation, attendance and retention. While long-term school attendance and participation rates are reported, published data do not provide breakdowns for this related to student health status, neither do they record reasons for school absence (ABS, 2014).

There are a number of common **limitations with the published ABS data** in light of the purposes of this report. These comprise:

- the categorisation of age groups presented, which frequently do not correspond to 'school age' and, in some instances, do not include anyone under the age of 15;
- limited quantification of time at school missed due to ill health: i.e. actual number of days rather than occurrence (or not) of an absence;
- focus on data for 'those with disability', which may not be comprehensive of all conditions students are likely to experience that may impact school attendance; and
- presentation of 'top level' data, with limited breakdown of results for those students with specific health conditions.

Australian Institute of Health and Welfare (AIHW)

The AIHW maintains detailed records and offers statistical publications on a wide range of health topics and audiences, including children and young people. Many of

the reports utilise datasets referenced elsewhere in this report, such as ABS collections and longitudinal surveys. Of particular relevance to this report are data publications relating to injuries sustained by children and young people, and hospitalisations arising as a result. This includes details around the type of injuries faced and the average length of hospitalisation as a result of injury (Eldridge, 2008).

Household Income and Labour Dynamics in Australia (HILDA) survey

The HILDA survey is a household-based study which has been conducted annually by the University of Melbourne since 2001. The questions asked each year have varied as new research questions arise, and the most recent collections have included questions about whether members of the household have experienced school absences **because** of illness. These data have yet to be released, and so have not been referenced in this report.

Longitudinal studies of children and youth (LSAC and LSAY)

Two large studies of Australian children and young people are conducted on a longitudinal basis with the purpose of tracking their development and experiences over time. With a large number of participants (in excess of 10,000), these studies offer a significant robust data resource for examining a wide range of issues:

Source	Details
Growing up in Australia: The Longitudinal Study of Australian Children (LSAC)	<p>LSAC is conducted in partnership between the Department of Social Services, Australian Institute of Family Studies and the ABS. Commencing in 2004 with two cohorts (families with 4-5 year olds and families with 0-1 year olds) findings are published on an annual basis through statistical reports and in topic papers developed by government departments and other researchers.</p> <p>The <i>2012 Annual Statistical Report</i> contains data pertaining to school attendance in primary school (Daraganova, 2012). This includes presentation of attendance data for students in a four week period, including analysis by disability status. However, there is no further breakdown by medical condition and the presentation of number of days absent from school is grouped (0, 1-2, 3+).</p>
The Longitudinal Study of	<p>LSAY is managed by the Department of Education in conjunction with a range of partners. Principally it collects data from several cohorts of youth once they turn 15 years old. As such it is fairly limited and</p>

Australian Youth (LSAY)	does not directly collect data on school attendance. Some metrics do exist in relation to health conditions or disabilities that may impact work or study, but no link appears to be made with actual impact on participation (e.g. days off).
--------------------------------	--

Non-government reporting bodies

A number of independent national organisations conduct research and analysis in the field of education and health. Two of these in particular are pertinent to this report:

Source	Details
Australian Curriculum, Assessment and Reporting Authority (ACARA)	ACARA is responsible for the development of a national curriculum, national assessment program, and data collection and reporting for students and schools. Its key publication is the <i>National Report on Schooling in Australia</i> . This includes student attendance data as a key performance monitor, and tables which break down attendance rates by gender and state. However, these data do not cover the causes of non-attendance, the actual time absent, or numbers of students with significant illness or injury (ACARA, 2013).
Australian Council for Educational Research (ACER)	ACER is a large, national independent organisation working to facilitate design, collection and analysis of educational research. Its publications include the TIMSS and PIRLS studies which monitor performance of Year 4 and Year 8 students in mathematics, language and literacy, and science. While some publications address school attendance, on the whole these focus on truancy or the attendance of Aboriginal and Torres Strait Islander students. One paper, delivered in 2004, offers a synopsis of available attendance data from public records in Australia and overseas (Withers, 2004).

State and territory government statistics and reporting

Monitoring and performance-reporting requirements mean that participation, attendance and absenteeism data is collected in schools and aggregated by state and territory education departments. Electronic systems in place for recording attendance offer significant scope for metrics related to absenteeism and ill health; however, on the whole there is little indication that specific details of the reason for absence are recorded and / or reported.

State and territory departments publish ‘top level’ attendance rates at least on an annual basis, with results often broken down by area and school type. For the purposes of this study, most published data is therefore of limited use in estimating absenteeism due to significant illness or injury. There were one or two exceptions where additional data was accessible, some of which may provide contextual information on school absence and estimation of days due to illness:

Source	Details
Queensland Government	The Queensland Government produces a listing of state school absences by reason and student demographic. This logs the number of FTE days lost by students due to absence, including specifically for ‘illness’. Unfortunately, no further breakdown of illness is available to examine specific conditions (Queensland Government, 2013a & 2013b).
Victorian Government	The Victorian Government (DEECD), like most states, publishes average attendance rates across the state. However, as cited in other studies, older data for attendance (pre-2008) offers a quantification of the number of days students were absent in the school year, though without attribution to cause.

Peak bodies and support organisations

There are numerous national and regional peak bodies related to specific medical conditions (e.g. Asthma Australia, Diabetes Australia), as well as other organisations involved in the field of child health, wellbeing and education (e.g. Barnados, UNICEF, Mission Australia). Some of these organisations conduct primary research as well as drawing on secondary sources for information. However, a scan of this work indicates little in the way of detailed data relevant to this report, other than population incidence of specific conditions:

Source	Details
Asthma Australia	Asthma Australia cites asthma as a major contributor to school absenteeism (Asthma Australia, 2013). A small survey conducted in NSW in 2007 also includes a measure of whether school attendance was impacted by asthma over the previous year (Asthma Foundation NSW, 2007).
Haemophilia Foundation Australia	This peak body conducted a consultation with young people with haemophilia and noted a reported impact on school attendance; however, this was a qualitative exercise and so no metrics are available

	(Haemophilia Foundation Australia, 2012).
The Peter Hughes Burn Foundation	Summary statistics are reported on the incidence of burns and scalds affecting children and the proportion who end up in hospital (and thus out of school) for one week or more because of this (Peter Hughes Burn Foundation, 2010).
Crohn's and Colitis Australia	This group commissioned a report into the economic costs of Crohn's disease and colitis, which itself draws on earlier studies (in the 1990s) indicating the impact of these conditions on school attendance in the United Kingdom (Access Economics, 2007).
Diabetes Australia	A 2006 needs analysis of young people (16-35 years) with diabetes included a self-reported measure of the impact of diabetes on their 'normal daily activities' (including going to work or school) (Diabetes Australia, 2006).
Ronald McDonald House Charities	Ronald McDonald House Charities provides a wide range of programs to help seriously ill children and their families across Australia. This includes the Ronald McDonald Learning Program, for which program statistics have been provided to ARACY and <i>MissingSchool</i> . This data includes details on program participants engaged between 2010 to 30 th July 2013, including their school grade, medical condition and broad amount of time absent from school due to their illness.

Other international research studies and statistics

The purpose of this report has been to focus on the audit of data specific significant illness or injury and school participation among Australian students; however, given apparent gaps and limitations in this data, a scan and review of pertinent international sources and studies has also been conducted. Potentially relevant metrics were observed in the following:

Source	Details
Child Trends	This authoritative US source of statistics and information outlines a 'Student Absenteeism' indicator within its databank. Using <i>US Government Education</i> statistics, the indicator shows the level of absenteeism of fourth and eighth-grade students classified as having a disability, compared to those who do not; however, it does not break down data any further on the basis of specific illnesses or injuries (Child Trends Databank, 2012).

Newacheck & Taylor (1992)	This study uses data from the 1988 US <i>National Health Interview Survey</i> to establish the average number of days students with various significant illnesses are absent from school as a result of this. Though now somewhat dated, it provides one of the more rigorous assessments of school absenteeism, although without comparison to that of peers without significant illness.
Shiu (2005)	A body of work has been completed with specific reference to the Australian context (particularly NSW) by Shiona Shiu. This has sought to examine the prevalence of significant illness and injury amongst students and the impact on school participation and attainment. A 2005 conference paper offers a useful synopsis of this work, including details of a study calculating the number of days off for students with significant illness or injury.
Shaw & McCabe (2008)	This paper draws on various studies to estimate the average number of days students with significant illness or injury are absent from school compared to their peers, broken down for several illnesses. The use of multiple sources of data limits the consistency of data presented and, in some cases, provides only a broad range of days absent rather than specific metrics.
Griffin (undated)	This study uses US <i>National Health and Nutrition Examination Survey</i> data and reports median number of school days missed due to injury or illness, including a breakdown on days absent for some illnesses.
Asthma & Allergy Foundation of America (1992; 1998; 2000)	In the report, <i>The Costs of Asthma</i> , an analysis is made of the cost impact of asthma in the US, calculating the number of school days missed per year due to this condition among 5 to 17 year olds.
Copeland (1992) French, et al. (2013)	Both of these papers cite consistently higher levels of school absenteeism amongst students with cancer, peaking in the first year of diagnosis but also remaining higher several years after diagnosis amongst survivors.
Calsbeek et al. (2002)	This study looks at the average number of weeks absent from school for students with chronic digestive disorders compared to control samples.
Glaab, Brown & Daneman (2005)	This Canadian study examines the attendance of students with Type 1 diabetes during a school year, compared to a control sample.
Ibekwe & Ojinnaka (2008)	This is a small study calculating the mean number of days absent for students with epilepsy, comparing this to a control sample.

Appendix II: Calculation of estimates made in this report

Absence through illness in Queensland state schools

The Queensland Government provides a detailed dataset enabling calculation of the proportion of school absences due to illness; however this data does not provide specific details of illness or the medical condition of students engaged in absence.

- Data shows that in 2012, a total of 4,030,258 FTE days were taken by student absence in state schools, of which 1,371,512 days (34 per cent) were attributed to illness, 1,251,844 days (31 per cent) were attributed to other factors, and 1,404,902 days (35 per cent) were 'unexplained'. Of all *specified* absences (i.e. excluding unexplained absences), illness accounted for 52 per cent (Queensland Government, 2013a) of FTE days.
- School enrolment data shows that in 2012 there were 498,531 students enrolled on a full-time basis in Queensland state schools (Queensland Government, 2013b).

These figures suggest that each student in Queensland was absent on average for 8.1 days during an academic year. *Assuming* 52 per cent were a result of illness it can be estimated that students were absent for an average of 4.2 days due to illness.

References

Access Economics for Australian Crohn's and Colitis Association (2007). *The economic costs of Crohn's disease and ulcerative colitis*. Access Economics Pty Ltd.

Adams, D. (1978). *The Hitchhiker's Guide to the Galaxy*. New York: Random House USA Inc .

Asthma and Allergy Foundation of America (1992, 1998 & 2000). *The costs of asthma*. Retrieved from www.aafa.org/display.cfm?id=8&sub=42#_ftn20

Asthma Australia (2013). *Children's asthma in education and care services*. Retrieved from:
www.asthmaaustralia.org.au/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=19327354315&libID=19327354290

Asthma Foundation NSW (2007). *The New South Wales asthma survey – Identifying the needs of people with asthma in NSW*. Retrieved from:
www.asthmaaustralia.org.au/uploadedFiles/Content/Research/NSW%20Asthma%20Survey%20Final.pdf

Attorney-General's Department (2005). *Disability standards for education*. Canberra.

Australian Bureau of Statistics (2000). Participation in education: Disability and schooling. *Australian Social Trends, 2000*. (Catalogue no. 4102.0). Canberra.

Australian Bureau of Statistics (2006). *Asthma in Australia: A snapshot, 2004-05*. (Catalogue no. 4819.0.55.001). Canberra.

Australian Bureau of Statistics (2007). *Health of children in Australia: A snapshot, 2004-05*. (Catalogue no. 4829.0.55.001). Canberra.

Australian Bureau of Statistics. (2008). *Childhood education and care* (Catalogue No. 4402.0). Canberra.

Australian Bureau of Statistics (2009). *National Health Survey: Summary of results, 2007-2008* (Reissue). (Catalogue no. 4364.0). Canberra.

- Australian Bureau of Statistics (2011). *Disability, vocation and education training, 2009*. (Catalogue no. 4438.0). Canberra.
- Australian Bureau of Statistics (2012a). *Australian Health Survey: First results, 2011-12*. (Catalogue no. 4364.0.55.001). Canberra.
- Australian Bureau of Statistics (2012b). *Profiles of disability, Australia, 2009*. (Catalogue no. 4429.0). Canberra.
- Australian Bureau of Statistics (2012c). *Children with a disability*, in *Australian Social Trends, June 2012*. (Catalogue no. 4102.0). Canberra.
- Australian Bureau of Statistics (2013a). *Australian Health Survey: Health service usage and health related actions, 2011-12*. (Catalogue no. 4364.0.55.002). Canberra.
- Australian Bureau of Statistics (2013b). *Disability, Ageing and Carers, Australia: Summary of Findings 2012*. (Catalogue no. 4430.0). Canberra.
- Australian Bureau of Statistics (2014). *Schools, Australia, 2013*. (Catalogue no. 4221.0). Canberra.
- Australian Curriculum, Assessment and Reporting Authority (2013). *National report on schooling in Australia 2011*. Sydney.
- Barnett, T., Hopkins, L., & Peters, S. (2014). *What happens when they go home? An investigation of education support for students following discharge from the RCH*. **Melbourne: The Royal Children's Hospital Education Institute.**
- Calsbeek, H., Rijken, M., Bekkers, M., Kerssens, J., Dekker, J., & van Berge Henegouwen, G. (2002). Social position of adolescents with chronic digestive disorders. *European Journal of Gastroenterology & Hepatology*, 14(5), 543-549.
- Child Trends Databank (2012). *Student absenteeism*. Retrieved from: www.childtrends.org/?indicators=student-absenteeism
- Copeland, D.R. (1992). Neuropsychological and psychosocial effects of childhood leukaemia and its treatment. *CA: A Cancer Journal for Clinicians*; 42 (5), 283-295.

Daraganova, G. (2012). Is it OK to be away? School attendance in the primary school years. In *The Longitudinal Study of Australian Children – Annual Statistical Report 2012*. Canberra: Australian Institute of Family Studies. 59-78.

Department of Education and Early Childhood Development, Victoria. *Benchmark publications, school management 1996 – 2007*. Retrieved from: www.education.vic.gov.au/school/principals/management/Pages/performbenchmark.aspx

Diabetes Australia (2006). *Young adults with diabetes – Needs analysis*. Retrieved from: www.diabetesaustralia.com.au/PageFiles/1218/Young%20Adults%20w%20Diabetes%20Needs%20Analysis%20Report.pdf

Dockett, S. (2004). **Everyone was really happy to see me!** – The importance of friendships in the return to school of children with chronic illness. *Early Childhood Australia*, 29(1), 27-32.

Donnan, B. & Webster, T. (2011). *Inquiry into the transition support for students with additional and/or complex needs and their families*. Submission to the NSW Parliament. Ronald McDonald House Charities.

Eldridge, D. (2008). Injury among young Australians. *AIHW bulletin no. 60*. (Catalogue no. AUS 102). Canberra: AIHW.

French, A.E. Tsangaris, E., Barrera, M., Guger, S., Brown, R., Urbach, S. Nathan, P.C. (2013). School attendance in childhood cancer survivors and their siblings. *The Journal of Paediatrics*; 162(1), 160-165. <http://dx.doi.org/10.1016/j.jpeds.2012.06.066>

Glaab, L.A., Brown, R. & Daneman, D. (2005). School attendance in children with type 1 diabetes. *Diabetic Medicine: a Journal of the British Diabetic Association*, 22(4), 421-426.

Griffin (n.d.). *Estimating missed school days attributable to chronic disease*. Retrieved from http://msom.technion.ac.il/sig_papers/PD/Griffin.pdf

Haemophilia Foundation Australia (2012). *Understanding Youth Needs Consultation – Results*. Retrieved from:
www.haemophilia.org.au/kidsandyouth/cid/86/parent/0/pid/84/t/kidsandyouthnew/title/results

Ibekwe, R.C. & Ojinnaka, N.C. (2008). Childhood epilepsy and school absence. *Tropical Doctor*, 38(4), 258-259.

Irwin, M. K. and Elam, M. (2011). Are we leaving children with chronic illness behind? *Physical Disabilities: Education and Related Services*, (2011), 67-80.

Jimerson, S. R., Pletcher, S. M. W., Graydon, K., Schnurr, B. L., Nickerson, A. B., & Kundert, D. K. (2006). Beyond grade retention and social promotion: Promoting the social and academic competence of students. *Psychology in the Schools*, 43(1), 85–97.

Kaffenberger, C. (2006). School re-entry for students with chronic illness: A role for professional counsellors. *Professional School Counseling*, 9, 223-230.

Lavoipierre, J. (2012). *Strategies to support the learning of students with serious medical conditions in rural areas*. Bathurst: All Saints College.

Newacheck, P.W. & Taylor, W.R. (1992). Childhood chronic illness: Prevalence, severity, and impact. *American Journal of Public Health*, 82(3), 364-371.

Peter Hughes Burn Foundation (2010). *Statistics*. Retrieved from:
<http://peterhughesburnfoundation.org.au/resource-centre/statistics/>

Porter, L. (2008). *Teacher-parent collaboration*. Melbourne: ACER Press.

Queensland Government (2013a). *State school student absence by reason*. Retrieved from <https://data.qld.gov.au/dataset/state-school-student-absence-by-reason/resource/67ccc8de-5774-4bb3-b8ba-d794348e9630>

Queensland Government (2013b). *February census of state school enrolments*. Retrieved from <https://data.qld.gov.au/dataset/state-school-enrolments-by-school-and-year-level-february-census/resource/4d8a3dcc-30c7-40dd-be11-f13e97e26414>

Ronald McDonald Learning Program (unpublished). *Program statistics*. Details of the program can be accessed at <http://learningprogram.rmhc.org.au/>

Shaw, S.R. & McCabe, P.C. (2008). Hospital-to-school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools, 45*(1), 74-87.

Shiu, S. (2001). Issues in the education of students with chronic illness. *International Journal of Disability, Development and Education, 48* (3), 269-281.
<http://dx.doi.org/10.1080/10349120120073412>

Shiu, S. (2004). Maintaining the thread: Including young children with chronic illness in the primary classroom. *Early Childhood Australia, 29*(1), 33-38.

Shiu, S. (2005). *Healthy solutions for children – making the right choice*. Paper presented at the 10th national conference for the Association for the Welfare of Child Health, 28-29 April 2005. Retrieved from:
www.awch.org.au/pdfs/conferences/2005/06_SHIU.%20Shiona_paper.pdf

Whiteford, C.M. (2010). *Children with special health care needs: social and learning competence in the early years*. Brisbane: Queensland University of Technology.

Wilkie, K.J. (2012). **'Absence makes the heart grow fonder': Students with chronic illness seeking academic continuity through interaction with their teachers at school.** *Australasian Journal of Special Education, 36* (1), 1-20.

Withers, G. (2004). *Disenchantment, disengagement, disappearance – Some recent statistics and a commentary on non-attendance in school*. A paper prepared for the Learning Choice Expo conducted by the Dusseldorp Skills Forum, Sydney, June 2004.



School connection for seriously sick kids
Part 2: How do we know what works?

MISSINGSCHOOL
KEEPING SERIOUSLY SICK KIDS CONNECTED

 **ARACY**
Australian Research Alliance for Children & Youth
Collaboration • Evidence • Prevention

Missing School 2015 – Part 2: School connection for seriously sick kids: how do we know what works?

Neil Stafford, *ARACY*

Megan Gilmour, Gina Meyers, Cathy Nell, *MissingSchool*

© 2015 *MissingSchool*

Missing School Inc. owns copyright of all material in this report. You may reproduce this material in unaltered form only (acknowledging the source) for your personal, non-commercial use or use within your organisation. Commercial use of material in this report is prohibited. Except as permitted above you must not copy, adapt, publish, distribute or commercialise any material contained in this publication without ***MissingSchool's* permission.**

ISBN: 978-1-921352-77-5

[Suggested citation](#)


Australian Research Alliance for Children and Youth (ARACY). (2015). *Missing School – Part 2: School connection for seriously sick kids: how do we know what works?* Canberra, ACT.

[Contact us](#)

If you have any queries about this report, please contact ARACY:

Mail: PO Box 5070, Braddon, ACT 2612 Email: enquiries@aracy.org.au Website: aracy.org.au

Phone: +61 2 6248 2400

 [@ARACYAustralia](https://twitter.com/ARACYAustralia)

ABN 68 100 902 921

Acknowledgements

This work was commissioned from ARACY by Missing School Inc. and supported by a generous grant from the St George Foundation, St George Bank.

The authors thank the many individuals and organisations who contributed to the work, including Barb Donnan (Ronald McDonald Learning Program) for insight into the RMLP collection of statistics around students with significant illness or injury, Megan Jackson (University of Canberra) for discussion of the use of technology to support the learning of students who miss school because of significant illness or injury, and Jenny Lavoipierre for thoughtful general comments.

In particular, the authors thank Liza Hopkins (The Royal Children's Hospital Education Institute) for significant contributions to the companion report *Whose job is it?* on research around current practice, and to Tony Barnett (The Royal Children's Hospital Education Institute) for providing valuable editorial comment.

Table of Contents

Suggested citation.....	62
Acknowledgements	63
Executive summary	65
Introduction	68
Definitions	73
School connection for seriously sick kids: how do we know what works?	77
Overview of investigation approach	77
The evidence gap and implications for models of practice.....	78
Aligning a model to the concept of inclusion	80
Inclusive approaches and practices for continuing education participation and connection	82
Approaches to continuing education out of school.....	86
Working towards a practice model	95
Recommendations.....	101
References.....	104

Executive summary

This report is one of three developed as part of a program of work undertaken by the Australian Research Alliance for Children and Youth (ARACY) and Missing School Inc. The program has sought to examine current evidence, policies and approaches for supporting the education of students who experience non-negligible school absences because of significant illness or injury. The aim is to understand the situation in which these students find themselves and whether it is adequately addressed. The focus of this report is on the evidence for practices and approaches that are demonstrated or considered to be promising in relation to the inclusion and participation of students in education.

Main findings

A paucity of robust research in this area means that there are no strongly evidence-based 'ideal model' or 'best practice' approaches to continuing the education participation and connection of students with significant illness or injury. However, it is possible to identify emerging evidence and commonalities in strategies and approaches.

The concept of inclusion and equity in education offers a sound underpinning to the development of practice models and approaches for students with significant illness or injury. Inclusion is supported by legislation and evidence around student outcomes. It implies that students with significant illness or injury should be able to continuously participate in, or remain connected to, their regular school.

Common practices to enable students with significant illness or injury to continue education in their regular school include: adoption and implementation of actions from an individualised planning process; adjustment of targeted educational programs, enabling environments and focused support in the classroom for students; and enhanced school-based health care provision.

Practices to facilitate continuing education participation and connection when absent from school focus predominantly on hospital and home-based education. Aspects of these that may be more conducive to enhanced participation and connection include: continuing formal provision in multiple locations and environments; personalised

needs-based learning, and flexibility to account for the nature of illness; communication between families, schools and health care practitioners; and alignment with education authority curriculum requirements.

New information and communication technologies (ICT) are one of the most promising prospects for continuing education participation and connection of students with significant illness or injury – particularly in a real-time, virtual environment. Small-scale trials of ICT in the classroom suggest that this can be beneficial for students, although some challenges need to be overcome (such as teacher confidence, privacy issues, technology capability etc).

Conclusions and key recommendations

Because of the limited evidence regarding 'best practice' and 'ideal models', a draft theoretical framework has been proposed, informed by the strategies used for educational inclusion and equity, as well as by some of the particular challenges for the ongoing participation of students with significant illness or injury.

This framework is based on an overarching desired outcome of educational inclusion and equity for students with significant illness or injury.

It outlines the pre-conditions for this outcome to be achieved, including: early intervention and planning; individualised and flexible approaches; integrated and consistent provision of education across environments; collaboration between healthcare and education services; and steps to ensure that social and emotional needs are met.

Finally, it suggests approaches and strategies to produce the desired outcome and its pre-conditions, including: developing awareness and knowledge of significant illnesses and injuries (including breaking down stigma); formalised and actionable documentation to plan and implement strategies for individual students; greater integration and alignment of health, education and social support provision; and methods to ensure students have continuing connection with their regular school when absent from it.

It is recommended that further development of this framework be undertaken through a collaborative process which allows for pathways to be identified, practices to be tested, impacts to be measured, and outcomes to be evaluated. Specifically, this includes :

- development of **'joined-up' education and health services** which work across a variety of settings;
- greater collaboration and **formalised links between all parties** involved in the education and care of students with significant illness or injury;
- engagement of **parents and students as equals** in the planning, implementing and review of education and care arrangements;
- development of a **culture of inclusion** in schools which improves knowledge of the needs of students with significant illness or injury;
- **practitioner support and 'up-skilling'** for both medical and teaching professionals;
- implementation and **integration of ICT into the school and home environments** to allow students to maintain connection with school; and
- ensuring that **provision is consistent across jurisdictions** so that students do not face discrimination based on where they live.

Continuing to incorporate further evidence of effective approaches as they become known – from Australia and overseas – would build the validity and specificity of such a framework over time, and inform practice models that are more likely to mitigate the disadvantage faced by students with significant illness or injury.

Introduction

Around Australia every day, thousands of children miss school because of illness. Some of these children will be missing a few days every year; some will be missing a few weeks every year; some will be missing months and possibly years of school.

One of the specific challenges facing students with critical or chronic illness is that they may experience frequent or extended absences from school, either because of illness or treatment. The double burden of illness and school absence has many long-term consequences which may include:

- delays in developmental skills due to missed experiences
- school refusal and absenteeism
- academic under-achievement
- behavioural problems
- increased anxiety
- attention and concentration problems
- reintegration difficulties
- specific learning needs
- low self-esteem
- disruption of friendships
- difficulties in forming and maintaining relationships
- reduced opportunities for social support
- increased vulnerability to other life stressors or secondary illnesses
- peer rejection

(Donnan and Webster, 2011; Whiteford, 2010; Shaw and McCabe, 2008; Dockett, 2004; Shiu, 2001).

This is a long list of **'possible side-effects'** and not all students will experience all of these problems. However, the research is clear that school absence resulting from illness is a significant problem for many students.

Retention, or 'repeating' a year or more at school, may be appropriate for some students – depending on the anticipated absence, when it occurs in their

schooling, and their general socio-emotional environment – but is otherwise not generally recommended. In a review of educational issues faced by students with chronic illness, Irwin and Elam (2011, quoting Jimerson et al., 2006) note that retention does not improve academic outcomes, but is instead detrimental to socio-emotional and behavioural outcomes, and has a negative impact on **students’ attendance and attitudes** toward school. They observe also that **“students perceive retention as a highly stressful life event, and retention is a strong indicator for dropping out of school.”**

The importance of maintaining connection between students and their schools in mitigating these problems has been frequently highlighted in the literature (Porter, 2008; Dockett, 2004; Shiu, 2004a). However, an absent student may be largely ‘invisible’ in the context of a busy school, and easy to overlook when planning for teaching and learning. **The extent to which the student’s needs are addressed** is heavily reliant on the disposition of individuals within the school, and there is thus widespread variability and inequity in the educational access afforded (Lavoipierre, 2012; Wilkie, 2012).

During a hospital admission, a student will generally have access to the hospital **school. The stated mission of most hospital schools is to work with the student’s** regular school to maintain continuity of learning. In practice, and for a variety of reasons, this is often not successful (Wilkie, 2012).

Current advances in healthcare also mean that many children requiring medical treatment receive their treatment on an outpatient basis, and may spend significant periods of time recovering at home rather than in hospital. They may be too vulnerable or fragile to attend school, although quite capable of undertaking school work and possibly craving social interaction. During this time, they have access to neither the hospital school nor their regular school.

The school experience of many students with critical or chronic illness or injury is one of isolation and marginalisation.

While the need for increased systemic support for students is clear, the educational environment is complex and it will take time to develop appropriate

solutions. Such solutions are likely to require improved linkages between educational and health sectors, and involvement of students and their families in uncovering the issues, barriers and possibilities faced by different individuals in different contexts. For example, variations in the nature of the significant illness or injury, the student's age, and the location, resources and capabilities of families, educators, and health professionals are all relevant factors.

MissingSchool is dedicated to working with families, educators and health professionals to identify best-practice models and raise awareness; and to advocating for change at a government systems level.

This work has been commissioned by *MissingSchool* in an attempt to understand the environment in Australia for children and young people with serious illness or injury who are also engaging with education.

Consolidation and synthesis of existing data has been problematic, largely because of the wide variability in language, terminologies and definitions used by different authors for different audiences. In order to maintain the coherence and 'readability' of these reports, we adopt a set of definitions, outlined in Definitions. When reviewing the literature and other data sources, we will note as appropriate where other authors have differed.

Even with a clear set of definitions, there is a wide range of complicating factors, not all of which can be adequately addressed in this document.

Significant illness or injury is likely at some stage to involve treatment in hospital. For students in metropolitan areas, medical care is generally close at hand. However, students in rural or regional areas may need to travel to the nearest large city to a specialist paediatric hospital. In some circumstances, the nearest hospital with an appropriate specialisation may be in a different state. Regular, although routine, processes and treatments may require a substantial amount of travel and time away from home, family and school. Lengthy treatment may involve re-locating the entire family to a different city for the duration of the treatment. In this case, maintaining contact with the student's regular school becomes significantly more difficult, and communication platforms adopted by the

different state education authorities may not be compatible. Until recently, different states have also maintained differing curriculum, assessment and reporting requirements, and while many of these differences have been dispelled with the adoption of national standards, some persist.

Students whose regular school is a 'home school' are not captured in any of the data, and their situation has not been examined.

There are many parties involved in the care of a student with significant illness, and all have a unique perspective on the nature of the illness and the purpose and relevance of school and education. These parties include the students, their school-aged siblings and families, their teachers, classmates, educational leadership, and school communities, medical and allied health staff. Surveys are designed to capture the data which the surveyors believe to be relevant; legislation is designed to reflect the imperatives of government authorities; interventions are developed to meet the needs assumed by their developers. The different – and sometimes conflicting – perspectives and perceptions of the different parties make it almost impossible to draw out a coherent understanding of the challenges arising.

Privacy issues come into play at the intersection of public spaces (schools and hospitals) and private spaces (the family home). While the state bears the ultimate responsibility of ensuring that its students have access to quality education, it must respect the rights of individuals and families to privacy in the home, and confidentiality at school.

Advances in information and communication technologies theoretically make it possible to connect individuals anywhere in the country, but challenges arise from concerns around privacy in the home, at hospital and at school, access and resourcing issues, and constraints on communication platforms in different jurisdictions.

Advances in medical technology mean that more and more children and young people are surviving illnesses which were previously incurable and unmanageable. A generation ago, or even less, these children and young people, and their

families and teachers, may not have had the time to consider the implications of their withdrawal from their schools and education. Today, they are likely to become adults in our communities and societies, and they will need access to quality education if they are to have the same opportunities as other children and young people to fulfil their potential. While dealing with significant illness, they remain students.

MissingSchool began this work in the hope of building some clarity around the systemic issues facing students with significant illness, and their families, teachers and schools in Australia. It offers no answers, but instead “rigidly defined areas of doubt and uncertainty” (Adams, Douglas: *The Hitchhiker's Guide to the Galaxy*, 1978). Further work remains to be undertaken by the parties who bear the responsibility for addressing the challenges in the system, and we hope that they may find this document a useful starting point.

Definitions

Absence

Different patterns of absenteeism will be experienced by students with different significant illnesses, and even by different students with the same illness. Some students may be absent for months and years at a time, others may be absent for shorter and more frequent periods. Absences have been described as 'prolonged', 'extended', 'frequent' or 'recurrent'.

At this stage we do not want to put a quantitative limit on the number of days which must be missed before an absence becomes 'non-negligible'. However, we expect that such an absence would mean either multiple months in one stretch, or else smaller absences of days or weeks which added up to multiple months or even years over the course of the student's school life. A single absence even of several weeks would not necessarily constitute a non-negligible absence.

At the school level, it is possible that the needs of the student will be more closely linked to the student's pattern of absenteeism than to the student's illness.

Disability

Medical conditions and illnesses are clearly included under definitions of disability in the Commonwealth legislation. In more general usage, disability may be understood to mean vision, hearing or mobility impairment or behavioural issue, and there may be confusion amongst teachers and families about whether the provisions of the disability legislation applies to the situation of students with significant illness (Department for Education, Employment and Workplace Relations, 2012). Families who are grappling with the import of a significant illness may view disability as a stigma or unwanted label. For the purposes of this report, we accept medical conditions, illnesses and injuries as disabilities as defined under the Commonwealth Disability legislation (Attorney-General's Department, 2005).

Enrolment / registration / attendance / participation

Different schools, different families, and different agencies have different understandings of what it means to be enrolled in a school. Simple enrolment in a school does not mean that

the student is attending. Simple attendance at a school does not mean that the student is participating. Equally, a student who is not actually attending school may still participate in the life of the class with the help of distance communication technologies and support strategies. In this report we will use 'participation' to mean that the student is engaged in meaningful activities which support his or her social or academic development.

Illness or injury

There are connotations associated with the words 'illness', 'disease' and 'condition', and language is often chosen on the basis of the perceived impact of those words. We have chosen to use the term **illness**, understanding that it is not communicable, and may be transient or permanent.

We restrict our use of 'illness' here to somatic illnesses only. We acknowledge the need to support students with mental illness, and would not reject discussion of those needs. However, the field around mental illness is complicated, and it is possible that the needs of students with mental illness are substantially different from the needs of students with somatic illness. Deeper investigation of those needs is warranted, but is not attempted here.

None of the terms mentioned above covers the possibility of an injury which leads to school absence. We have thus chosen to refer to **illness or injury**. Use of either word should be read as including the other unless explicitly indicated.

Regular school

The school which the student ordinarily attends when not experiencing illness-related absence is referred to as the **regular** school. This is in order to avoid the misunderstandings inherent in the use of 'home school' (which may instead refer to the education of the student at home), 'mainstream school' (which raises interesting but unhelpful questions around the boundaries of inclusivity), 'origin school' (which is not commonly used, and is open to misinterpretation), and 'census school' (which is a term used by state education authorities and not familiar to the other parties who may read these reports).

School

We understand schools to include any provider of formal education up to Year 12. While students in pre-school and tertiary environments also face challenges associated with illness-related absences, the constraints in these environments are different from those in primary and secondary schools and beyond the scope of this report.

Siblings

The school-aged siblings of students with a significant illness are also at risk of missing school. They may travel with their families to accompany the ill student elsewhere for treatment, and thus be removed from their regular schools. They may miss school activities simply because their families are preoccupied with the care of the ill student. Older siblings may be expected to stay at home with their ill sibling as the family's economic circumstances require parents and carers to work outside the home. Siblings' needs are different, but also arise from the experience of living with a significant illness in the family.

Siblings are here understood as **school-aged siblings**. We acknowledge that much older or younger siblings may also be affected by the experience of living daily with a significant illness, but our focus is on their needs which arise from missing school.

Significant

Illness or injury may be variously described as 'serious', 'critical', 'chronic', or 'life-limiting'. All of these words are contestable, and different definitions are adopted by different authors and agencies to meet their own needs. Use of any of these words raises the possibility of disagreement about the nature and severity of the illness or injury.

Our focus is on neither the nature nor severity of the illness or injury but on the school absence which results from it. We have thus chosen to use the word **significant** to describe any illness or injury which has a non-negligible impact on school attendance. The definition of what is non-negligible is discussed above.

Students

In literature and casual discussion, we refer to 'children', 'adolescents', 'teenagers', 'young people', 'kids', 'students', 'learners', 'pupils', etc. We have chosen to adopt the term

students to describe all these people. This avoids categorisation by age, and also highlights the fact that we are focusing on the dimension of their lives which revolves around school. Given this whole school focus, we are concerned with students from Foundation to Year 12.

School connection for seriously sick kids: how do we know what works?

Overview of investigation approach

As discussed in the introduction to this report, the effects on students (and their families) of missing school because of significant illness or injury can be adverse and long-term. The adoption of models and approaches which focus on continuing education and connection and maintaining consistency is a logical attempt to improve educational outcomes for students with significant illness or injury.

This investigation seeks to inform the debate and development of such models of practice by reviewing some of the common approaches in place in Australia and internationally. The aim of the investigation is to identify any evidence-based models and approaches that might be considered to demonstrate 'best practice' in terms of supporting academic outcomes and social and emotional wellbeing for students with significant illness or injury. However, the limitations of available evidence in this field means that 'best practice' cannot be conclusively established and the term itself is misleading. Therefore, the investigation proposes a **theoretical framework** based on promising common or emergent practices relating to inclusion and participation of students in education (this approach is discussed in further detail in page 79).

The investigation sought evidence through a search and review of literature related to child health and education, predominantly drawn from Australia, New Zealand, the UK, USA, and Canada. This included examination of primary research studies, program evaluation, policy analysis, case studies and consultation, and general discussion papers and reviews relevant to the topic. Systematic program review databases and libraries were also examined to identify any relevant interventions or approaches for students with significant illness or injury supported by strong or promising evidence.

It should be noted that the approach for identifying evidence was not exhaustive and may not necessarily include all studies and documentation related to student

health and education participation and connection. However, the literature identified in this investigation provides a sound basis from which to extract key themes, potential strategies, and approaches to inform the development of practice models for students with significant illness or injury.

The evidence gap and implications for models of practice

The initial goal of this investigation was to identify any 'best practice' models and approaches which support students with significant illness or injury to participate in, and connect with, education. However, the work has highlighted a **scarcity of directly relevant, well-evidenced studies and literature**. Specifically:

1. Many empirical studies with the strongest evaluation methodologies (i.e. experimental or quasi-experimental designs) have so far focused on the relationship between child health and outcomes. They measure academic and, in some cases, social and emotional outcomes for students with significant illness or injury compared to control students; they do not examine or test strategies or approaches to address these differing outcomes.
2. Levels of evaluation evidence assessing approaches for students with significant illness or injury are mostly of a lower standard (e.g. case studies, example practices, anecdotal or assumed outcomes). While the weight and consistency of evidence across this literature as a whole can provide some insight into common approaches and strategies likely to work, it cannot clearly determine 'best practice' or 'ideal approaches'.
3. Practices for students with significant illness or injury are – invariably – diverse, dynamic, and difficult to measure. For instance, approaches used at the local school level are not consistently measured, nor is there the capacity for rigorous analysis or reporting of outcomes.
4. Much of the literature adopts a broad focus on special education needs and disability. While there is value in exploring the principles and strategies reported in this literature, its direct application to students with significant illness or injury is somewhat limited.

5. The literature generally focuses on traditional education models and methods of teaching and support. While there is emergent literature in relation to technology and online approaches, rigorous evidence on outcomes of the use of this for students with significant illness or injury is yet to be strongly established. While technology represents a potential 'game-changer' in this area, further evidence around its application and implications for practice need to be gathered.

In sum, the limitations observed make it apparent that there are currently no strongly accepted, evidence-based 'ideal models' or 'best practice' approaches which support students with significant illness or injury to participate in, and connect with, education. While some models operating internationally have been raised as exemplars of good practice, these too appear limited in available supporting evidence and, crucially, their application to an Australian context.

It is important to note here that lack of evidence does not mean that models and approaches in place are not working. It may be that there are school staff, health professionals, educators and parents who are using innovative approaches and observing positive outcomes. The issue is that these practices are not documented and outcomes are not measured, and this makes it impossible to draw robust, universal conclusions on what does and does not work for students with significant illness or injury.

Adopting a theoretical framework for practice

In order to overcome the evidence gap and achieve a practical outcome, this investigation will seek to establish a **theoretical framework for practice**. This theoretical framework will draw on the evidence that does exist and common approaches that have been posited – not just in terms of students with significant illness or injury, but also, where relevant, in relation to other areas such as inclusion, special needs education etc. As a theoretical framework it will outline the factors likely to be influential in supporting students with significant illness or injury, but for which further discussion, expansion, testing, validation, and evaluation activity is necessary.

The establishment of this framework draws in part from principles and structures adopted in the *Theory of Change* process model (Harvard Family Research Project, 2005; Taplin & Clarke, 2012). Briefly, Theory of Change is a 'backwards mapping' process commonly used in social and community policy and planning environments. The process first establishes a desired outcome in relation to an issue, and then identifies preconditions for this outcome to be realised, before documenting the approaches and interventions that can be adopted to (hypothetically) lead to the preconditions being achieved. It often commences as a collaborative 'workshopping' process amongst key stakeholders and agents. As such, it is theoretical and subject to validation, testing, and refinement as new information and evidence about what works comes to light (Harvard Family Research Project, 2005; Taplin & Clarke, 2012).

Aligning a model to the concept of inclusion

There is sound rationale for aligning a theoretical framework with the concept of inclusion and equity in education. This is a widely-accepted concept, reinforced **through Australia's** signatory status to the UN Convention on the Rights of the Child and articulated in legislation in Australia and many other developed countries. Inclusion is also partly supported by evidence (noting that this could be more developed, particularly in relation to students with significant illness or injury) and rests on principles of equity and social justice (Mitchell, 2010).

The accompanying report in this series (*Whose job is it?*) provides a more detailed overview of legislation in place to mandate and support equity in education. This asserts that access to free education should be provided without discrimination and that additional support should be provided to those who need it to ensure that their right to an education is upheld. Associated legislation addresses in general terms the educational provisions for students with 'disability' and 'special needs', and defines 'disability' to include critical and/or chronic health conditions. For students with significant illness or injury, the critical and/or chronic health conditions they experience are likely to represent the 'disabling' factor and mean they are subject to provisions and 'reasonable adjustments' under such legislation (Attorney-General's Department, 2005).

The legislation essentially embraces an **inclusive model of education** which aligns with the notion of equity in education. The implication for students with significant illness or injury is that their education should continue, *wherever possible*, within a regular school and classroom, and in an environment in which they are accepted and their needs are met (Allen & Cowdery, 2012). However, it also implies provision of education and continuing connection with school when participation in the regular school and classroom is not possible.

To date, the evidence for the efficacy of inclusion has focused on students with learning, behavioural, and serious physical disability rather than on students who have significant illnesses or injury. While the evidence is somewhat mixed, it leans towards a positive or neutral effect (Dyson, Howes & Roberts, 2002; EPPI-Centre, 2006-2009; Kavale & Mostert, 2003; Lindsay, 2003; Mitchell, 2010). Positive benefits outlined for students include:

- academic achievement: research shows that students with disability achieve better academic outcomes in inclusive education settings than in more segregated environments. The evidence also indicates that the attainment for other students is not adversely affected in inclusive settings.
- social skills and relationships: research into inclusive school models report improvements in social competence, understanding of differences and tolerance, and more collaborative learning and relationship-forming between students.
- emotional wellbeing: studies report that students in an inclusive environment show greater sensitivity to others, and have increased awareness of their own strengths and weaknesses.

Many of the research studies evaluating inclusive approaches draw comparisons with segregated approaches. Inclusion is typically shown to result in better academic achievement and better achievement on other measures (e.g. social skills), compared with segregation. Further studies are said to demonstrate a lack of evidence for the benefits of segregated approaches (Mitchell, 2010). However,

segregation may be appropriate if it is supported by parents and educators, and considered by them to be in the student's best interest – for instance, if the student's education needs cannot be met otherwise, or if they have very high-dependency healthcare needs. Examples cited include needs related to autism-spectrum disorder, sensory impairment, vision impairment, and severe physical disability (Shaddock, Nielsen, Giorcelli, Kilham & Hoffman-Rapp, 2007).

In summary, the resounding emphasis placed on inclusion and equity in education through the Rights of the Child and relevant legislation, along with – at the very least – the neutral impact of inclusive models on general student outcomes, positions this as a strong guiding concept for development of a theoretical framework for supporting students with significant illness or injury. There is no 'model of inclusion' per se, but the ethos and philosophy informs development of a theoretical framework which supports the inclusion and participation of students with significant illness or injury without discrimination in education.

Inclusive approaches and practices for continuing education participation and connection

Any desired outcome will be aligned with inclusion and equity in education, and will be supported by approaches and practices which:

- seek to maintain the student's participation in their regular school; and
- **provide learning experiences and connection to the student's regular school** when they are unable to physically attend in the classroom.

It is recognised that, more widely, public and community health approaches to prevent and manage significant illness or injury would have an impact on overall levels of participation and connection with school. For instance, strategies which support students in managing asthma show some demonstrable effects on reducing the disruption this causes to their education participation (Chrisler, 2012; DEECD, 2013; Liao, Morphew, Amaro & Galant, 2006; Patel et al., 2007). However, a focus on preventative health strategies and management and treatment of illness is beyond the scope of this current investigation; instead, the

emphasis is on identifying approaches and practices for supporting students who do experience non-negligible school absence because of their illness or injury.

The literature reviewed for this investigation outlines a variety of practices and approaches potentially applicable to supporting students with significant illness or injury. As mentioned previously, there are limitations with this literature: evidence of efficacy is either lacking or not strongly supported; approaches and practices often focus on students with 'disability' or 'special needs'; and there are no consistent, unified 'best practice' models or approaches. That said, some **common practices and approaches** emerge from the literature which are supported by some level of evidence or consensus around their efficacy. By examining these approaches and considering the principles underpinning them, we can derive some insight into the elements of practice and types of interventions that would be likely to support students with significant illness or injury in participating in, and connecting to, education.

Approaches to continuing education in the regular school

The literature outlines means by which students with significant illness or injury can be supported to continue their education within their regular school setting. This includes individualised planning tailored to the needs of the student; provision of additional support and adaptation of school environments, requirements and curricula; and the provision of more advanced health care support in schools. While there is limited evidence of the efficacy of such approaches, some research findings note perceived benefits for students, staff, and parents.

Individualised planning

Given the dominant ideology and legislation advocating inclusion for students with significant illness or injury, a common strategy adopted in the education system has been the development of '**individualised' planning for learning and health care needs**. This strategy is formalised through the documentation of

Individual Education Plans (IEPs) or equivalent¹ in countries like Australia, the USA, and the UK.

In Australia, individualised plans are a written plan of goals and objectives, customised in light of any special needs the student has as a result of significant illness or injury. The plan is intended to detail programs or resources to address the student's needs, and document adjustments which enable the student to participate in regular school culture and learning. In the USA, a '504 Plan' is a similar document which is specifically designed for students to be educated in their regular classroom setting with modifications put in place. This is noted as being appropriate for some students returning after a significant illness or injury (Kids Health, 2013).

Evidence regarding the effectiveness of IEPs is surprisingly scarce. A review of over 250 IEP items identified only one piece of research which explored efficacy, and this was considered not a strong source of evidence (Mitchell, Morton & Hornby, 2010). However, they are assumed to have value as key component of an inclusive approach – which can lead to academic and other benefits. This is reflected in some research with teachers who report that the IEP is a useful tool for identifying student need and areas of additional support required, as well as providing direction and structure to curriculum preparation. There is also a perceived value in the collaborative processes underpinning the development of an IEP and the engagement of parents and students – and other parties as appropriate – in the process (Mitchell, Morton & Hornby, 2010).

Adjustments and customised delivery

One of the desired outcomes of the IEP process is the identification and implementation of adjustments for students so that they can continue their education within a regular school setting. A common adjustment is the use of **teaching assistants** (or similar) in the classroom. A review of international

¹ Note: terminology of such planning varies across Australian and international jurisdiction: Individual Learning Plans, Individual Education Plans, Personalised Learning Plans, Individual Healthcare Plans, Educational Adjustment Plans, Student Health Plans, Individual Support Plans etc.

studies regarding the role of teaching assistants shows that there are many positive benefits for students, teachers and schools. However, two of the more robust quantitative studies demonstrate that their impact on academic attainment is small. Instead, teaching assistants are shown to facilitate a culture of inclusion for all students in the classroom and act as an effective 'socio-cultural' mediator for students and staff. This is enhanced when they have a detailed, personal knowledge of the students they support (Alborz, Pearson, Farrell, & Howes, 2009).

Other academic support measures noted as desirable for students with significant illness or injury include **adjustments to educational programs and curriculum requirements**. Examples of these might be: flexible timetabling, additional tutoring, peer support opportunities for shared learning, flexibility in assignment requirements and deadlines, and strategies to ensure students can continue to undertake study out-of-school (Shiu, 2004).

Other actions implemented within schools to support students with significant illness or injury may be **environmental**. Examples noted by some parents and teachers as being beneficial include modifications to classrooms and schools to facilitate access, provision of treatment and rest rooms, special equipment, and specific IT resources to assist learning (Shiu, 2004). A few studies have looked at the impact of wider environmental adjustments made to reduce hazards – most notably triggers for asthma – which have shown a positive reduction in frequency of asthma related incidents (Child Trends, 2010).

In-school health services and support

Regulations and procedures to protect the health of students and staff, and provision for students who experience health issues are commonplace within Australian schools. Mostly these are generic **health support services** for students who experience a minor illness or injury, such as treatment rooms, school nurses, and staff equipped to provide first aid. As such, they are arguably irrelevant to students with significant illness or injury, though some literature notes the role of school staff in providing access to medications and treatment to help manage illnesses such as asthma (DEECD, 2013).

In the US, examples of approaches integrating more sophisticated health services within a school setting illustrate a potential way to better support students with significant illness or injury. **School-Based Health Centres** (SBHCs) provide a range of health services accessible from within school. One such program documented in Baltimore includes centres which systematically identify and then work with students who experience significant illness or injury. This includes forming a chronic illness management plan for students and, where illness impacts attendance, referral to a program which provides at-home supplementary and remedial tuition (The Baltimore Student Attendance Campaign & Elev8 Baltimore, 2012). While evaluation of this particular model is not yet documented, other evaluations of SBHCs demonstrate positive outcomes on health, management of conditions, reduced hospitalisations and improved attendance. However there is limited evidence on their influence on academic outcomes (Van Cura, 2010).

Approaches to continuing education out of school

For students who are unable to continue education in their regular school environment, or for whom participation is interrupted, the literature principally focuses on provision of education via hospital schools and / or home-based instruction. The identification of effective approaches in this context is largely based on examples, case studies and feedback from students, parents and teachers involved. Nonetheless, despite the limitations in the evidence base, a number of consistent strategies emerge: individualisation; tailoring of approaches to need and circumstance; recognition of the importance of social connections as well as academic; and the use of technology. It is perhaps this last element – technology – which represents an opportunity for significant change in how students with illness or injury can effectively maintain a connection with education and their regular school. Trials in this area and emerging international evidence suggest technology could play a pivotal role in achieving desired outcomes of educational inclusion and access.

Hospital-based education

Education can be provided by hospital schools for students with significant illness or injury who are absent from school for non-negligible periods. However, this

may entail as little as one or two hours' of tuition a week and can vary considerably from site to site. Additionally, not every hospital has a hospital school. Detailed analysis of the hospital school provision currently available in Australian (and New Zealand) jurisdictions is undertaken in the accompanying *Whose job is it?* in this series.

There is limited evidence to identify the approaches for hospital-based education that are effective in maintaining the participation and connection of students with learning and their regular school. Examples cited below are based on available research evidence and documentation, chiefly comprising case study examples, qualitative feedback from parents and students, and independent auditing. It is anticipated that other hospital schools may be engaged in similar approaches or evolving their practice in such ways; however there is limited evidence or documentation available at this point regarding their efficacy.

In Australia, the model developed in Western Australia appears to take a 'joined-up', cohesive approach to education for students with significant illness or injury, whether in hospital or in other, non-school environments. Here, the School of Special Educational Needs (SSEN) operates under a Memorandum of Understanding between the WA Departments of Health and Education. The SSEN is based in the Princess Margaret Hospital, but provides programs in 18 different locations and includes a home-based education service (see *Whose job is it?*). While considered a promising approach, particularly in terms of formal integration of healthcare and education sectors, detailed evidence of efficacy is not yet available at this stage.

In Victoria, The Royal Children's Hospital Education Institute (RCHEI) notes that "there is little to no research that has attempted to develop a best-practice framework for children's learning in these spaces or to study a children's hospital **as an alternative learning space**" (RCH, 2014). Here, the Institute has engaged in several research projects in an attempt to address this gap, including a review of their education model as a whole as well as studies into some different programs and interventions used, such as technology platforms. The Organisation for Economic Cooperation and Development (OECD) includes the RCHEI as a case

study in its Innovative Learning Environments project, and a joint OECD-RCH report notes the types of approaches in place in hospital schools said to support students with significant illness or injury in maintaining education participation and connection. These include:

- adopting **pedagogical learning approaches** based on student needs, experiences, learning styles, etc.;
- **personalised learning** and **flexibility** in delivery depending on the health situations of the individual student on any given day;
- use of **multiple learning spaces** within the hospital environment;
- connections and **alignment with curriculum and assessment requirements**; and
- the trial and implementation of **ICT resources to facilitate connection** between students and their regular school (OECD & RCH, 2012).

Such approaches may also feature in the practices of other hospital schools in Australia. While they indicate the elements in hospital schools that support students with significant illness and injury with their education, independent and robust assessment of their impact and effectiveness appears still to be largely absent.

Similar examples of hospital-based education practices and approaches emerge in the UK, and some of these are supported by independent assessment. One well-rated case study is that of the hospital school and home tuition service in **Coventry**. This is said to work continuously with a student's regular school and other parties supporting the student throughout their illness or injury. Full-time education can be provided in hospital, and home tuition is used to assist those who are being re-integrated back into their regular school (Department for Education and Employment, 2000). Independent auditing rates the service well: students are said to make good progress in their education and often achieve impressive results. **Collaboration with the student's parents and their regular schools** is identified as an important aspect assisting continuity and reintegration

back into school. The service is also reported to offer good pastoral care and guidance for students, contributing to positive personal development and wellbeing (OFSTED, 2007).

Finally, in New Zealand, nationwide provision for students who miss school because of significant illness or injury is split between three regional health schools. The health schools offer a flexible approach to learning delivery across multiple settings (including hospital bedside and classrooms, home tuition, and online learning), with tuition based on the assessed educational needs of individual students (Ministry of Education, NZ). Again, there is little robust evidence available on the efficacy of this approach. A survey of a small number of participants involved in the Northern Health School indicates positive outcomes, with around three-quarters of students saying that their involvement with the health school made it easier for them to return to their regular school (Hamilton, 2010). More broadly, the New Zealand model has been noted amongst stakeholders engaged during the course of this current investigation as a promising approach, particularly when contrasted with Australia. One factor suggested to be in New Zealand's favour is its smaller geographic reach and jurisdictional division, and the operation of this model on a national basis.

Home-based education

A recent report produced by The Royal **Children's Hospital Education Institute** examined the experiences of students and their families when they were discharged from hospital following significant illness or injury. This observed that almost one half received some help with their education while at home or in public places (other than hospital schools), with the most common providers of this **support being the student's regular school, family and friends, and community and charitable providers** such as RedKite and Ronald McDonald House Charities (Barnett, Hopkins & Peters, 2014). Charitable providers generally are unable to attend the home, for child protection and safety reasons, and provide support in public places or at school when the student is well enough to attend.

It is noted in other literature that, for some students with significant illness or injury, home-based instruction may offer the least restrictive environment for

them to continue education (Paterson, 2007). However, the complexity and individuality of home-based instruction and the fact that this is sporadically delivered via various providers means that robust evaluation of the efficacy of home-based instruction is lacking.

For school practitioners providing home-based instruction, some general approaches and strategies are suggested based on a review of literature and case studies in this field. These include:

- pre-planning and familiarisation with the student, their family and their circumstances;
- communication and rapport-building prior to and during visits with the student and family;
- a flexible approach to tuition and learning activities; and
- iterative reflection and review of visits to adapt and refine tutoring approaches over time (Paterson, 2007).

However, more fundamentally, the biggest challenge with effective home-based instruction is in the adequacy of provision itself. The RCH study noted above indicated that half of the students did not receive any help with home-based education; for those who did, one in three parents believed it was inadequate. Parents reported a need for information about the availability of home tutoring, **better communication with the student's regular school, and more social support** from classmates or the teacher. Flexibility in approaches was also considered key, given the day-to-day variability **in the student's condition. The study concludes** that there is a strong case for improvements to be made in the management and co-ordination of home-based educational support, particularly as the bulk of the responsibility to provide support falls to the parent in many cases (Barnett, Hopkins & Peters, 2014).

Technology to assist students to maintain connection

Both hospital-based and home-based education approaches appear to be making increasing use of ICT to support students with significant illness or injury to maintain their connection to education. As this technology develops, so too does

its capacity for facilitating effective learning and maintaining connections for students outside the school environment. A review of several trials demonstrates the potential of this technology, although evaluation methods have, to date, mostly been small-scale and qualitative in nature (see Table 1).

Overall, these findings and the associated literature indicate that the use of technology represents a significant opportunity for connecting students with significant illness or injury to their regular school and education curriculum. The methods appear to have been generally well-received and endorsed by students and use of the technology for both school work and social connection with peers is reported. Challenges invariably have entailed the ability and capacity of schools and teachers to incorporate such technology, hardware, platform and connection issues, and requirements for additional resources (such as software development, training, teacher time) for these to be successfully utilised. In addition, the issues associated with consent and privacy (of students and teachers) in a 'virtual' classroom environment must be addressed.

It has been noted that where schools take a proactive, inclusive approach to education in general, they have been more likely to engage with technology and use it effectively to connect with students who are absent due to significant illness and injury (Wilkie & Jones, 2008). Also, teacher readiness to engage with technology and use it effectively is strongly correlated with the teacher's experience and confidence with the use of ICT, rather than with age or length of teaching service (Jackson, in press).

The evolution of technology use and application can be traced over the course of the selected studies noted in Table 1. Initially, technology was primarily used as an additional communication channel to connect students with their school work, via email and, increasingly, other online platforms (e.g. forums, school websites, online assessment modules etc.). More recently, technology has been used to allow students to interact with and engage with their teachers and class in a real-time virtual environment, through remote videoconferencing. The approach used in the Netherlands (KlasseContact) appears to represent the most advanced and established model in this regard. Such approaches signify a potential 'game

changer' in how students with significant illness or injury can continue to connect with and participate in their regular school, by retaining a virtual presence in the classroom whilst being physically absent. Developing, trialling, and further evaluating such approaches for their efficacy in the Australian context is warranted.

Table 1: Summary of selected studies and approaches using technology to connect students with significant illness or injury to education and their regular school

Program / intervention	Method	Outcomes / findings
CYCLE – use of a range of ICT tools to facilitate connection between student in hospital and their regular school. (Fels, Shrimpton & Robertson, 2003)	Small pilot involving semi-structured interviews with students	Most participants found the technology to be motivating, reported a positive effect on their participation in school, and facilitated a connection with school, family and friends.
WellCONNECTED – Web-based connection establishing a virtual classroom through which students and their school teachers maintained contact with each other, mainly through email and completion of online assignments and tests. (Wilkie & Jones, 2008)	Pilot involving semi-structured interviews with students and teachers	Students were positive about the technology and would recommend it to others in their situation. However, the technology was considered complex and a major problem was observed in teacher ICT skills being inadequate to use the platform, despite intensive training.
Use of laptops in a paediatric hospital – a study examining use of students	Semi-structured interviews with 71 students	It was concluded that the laptops provided students with a tool to

own and/or provided laptops whilst in hospital, including use for education connection and participation. (Nisselle, Hanns, Green & Jones, 2012)		maintain contact with both their peers and their regular school, and this was a factor contributing to their social and emotional wellbeing and transition back to school.
The 'Connectivity Project'— Videoconferencing facilities to connect children with cancer to regular school by 'dialling in' from hospital or home. (Ellis, Drew, Wakefield, Saikal, Punch & Cohn, 2014)	Semi-structured interviews with 8 parents, 3 students and 5 teachers	Reported positive impacts on sense of connection and normalcy with outside world and student relationships with classmates and teachers. Barriers noted in relation to time and cost, bureaucratic hurdles (e.g. privacy and consent), and technical and logistical difficulties.
Individualised Literacy Learning using an iPad with a multi-modal book creation app for early years literacy development (Hopkins, Barnett & Sayer, 2014)	Small randomised control trial with students and a focus group with teachers	Some evidence that use of book creator app was more effective than teaching as normal as measured by concepts of print test. Teachers report app as easy-to-use, useful and effective.
Ambient technology for connecting hospitalised children with school and home – a tablet- based application which created a sense of the social presence	Pre-trial and post-trial qualitative interviews with students, parents and	The use of an ambient technology to support the social presence of a hospitalised child was generally well received by children and teachers,

of the distant other, using mobile devices that could be integrated into hospitals, schools and homes. (Wadley, Vetere, Hopkins, et al., 2014)	teachers, and diary completion built into the tablet.	though less so by parents.
KlasseContact - ICT adopted in the Netherlands allowing students who are absent from school to actively join in with lessons using a portable, remotely-activated webcam and laptop. (Ziezou, 2014)	Participation data. Methodology of evaluation not known	Average of 200 students a year have been connected to their regular schools using KlasseContact. Research conducted in 2011 reports beneficial effects on social contacts and academic performance.
LIVE (Learning in Virtual Environments) – use of webcam technology in New Zealand to allow teachers at a student's regular school to conduct online home visits. (Northern Health School, 2014)	None observed to date	Approach relies on student having access to a Windows computer and sufficient Internet connection.
Designing Communication Technologies for Children with a Chronic Illness – an investigation into how children with chronic illness use current technologies to stay connected. (Liu, 2014)	Semi-structured interviews with 22 participants (16 health care professionals and 6 parents).	Further research to be conducted into the design of technologies through participatory design sessions working with children with chronic illness.

Working towards a practice model

This investigation has shown that there is currently no widely supported, easily replicable and transferable practice model to support students with significant illness or injury to continue their participation in, and connection to, education. Approaches in place internationally – specifically in the Netherlands and New Zealand – offer some insight into how a universal model for such students could work, although even here the strength of evidence appears to be limited to date.

To advance development of 'best' or 'ideal' models and practices, we have examined approaches in the context of inclusion and equity in education. Inclusion is a salient principle of education practice in Australia and implies that, wherever possible, students with significant illness or injury should be involved in regular classes and continue to be linked to these throughout their illness or injury. These students are part of the diversity of students within the school and are likely to benefit academically, socially and emotionally by remaining connected.

The question is *how is this best achieved?* The answer is not straightforward and, given the complexity of illness, injury and learning, and the numerous parties involved, it is perhaps simplistic to expect a single model to ensure the needs of all students are met. Generally, the literature suggests that students with significant illness or injury are better equipped to continue education when there are holistic approaches in place, which offer:

- a continuum of support and learning opportunities; support in the school for self-care and management;
- health service support and interventions in the school setting;
- connection between the in-school and out-of-school environment; and
- broad peer support and community understanding of the role and benefits of continued connection to school and learning.

Draft theoretical framework

To further illustrate how a model for maintaining education participation and connection for students with significant illness or injury might evolve, a draft theoretical framework is presented (Figure 1). This is based on the approaches

(and the strategies and elements behind these) that have emerged in the evidence reviewed, as well as some of the common issues and implications drawn from the research literature. It is again worth noting that the evidence base for this is not strong, the framework is not necessarily inclusive of all possible approaches and outcomes and – as such – further articulation and development of specific practices, testing, validation, evaluation and review is necessary over time.

The draft framework is structured to support a desired **overarching outcome** based on educational inclusion and the rights of students with significant illness or injury to receive an inclusive and equitable education (stemming from key attributes of the UN Convention on the Rights of the Child).

Pre-conditions which are associated with this outcome are the factors that are described in the literature as being perceived to lead to student inclusion and participation. They comprise early intervention and planning; individualised and flexible approaches; integrated and consistent provision of education across environments; health and education service collaboration; and steps to ensure social and emotional needs are met.

Beneath this, the **approaches and strategies** likely to address such pre-conditions are considered. These stem from common practices that may be in place already and for which we may expect some impact based on the limited available evidence. Suggested approaches also derive from some of the issues and implications reported in the literature, and potential solutions or ways to address these.

The suggested approaches and strategies include developing awareness and knowledge of serious illnesses and injuries, including breaking down stigma more widely about these; formalised and actionable documentation to plan and implement strategies for individual students; greater integration and alignment of health, education and social support provision; and methods to ensure students have connection with their regular school when absent from it.

Figure 1: Draft theoretical framework for supporting students with significant illness or injury to maintain education participation and connection.

DESIRED OUTCOME

Students with significant illness or injury participate in education on an inclusive and equitable basis without discrimination and are provided with additional support or care to ensure they can reach the highest level of education of which they are capable

Example pre-conditions of this outcome

Early identification, intervention and planning is in place to reduce the impact of significant illness or injury on learning

An individualised, long-term and flexible approach exists for students with significant illness or injury

A consistent and integrated level and standard of education is provided across environments

Education and health service linkages are in place to support the management of significant illness or injury and its impact on school participation and connection

The student's and family's social and emotional needs are considered

Potential strategies and approaches to address the pre-conditions

Build awareness and knowledge amongst parties directly engaged in the care and education of students with significant illness or injury (e.g. parents, teachers, health professionals) and ensure that these parties also have the information, data, training and support that they need

Ensure students have a customised and integrated education and health plan (in which students and families have significant input); these must provide actionable measures that are implemented and regularly reviewed

Provide accessible and integrated health services and treatments at school, home, and across the community

Offer pastoral care and support to students to meet the physical, social and emotional challenges of living with a significant illness or injury and managing this within school

Seek ways to develop a stronger culture of diversity and understanding amongst school leaders, teachers, peers and the wider community for students with significant illness or injury, tackling stigmas and barriers to inclusion

Implement integrated tuition and learning that maintains connection for a student with significant illness or injury with their regular school when absent; this could be achieved through:

- maintaining dedicated teacher contact and instruction throughout the course of absence.
- alignment of school curricula with hospital or homebound education environments.
- **adopting effective technology to provide 'real time', virtual participation in the classroom.**
- ensuring a transition plan and suitable measures are in place to support absence management and a return to school.

Reduce jurisdictional barriers and inconsistencies in approaches for students arising as a result of where they live and go to school.

Guiding principles and underpinning elements

Complementing this draft framework, a number of literature items examined and recommended key principles and underpinning elements considered important in the implementation of inclusive education (Department for Education and Employment, 2000; Scottish Executive, 2001; Shiu, 2004b; DEECD, 2008; Yates, et al., 2010). These largely corroborate the tone and nature of approaches outlined in the framework above, and offer some overarching philosophies and necessary considerations for practical implementation. There would be value in taking into account these principles and underpinning elements and ensuring they continue to apply to practice models as they develop and evolve.

In particular, three common **guiding principles** emerge:

- individualisation of approaches so that they are targeted and customised towards students and their families and, in the case of significant illness or injury, accommodate the changeable nature of illness or injury;
- collaborative approaches, with relationships formed and managed across all parties involved in the education and health of a student. This should include a clear chain of communication and allocation of roles and responsibilities (which could be formalised);
- equitable approaches in which students and their families are treated as equal partners and actively involved in planning, implementation and review.

There also appear to be four main **underpinning elements** which are likely to be necessary for strategies and approaches to be implemented effectively:

- legislative policy and accountability, so that approaches are mandated as a norm, can be funded, promoted and supported, and are subject to scrutiny and accountability;
- financial, infrastructure and time resources needed to develop, implement and review strategies and approaches (e.g. teaching staff, medical equipment);

- leadership to advocate, promote and implement approaches and strategies. This may manifest at a local level (e.g. school principals driving their school strategy and actions to support students with significant illness or injury) or at a wider community, social, or political level; and
- human capacity and capability to be able to deliver the approaches required. For instance, training of educators and health practitioners to implement approaches, provision of additional time to perform certain roles, information for parents and families so that they are best placed to advocate for their child and access appropriate support etc.

A model in action – learning from The Netherlands

During the review of literature and discussions with stakeholders as part of this body of work, it became apparent that the approach taken in The Netherlands offered a well-regarded, working example of a model established to support students with significant illness or injury to continue education participation and connection. It is difficult to gauge the long-term efficacy of this model through robust evaluative data, and application of such a model in Australia may be more challenging due to factors such as size, remoteness, infrastructure, and governance structures. However, the approaches and practices adopted in The Netherlands mirror many of those outlined previously in this report, and are provided in a cohesive and integrated fashion.

In brief, education laws introduced in The Netherlands stipulate that, if a student sustains a significant illness or injury, the school where the student is enrolled retains responsibility for their education. Consultants placed at Education Centres or Education Advisory Bureaus offer guidance to students, their families, health providers and schools, and support the implementation of connective learning strategies and activities.

Educators in the regular school are provided with guidance and support to sustain the student's engagement in learning. Many of the approaches promoted – liaising with students and parents throughout, individual planning, making adjustments to the environment and curriculum delivery, raising awareness amongst class peers,

and integrating students back into the classroom – reflect practices that have emerged throughout this report. One particularly innovative approach for students unable to attend school due to their medical circumstances has been the application of real-time interactive, two-way audio-visual links between student and classroom.

Continuing to monitor models and practices implemented overseas and connecting with stakeholders involved in the delivery of such models would be a useful strategy in terms of developing appropriate and effective practice models in Australia.

Recommendations

Developing a robust model to support inclusion

There is much to learn and much to do before we can be certain of the most effective practices and models for supporting students with significant illness or injury in Australia to maintain their participation in, and connection to, education. A key recommendation from this investigation is thus the **advancement of research and evaluation** in this space. While acknowledging that research and evaluation can be complex and resource-intensive – particularly at a localised level – the degree of certainty over what may well be ‘effective’ or ‘best’ practice will always be questionable without it.

Better evidence will undeniably lead to a more robust model for practice, but there are opportunities to enhance the theoretical framework proposed in this report in the short term. Theories of Change are often initially formed through a collaborative workshopping process amongst key policymakers, practitioners, advocates and the communities they affect. Undertaking a similar **collaborative process to develop, refine and build consensus around the theoretical framework** proposed here would add to its strength. It would also serve to set a common agenda for testing of theories, validation of approaches, identification of outcome indicators and measures, and development and/or identification of research to inform model development.

The implications of the draft theoretical framework presented in this investigation on implementation and current practice are somewhat pre-emptive and problematic to ascertain. However, the overarching outcome of inclusion has been supported by Australian legislation and backed by reasonable evidence for some time. Ensuring that it occurs in practice for students with significant illness or injury may require more focused and potentially transformative approaches for various parties. For instance:

- comprehensive and **‘joined-up’ education and health services** delivered across settings, including schools, hospitals and home;

- greater collaboration and **formalised links between all parties** involved in the education and care of a student with significant illness or injury;
- engagement of **parents and students as equals** in the planning, implementing and review of education and care arrangements;
- development of a strong **'culture of inclusion'** in schools, with practical assistance for implementing support measures and improving knowledge and perceptions of the whole school community towards students with significant illness or injury;
- **practitioner support and 'up-skilling'** for both medical and teaching professionals to be better equipped / more confident to respond to a **student's illness or injury and manage their learning in light of their situation**;
- implementation and **integration of technology into a school-home environment**, with sufficient capacity (hardware, bandwidth) and ability (confidence, know-how) to be able to make the technology an effective means for students to maintain connection with school; and
- universal opportunities and **provision that is consistent across jurisdictions** so that students with significant illness or injury are not inadvertently discriminated against because of their background or where they live.

With any approach it is imperative to take into account the context of the individual student, their family, and the wider school and healthcare environment. Relevant factors include the student's age and capacity for self-advocacy, the nature and impact of the illness or injury, the location and resources of the family, schools, hospitals, etc., and the confidence and capabilities of all practitioners involved.

Such contextual nuance suggests that a rigid, 'one size fits all' approach would have limited effectiveness and that there may not be a single 'ideal model'. Instead, it may be possible to identify a series of common practices and strategies which are likely to mitigate the disadvantage experienced by some students with

significant illness or injury as a result of non-negligible school absence. Building evidence and developing a framework to guide practice, based on concepts of inclusion and equity, should offer a pathway to improving the education and overall life prospects and outcomes of such students. Associated benefits would flow to their families and the wider community.

References

Adams, D. (1978). *The Hitchhiker's Guide to the Galaxy*. New York: Random House USA Inc .

Alborz, A., Pearson, D., Farrell, P. & Howes, A. (2009). *The impact of adult support staff on pupils and mainstream schools – technical report*. London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.

Allen, K.E. & Cowdery, G.E. (2012). *The exceptional child: Inclusion in early childhood education* (7th ed.). Belmont CA: Wadsworth Cengage Learning.

Attorney-General's Department (2005). *Disability standards for education*. Canberra.

Barnett, T., Hopkins, L. & Peters, S. (2014). *What happens when they go home? An investigation of education support for students following discharge from the RCH*. Melbourne: The Royal Children's Hospital Education Institute.

Child Trends Databank (2010). *Untitled comprehensive school-based asthma program*. Retrieved from: www.childtrends.org/?programs=untitled-comprehensive-school-based-asthma-program

Chrisler, A. (2012). *What Works for Asthma Education Programs. Lessons from Experimental Evaluations of Social Programs and Interventions for Children*. Washington DC: Child Trends.

Department for Education and Employment, UK (2000). *Consultation on the education of sick children*. Nottinghamshire.

Department of Education and Early Childhood Development, Victoria (2008). *Every child every opportunity – Effective strategies to increase school completion report*. Melbourne.

Department of Education and Early Childhood Development, Victoria (2013). Hospitalisation rate for asthma. In *Early Childhood and Adolescent Indicators, Catalogue of Evidence*. Retrieved from: www.education.vic.gov.au/about/research/Pages/asthmaid1.aspx

Department for Education, Employment and Workplace Relations (2012). *Report on the review of disability standards for education 2005*. Canberra.

Dockett, S. (2004). 'Everyone was really happy to see me!' – The importance of friendships in the return to school of children with chronic illness. *Early Childhood Australia, 29*(1), 27-32.

Donnan, B. & Webster, T. (2011). *Inquiry into the transition support for students with additional and/or complex needs and their families* – Submission to the NSW Parliament. *Ronald McDonald House Charities*.

Dyson, A., Howes, A. & Roberts B. (2002). *A systematic review of the effectiveness of school-level actions for promoting participation by all students*. London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.

Ellis, S.J., Drew, D., Wakefield, C.E., Saikal, S.L., Punch, D. & Cohn, R.J. (2013). Results of a nurse-led intervention: Connecting paediatric cancer patients from the hospital to the school using videoconferencing technologies. *Journal of Paediatric Oncology Nursing, 30*(6), 333-341.

Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) (2006-2009). *Special educational needs in mainstream schools*. Retrieved from: <http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=490>

Fels, D.I., Shrimpton, B. & Robertson, M. (2003). Kids in hospital, kids in school. In D. Lassner & C. McNaught (Eds.), *Proceedings of world conference on educational multimedia, hypermedia and telecommunications 2003*, 2358-2363.

Hamilton, M. (2011). *Research into successfully reintegrating students into school*. Report to Principal and Board of Trustees of Northern Health School. Auckland: Northern Health School.

Harvard Family Research Project (2005). *An introduction to theory of change*. The Evaluation Exchange; xi (2). Retrieved from: www.hfrp.org/evaluation/the-evaluation-exchange/issue-archive/evaluation-methodology/an-introduction-to-theory-of-change

Hopkins, L., Barnett, T. & Sayer, L. (2014). *What do I do now? Individualised literacy learning using the iPad*. Melbourne: **The Royal Children's Hospital Education Institute**.

Irwin, M. K. and Elam, M. (2011). Are we leaving children with chronic illness behind? *Physical Disabilities: Education and Related Services* (2011), 67-80.

Jackson, M. (in press). *Exploring teachers' approaches to students with chronic illness and the use of real time 2 way digital communications in the senior secondary context*.

Jimerson, S. R., Pletcher, S. M. W., Graydon, K., Schnurr, B. L., Nickerson, A. B., & Kundert, D. K. (2006). Beyond grade retention and social promotion: Promoting the social and academic competence of students. *Psychology in the Schools*, 43(1), 85-97.

Kavale, K.A. & Mostert, M.P. (2003). River of ideology, islands of evidence. *Exceptionality*, 11 (4), 191-208.

Kids Health (2013). *504 education plans*. Retrieved from: http://kidshealth.org/parent/positive/learning/504-plans.html?tracking=P_RelatedArticle#

Lavoipierre, J. (2012). *Strategies to support the learning of students with serious medical conditions in rural areas*. **Bathurst: All Saints' College**

- Liao, O., Morphey, T., Amaro, S. & Galant, S.P. (2006). The Breathmobile: A novel comprehensive school-based mobile asthma care clinic for urban underprivileged children. *Journal of School Health*, 76 (6), 313-319.
- Lindsay, G. (2003). Inclusive education: A critical perspective. *British Journal of Special Education*; 30 (1), 3-12.
- Liu, L.S. (2014) *Designing communication technologies for children with a chronic illness*. Retrieved from:
www.acm.org/conferences/group/conferences/group14/p258.pdf
- Ministry of Education, NZ. *Regional Health Schools*. Retrieved from:
www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/ServicesAndSupport/RegionalHealthSchools.aspx
- Mitchell, D. (2010). *Education that fits: Review of international trends in the education of students with special educational needs*. Christchurch: University of Canterbury.
- Mitchell, D., Morton, M. & Hornby, G. (2010). *Review of the literature on individual education plans*. Christchurch: New Zealand Ministry of Education.
- Nisselle, A., Hanns, S., Green, J. & Jones, T. (2012). Accessing flexible learning opportunities: children's and young people's use of laptops in a paediatric hospital. *Technology, Pedagogy and Education*, 21(1), 3-20.
- Northern Health School. How does LIVE work?, in *About Us*. Retrieved from:
www.nhs.school.nz/about/
- OECD & The Royal Children's Hospital Education Institute (2012). *Innovative learning environments – Inventory Case Study: The Royal Children's Hospital Melbourne*. Retrieved from: www.oecd.org/edu/cei/50358701.pdf
- Office for Standards in Education, Children's Services and Skills [OfSTED] (2007). *Inspection Report* (Reference number 134970). Retrieved from:
www.ofsted.gov.uk/filedownloading/?id=856755&type=1&refer=1

Patel, B., Sheridan, P., Donnersberger, D., Gluck, E., Malamut, K., Whyte, S., Qing, H., et al (2007). Success of a comprehensive school-based asthma intervention on clinical markers and resource utilization for inner-city children with asthma in Chicago: the Mobile C.A.R.E. Foundation's asthma management program. *Journal of Asthma; 44(2)*, 113-118. doi:10.1080/02770900601182343

Paterson, P.D. (2007). *Guidelines for providing homebound instruction to students with disabilities*. Retrieved from: www.brainline.org/content/2008/10/guidelines-providing-homebound-instruction-students-disabilities_pageall.html

Porter, L. (2008). *Teacher-parent collaboration*. Melbourne: ACER Press.

Scottish Executive Education Department (2001). *Guidance on education of children absent from school through ill-health*, (Annex B). Edinburgh: Scottish Executive.

Shaddock, A.J, Nielsen, T.W., Giorcelli, L., Kilham, C.H., & Hoffman-Rapp, L. (2007). *What are the critical factors in ensuring successful collaboration between mainstream teachers and teaching assistants?* Canberra: Department of Education, Science and Training.

Shaw, S.R. & McCabe, P.C. (2008). Hospital-to-school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools, 45(1)*, 74-87.

Shiu, S. (2001). Issues in the education of students with chronic illness. *International Journal of Disability, Development and Education, 48(3)*, 269-281.

Shiu, S. (2004a). Maintaining the thread: Including young children with chronic illness in the primary classroom. *Early Childhood Australia, 29(1)*, 33-38

Shiu, S. (2004b). Positive interventions for children with chronic illness: Parents' and teachers' concerns and recommendations. *Australian Journal of Education, 48(3)*, 239-252.

Taplin, D.H. & Clark, H. (2012). *Theory of change basics: A primer on theory of change*. New York: ActKnowledge, Inc.

The Baltimore Student Attendance Campaign & Elev8 Baltimore (2012). *State of chronic absenteeism and school health, a preliminary review for the Baltimore community*. Baltimore MD.

The Royal **Children's Hospital Melbourne (2014)**. *Children's learning at The Royal Children's Hospital CL@RCH*. Retrieved from:
www.rch.org.au/education/research/childrens-learning-at-the-rch/

Van Cura, M. (2010). The relationship between school-based health centers, rates of early dismissal from school, and loss of seat time. *Journal of School Health; 80*(8), 371-377.

Wadley, G., Vetere, F., Hopkins, L., Green, J. & Kulik, L. (2014). Exploring ambient technology for connecting hospitalised children with school and home. *International Journal of Human-Computer Studies, 72*, 640-653.

Whiteford, C.M. (2010). *Children with special health care needs: Social and learning competence in the early years*. Brisbane: Queensland University of Technology.

Wilkie, K.J & Jones, A.J. (2008). Link and learn: Students connecting to their schools and studies using ICT despite chronic illness. In P. Jeffrey (Ed.). *AARE Conference Proceedings (2008)*. Brisbane: Australian Association for Research in Education.

Wilkie, K.J. (2012). 'Absence makes the heart grow fonder': Students with chronic illness seeking academic continuity through interaction with their teachers at school. *Australasian Journal of Special Education; 36* (1), 1-20.

Yates, L., Bond, L., Dixon, M., Drew, S., Ferguson, P., Hay, T., White, J. (2010) et al. *Keeping connected: Identity, social connection and education for young people living with chronic illness*. Melbourne: Melbourne Graduate School of Education, University of Melbourne.

Ziezon (2014). *KlasseContact: Off sick, but still in the classroom!* Retrieved from: www.ziezon.nl/ziezon-caring-about-taking-care-of-pupils-with-chronic-or-long-term-illnesses/klassecontact-off-sick-but-still-in-the-classroom



School connection for seriously sick kids

Part 3: Whose job is it?

Missing School 2015 – Part 3: School connection for seriously sick kids: whose job is it?

Neil Stafford, *ARACY*

Liza Hopkins, *The Royal Children's Hospital Education Institute*

Megan Gilmour, Gina Meyers, Cathy Nell, *MissingSchool*

© 2015 *MissingSchool*

Missing School Inc. owns copyright of all material in this report. You may reproduce this material in unaltered form only (acknowledging the source) for your personal, non-commercial use or use within your organisation. Commercial use of material in this report is prohibited. Except as permitted above you must not copy, adapt, publish, distribute or commercialise any material contained in this publication without ***MissingSchool's* permission.**

ISBN: 978-1-921352-78-2

[Suggested citation](#)


Australian Research Alliance for Children and Youth (ARACY). (2015). *Missing School – Part 3: School connection for seriously sick kids: whose job is it?*. Canberra, ACT.

[Contact us](#)

If you have any queries about this report, please contact ARACY:

Mail: PO Box 5070, Braddon, ACT 2612 Email: enquiries@aracy.org.au Website: aracy.org.au

Phone: +61 2 6248 2400

 [@ARACYAustralia](https://twitter.com/ARACYAustralia)

ABN 68 100 902 921

Acknowledgements

This work was commissioned from ARACY by Missing School Inc. and supported by a generous grant from the St George Foundation, St George Bank.

The authors thank the many individuals and organisations who contributed to the work, including Barb Donnan (Ronald McDonald Learning Program) for insight into the RMLP collection of statistics around students with significant illness or injury, Megan Jackson (University of Canberra) for discussion of the use of technology to support the learning of students who miss school because of significant illness or injury, and Jenny Lavoipierre for thoughtful general comments.

In particular, the authors thank Liza Hopkins (The Royal Children's Hospital Education Institute) for significant contributions to this report on research around current practice, and to Tony Barnett (The Royal Children's Hospital Education Institute) for providing valuable editorial comment.

Table of Contents

Suggested citation.....	112
Acknowledgements	113
Executive summary	115
Introduction	118
Definitions	122
School connection for seriously sick kids : whose job is it?	125
Overview of review approach	125
Australian federal legislation	126
Current policy and practice supporting the education of students with significant illness or injury	130
How does current effort fare in relation to theoretical models and approaches for effective practice?	149
Recommendations.....	153
Appendix I: Numbers of students seen in hospital schools.....	156
References.....	158

Executive summary

This report is one of three developed as part of a program of work undertaken by the Australian Research Alliance for Children and Youth (ARACY) and Missing School Inc. The program has sought to examine current evidence, policies and approaches for supporting the education of students who experience non-negligible school absences because of significant illness or injury. The aim is to understand the situation in which these students find themselves and whether it is adequately addressed. The focus of this report is on current legislation and policy approaches existing in Australia for such students and their families.

Main findings

Current policy and philosophy in Australia strongly supports the inclusion and equitable participation of all children in education, implicitly embedding the rights of students with significant illness or injury to be given additional support to continue learning and to remain connected to their regular school.

However, the policies and processes covering the education of students with significant illness or injury are often subsumed into a disability and/or special needs area that may not directly relate or easily apply to such students. This may hamper awareness, recognition and clarity around the rights of these students to receive support.

State and territory education policies and processes show a number of commonalities relating to the education of students with significant illness or injury. There is a focus on individualisation of approaches and flexibility according to student need, although whether these are effectively implemented is unclear.

Alternative education programs and services provide a source of support for some, but not all, students with significant illness or injury. Hospital schooling varies considerably from state to state in terms of accessibility, eligibility, extent of tuition, and attachment to **the student's regular school. The result is uneven and sporadic provision, which is likely to differ depending on where a student lives and goes to school.**

One of the biggest limitations in current policy, process and provision appears to be the continuing formal learning out of school and out of hospital, i.e. while at home. Such learning appears to be ad hoc and reliant on individual parties and localised approaches that may be in place.

Conclusions and key recommendations

The evidence signifies a gap in current policy and provision for students with significant illness or injury, despite the efforts of educators, parents, policymakers and others in the field. Potential means of addressing the gaps and limitations emerging could include:

- development of **national legislation** specific to the needs of students with significant illness and injury, mirrored by policies and procedures developed at the state and territory level to explicate the processes to support such students. These should be clearly communicated to educators, parents, students and other stakeholders, and their implementation monitored through regular review and reporting;
- development of **specific policy for students with significant illness or injury**, and not merely subsuming this into disability;
- formalising **health and education data linkage and collection processes** to allow for improved monitoring and research into the numbers of students with significant illness or injury, and the extent of their absence, and to determine support needs and resources accordingly;
- ensuring that **funding, infrastructure, resources and staff development opportunities** are available to support the additional needs of students with significant illness or injury as a legislated entitlement. This should recognise that there may be a continuing need for educational and learning support across the **student's school life whether the illness is ongoing, or whether the student has recovered from the illness or injury leading to the absence**;
- advancing **health initiatives and health services within school settings** to support awareness and management of illness, managing environmental barriers to attendance, and enhancing integration of education and health services;
- advancing **educational initiatives within medical settings** to promote understanding amongst medical staff of the importance of the child's education and learning needs, and wellbeing and identity as a student or learner;
- formalising **linkages between the healthcare and education sectors** in order to develop a cohesive, integrated education model that maintains students' connections

with their regular schools, and making explicit the legislated responsibility of schools to support the education of all their students;

- incorporating and facilitating the use of **information and communication technology** as an integral part of learning, allowing for remote education and 'virtual' presence in school; and
- **formalising the roles and responsibilities of all parties**, including parents and carers, in supporting students with significant illness or injury.

Introduction

Around Australia every day, thousands of children miss school because of illness. Some of these children will be missing a few days every year; some will be missing a few weeks every year; some will be missing months and possibly years of school.

One of the specific challenges facing students with critical or chronic illness is that they may experience frequent or extended absences from school, either because of illness or treatment. The double burden of illness and school absence has many long-term consequences which may include:

- delays in developmental skills due to missed experiences
- school refusal and absenteeism
- academic under-achievement
- behavioural problems
- increased anxiety
- attention and concentration problems
- reintegration difficulties
- specific learning needs
- low self-esteem
- disruption of friendships
- difficulties in forming and maintaining relationships
- reduced opportunities for social support
- increased vulnerability to other life stressors or secondary illnesses
- peer rejection

(Donnan and Webster, 2011; Whiteford, 2010; Shaw and McCabe, 2008; Dockett, 2004; Shiu, 2001).

This is a long list of 'possible side-effects' and not all students will experience all of these problems. However, the research is clear that school absence resulting from illness is a significant problem for many students.

Retention, or 'repeating' a year or more at school, may be appropriate for some students – depending on the anticipated absence, when it occurs in their schooling, and their general socio-emotional environment – but is otherwise not generally recommended. In a review of educational issues faced by students with chronic illness, Irwin and Elam (2011, quoting

Jimerson et al., 2006) note that retention does not improve academic outcomes, but is instead detrimental to socio-emotional and behavioural outcomes, and has a negative impact on **students' attendance and attitudes toward school. They observe also that "students perceive retention as a highly stressful life event, and retention is a strong indicator for dropping out of school."**

The importance of maintaining connection between students and their schools in mitigating these problems has been frequently highlighted in the literature (Porter, 2008; Dockett, 2004; Shiu, 2004a). However, an absent student may be largely 'invisible' in the context of a busy school, and easy to overlook when planning for teaching and learning. The extent to which the **student's needs are addressed is heavily reliant** on the disposition of individuals within the school, and there is thus widespread variability and inequity in the educational access afforded (Lavoipierre, 2012; Wilkie, 2012).

During a hospital admission, a student will generally have access to the hospital school. The **stated mission of most hospital schools is to work with the student's regular school to maintain** continuity of learning. In practice, and for a variety of reasons, this is often not successful (Wilkie, 2012).

Current advances in healthcare also mean that many children requiring medical treatment receive their treatment on an outpatient basis, and may spend significant periods of time recovering at home rather than in hospital. They may be too vulnerable or fragile to attend school, although quite capable of undertaking school work and possibly craving social interaction. During this time, they have access to neither the hospital school nor their regular school.

The school experience of many students with critical or chronic illness or injury is one of isolation and marginalisation.

While the need for increased systemic support for students is clear, the educational environment is complex and it will take time to develop appropriate solutions. Such solutions are likely to require improved linkages between educational and health sectors, and involvement of students and their families in uncovering the issues, barriers and possibilities faced by different individuals in different contexts. For example, variations in the nature of the significant illness or injury, the student's age, and the location, resources and capabilities of families, educators, and health professionals are all relevant factors.

MissingSchool is dedicated to working with families, educators and health professionals to identify best-practice models and raise awareness; and to advocating for change at a government systems level.

This work has been commissioned by *MissingSchool* in an attempt to understand the environment in Australia for children and young people with serious illness or injury who are also engaging with education.

Consolidation and synthesis of existing data has been problematic, largely because of the wide variability in language, terminologies and definitions used by different authors for different audiences. In order to maintain the coherence and 'readability' of these reports, we adopt a set of definitions, outlined in Definitions. When reviewing the literature and other data sources, we will note as appropriate where other authors have differed.

Even with a clear set of definitions, there is a wide range of complicating factors, not all of which can be adequately addressed in this document.

Significant illness or injury is likely at some stage to involve treatment in hospital. For students in metropolitan areas, medical care is generally close at hand. However, students in rural or regional areas may need to travel to the nearest large city to a specialist paediatric hospital. In some circumstances, the nearest hospital with an appropriate specialisation may be in a different state. Regular, although routine, processes and treatments may require a substantial amount of travel and time away from home, family and school. Lengthy treatment may involve re-locating the entire family to a different city for the duration of the treatment. In this case, maintaining contact with the student's regular school becomes significantly more difficult, and communication platforms adopted by the different state education authorities may not be compatible. Until recently, different states have also maintained differing curriculum, assessment and reporting requirements, and while many of these differences have been dispelled with the adoption of national standards, some persist.

Students whose regular school is a 'home school' are not captured in any of the data, and their situation has not been examined.

There are many parties involved in the care of a student with significant illness, and all have a unique perspective on the nature of the illness and the purpose and relevance of school and education. These parties include the students, their school-aged siblings and families, their teachers, classmates, educational leadership, and school communities, medical and allied health staff. Surveys are designed to capture the data which the surveyors believe to be relevant; legislation is designed to reflect the imperatives of government authorities;

interventions are developed to meet the needs assumed by their developers. The different – and sometimes conflicting – perspectives and perceptions of the different parties make it almost impossible to draw out a coherent understanding of the challenges arising.

Privacy issues come into play at the intersection of public spaces (schools and hospitals) and private spaces (the family home). While the state bears the ultimate responsibility of ensuring that its students have access to quality education, it must respect the rights of individuals and families to privacy in the home, and confidentiality at school.

Advances in information and communication technologies theoretically make it possible to connect individuals anywhere in the country, but challenges arise from concerns around privacy in the home, at hospital and at school, access and resourcing issues, and constraints on communication platforms in different jurisdictions.

Advances in medical technology mean that more and more children and young people are surviving illnesses which were previously incurable and unmanageable. A generation ago, or even less, these children and young people, and their families and teachers, may not have had the time to consider the implications of their withdrawal from their schools and education. Today, they are likely to become adults in our communities and societies, and they will need access to quality education if they are to have the same opportunities as other children and young people to fulfil their potential. While dealing with significant illness, they remain students.

MissingSchool began this work in the hope of building some clarity around the systemic issues facing students with significant illness, and their families, teachers and schools in Australia. It offers no answers, but instead **“rigidly defined areas of doubt and uncertainty”** (Adams, Douglas: *The Hitchhiker's Guide to the Galaxy*, 1978). Further work remains to be undertaken by the parties who bear the responsibility for addressing the challenges in the system, and we hope that they may find this document a useful starting point.



Definitions

Absence

Different patterns of absenteeism will be experienced by students with different significant illnesses, and even by different students with the same illness. Some students may be absent for months and years at a time, others may be absent for shorter and more frequent periods. Absences have been described as 'prolonged', 'extended', 'frequent' or 'recurrent'.

At this stage we do not want to put a quantitative limit on the number of days which must be missed before an absence becomes 'non-negligible'. However, we expect that such an absence would mean either multiple months in one stretch, or else smaller absences of days or weeks which added up to multiple months or even years over the course of the student's school life. A single absence even of several weeks would not necessarily constitute a non-negligible absence.

At the school level, it is possible that the needs of the student will be more closely linked to the student's pattern of absenteeism than to the student's illness.

Disability

Medical conditions and illnesses are clearly included under definitions of disability in the Commonwealth legislation. In more general usage, disability may be understood to mean vision, hearing or mobility impairment or behavioural issue, and there may be confusion amongst teachers and families about whether the provisions of the disability legislation applies to the situation of students with significant illness (Department for Education, Employment and Workplace Relations, 2012). Families who are grappling with the import of a significant illness may view disability as a stigma or unwanted label. For the purposes of this report, we accept medical conditions, illnesses and injuries as disabilities as defined under the Commonwealth Disability legislation (Attorney-**General's Department, 2005**).

Enrolment / registration / attendance / participation

Different schools, different families, and different agencies have different understandings of what it means to be enrolled in a school. Simple enrolment in a school does not mean that the student is attending. Simple attendance at a school does not mean that the student is participating. Equally, a student who is not actually attending school may still participate in the life of the class with the help of distance communication technologies and support strategies. In this report we will use 'participation' to mean that the student is engaged in meaningful activities which support his or her social or academic development.

Illness or injury

There are connotations associated with the words 'illness', 'disease' and 'condition', and language is often chosen on the basis of the perceived impact of those words. We have chosen to use the term **illness**, understanding that it is not communicable, and may be transient or permanent.

We restrict our use of 'illness' here to somatic illnesses only. We acknowledge the need to support students with mental illness, and would not reject discussion of those needs. However, the field around mental illness is complicated, and it is possible that the needs of students with mental illness are substantially different from the needs of students with somatic illness. Deeper investigation of those needs is warranted, but is not attempted here.

None of the terms mentioned above covers the possibility of an injury which leads to school absence. We have thus chosen to refer to **illness or injury**. Use of either word should be read as including the other unless explicitly indicated.

Regular school

The school which the student ordinarily attends when not experiencing illness-related absence is referred to as the **regular** school. This is in order to avoid the misunderstandings inherent **in the use of** 'home school' (which may instead refer to the education of the student at home), 'mainstream school' (which raises interesting but unhelpful questions around the boundaries of inclusivity), 'origin school' (which is not commonly used, and is open to misinterpretation), and 'census school' (which is a term used by state education authorities and not familiar to the other parties who may read these reports).

School

We understand schools to include any provider of formal education up to Year 12. While students in pre-school and tertiary environments also face challenges associated with illness-related absences, the constraints in these environments are different from those in primary and secondary schools and beyond the scope of this report.

Siblings

The school-aged siblings of students with a significant illness are also at risk of missing school. They may travel with their families to accompany the ill student elsewhere for treatment, and thus be removed from their regular schools. They may miss school activities simply because their families are preoccupied with the care of the ill student. Older siblings may be expected to stay at home with their ill sibling as the family's economic circumstances require parents

and carers to work outside the home. Siblings' needs are different, but also arise from the experience of living with a significant illness in the family.

Siblings are here understood as **school-aged siblings**. We acknowledge that much older or younger siblings may also be affected by the experience of living daily with a significant illness, but our focus is on their needs which arise from missing school.

Significant

Illness or injury may be variously described as 'serious', '**critical**', 'chronic', or 'life-limiting'. All of these words are contestable, and different definitions are adopted by different authors and agencies to meet their own needs. Use of any of these words raises the possibility of disagreement about the nature and severity of the illness or injury.

Our focus is on neither the nature nor severity of the illness or injury but on the school absence which results from it. We have thus chosen to use the word **significant** to describe any illness or injury which has a non-negligible impact on school attendance. The definition of what is non-negligible is discussed above.

Students

In literature and casual discussion, we refer to 'children', 'adolescents', 'teenagers', 'young people', 'kids', 'students', 'learners', 'pupils', etc. We have chosen to adopt the term **students** to describe all these people. This avoids categorisation by age, and also highlights the fact that we are focusing on the dimension of their lives which revolves around school. Given this whole school focus, we are concerned with students from Foundation to Year 12.

School connection for seriously sick kids: whose job is it?

Overview of review approach

This report provides an overview of the current Australian legislation and policy addressing the educational needs of students who miss school because of significant illness or injury. It does not seek to detail whether or how these policies are implemented, although the lack of data around the numbers of students involved (refer to the accompanying *Who are they?*) suggests that this would be an extremely difficult question to address. By mapping out the legislation and policies already in place, the report seeks to highlight strengths, limitations, and gaps in provision, in comparison to theoretical practice models and approaches (as outlined and developed in the accompanying *How do we know what works?*).

There are three areas of investigation for this review: Australian Government legislation relating to equity in education, including examination of disability legislation and related Council of Australian Governments (COAG) declarations; state and territory government policies for student health and education; and hospital schooling and home-based education provisions across Australian jurisdictions.

The approach involved collaboration between ARACY, *MissingSchool* and The Royal Children's Hospital (RCH) Education Institute. The reviews of federal legislation and state and territory government policies for student health and education were undertaken and written by ARACY and *MissingSchool*. The review of hospital schooling was conducted and written by the RCH Education Institute as part of their more detailed and recently completed work on a national review.

This review has sought to identify existing policy and legislative mechanisms that are documented by agencies responsible for supporting the education of students with significant illness or injury. It is possible that the review is not exhaustive, and may be limited in the detail and depth of coverage of individual programs and approaches. Furthermore, policy and processes may have evolved or changed since the review was carried out.

It is impossible to identify or quantify informal programs of support for students with significant illness or injury. Since the responsibility of ensuring that the educational needs of all **students are met rests ultimately with the nation's government, the focus of this report is necessarily on formal and legislated mechanisms.**

Australian federal legislation

The right to a quality education

Australian society accepts that everyone has a right to education, regardless of age, ability, beliefs or personal circumstances. This right is enshrined in international human rights agreements ratified by the Australian government. The **UN Convention on the Rights of the Child** stipulates that “all children have the right to a primary education, which should be free” and that “young people should be encouraged to reach the highest level of education of which they are capable” (UNICEF, Article 28). It states that this right is held by all children, regardless of disability (UNICEF, Article 2). Furthermore, it states that children with a disability are entitled to additional care and support to ensure that their rights under the Convention are upheld (UNICEF, Article 23). This means that students with additional support needs can expect as a matter of course that additional support will be provided, and that failure to do so is a denial of their rights. In Australia, education is compulsory for children between the ages of five and at least fifteen.

Equity in education is thus the basis on which all Australian education legislation is built. The **Melbourne Declaration on Educational Goals for Young Australians 2008** was endorsed by all Australian Education Ministers and declares that access to education should be “free from discrimination based on gender, language, sexual orientation, pregnancy, culture, **ethnicity, religion, health or disability, socioeconomic background or geographic location**”. The emphasis on equity is reflected in commitments to reduce the effect of disadvantage on educational participation and attainment. The Declaration commits to collaboration across government jurisdictions, school sectors and the community to achieve educational goals for all young Australians and, where needed, more tailored and individualised support for those experiencing educational disadvantage (MCEETYA, 2008).

The recent **Commonwealth Education Act 2013** holds that all students 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”. **It stipulates that this 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”**. **The Act goes on to state that “Australian schooling will place the highest priority on identifying and addressing the needs of school students, including barriers to learning and wellbeing, and providing additional support to school students who require it”** (Australian Government, 2013).

Disability, illness and education participation

The federal legislation outlined above makes explicit mention of 'personal circumstances' and a requirement to take into account such circumstances so that all students have full and equitable access to education. This includes taking account of health situations and needs arising from significant illness or injury. These situations and needs are covered – with varying degrees of specificity – under the umbrella of 'disability' legislation, which defines disability to include illness.

The **Disability Discrimination Act 1992** (DDA) and **Disability Standards for Education 2005** define disability to include:

total or partial loss of bodily or mental functions; total or partial loss of a part of the body; presence of organisms causing or capable of causing disease or illness; a bodily malfunction or disfigurement; a disorder or malfunction that results in a person learning differently; or a **disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or results in disturbed behaviour** (Australian Government, 1992; Attorney-General's Department, 2005).

The DDA made it unlawful for education authorities and providers to discriminate against persons with disability in regard to education enrolment, access, and participation. Stemming from this, the Disability Standards for Education provide a framework for eliminating discrimination on the grounds of disability, ensuring that people with disability have access to education and educational opportunities on the same basis as the rest of the community, and promoting recognition and acceptance within the community that persons with disability have the same fundamental rights as the rest of the community (Attorney-General's Department, 2005).

The Disability Standards for Education outline five areas in which to ensure that a student with disability is treated on the same basis as a student without disability. These are: enrolment; participation; curriculum development, accreditation and delivery; student support services; and harassment and victimisation. Within each area, providers are obligated to make 'reasonable adjustment' in consultation with the student and his or her associates to allow them to participate on the same basis and without discrimination (Attorney-General's Department, 2005).

The Disability Standards for Education also outline general examples of measures that schools may put in place to facilitate access and participation of students with disability. These include accessibility and formats of materials, adjustments to course program activities, appropriate

substitute activities, additional support personnel or programs, inclusive extra-curricular activities, adjustments to assessment procedures, and policies and structures for addressing harassment and bullying. If a specialised service is required by a student to participate in school then the education provider must take 'reasonable steps' to provide the service or to facilitate provision by another person or agency (Attorney-General's Department, 2005).

In 2012, the Council of Australian Governments (COAG) detailed further actions (and related funding) to support students with disability to participate in schooling on an equitable basis without discrimination. The **National Partnership Agreement for More Support for Students with Disabilities** (MSSD) is said to "strengthen the capacity and expertise of Australian schools and teachers to provide additional support to students with disabilities, contributing to improvements in their learning experiences, educational outcomes and transitions to further education or work" (COAG, 2012). It is intended that this will be achieved by allowing states and territories to select and deliver a number of 'outputs' that address the overall objective and proposed outcomes of the Agreement. These are detailed in Table 1 below.

Table 1: More support for students with disabilities – objective, outcomes and outputs

Objective	Australian schools and teachers are better able to support students with disabilities, contributing to improved student learning experiences, educational outcomes and transitions to further education or work
Outcomes	Students with disabilities have improved learning experiences and educational outcomes
	Schools are better able to meet the educational needs of students with disabilities, in collaboration with parents, carers, and students
	Schools become more inclusive environments, recognising the diversity students with disabilities bring
	Principals and school leaders are better able to support teachers and teachers are more capable of identifying and addressing the educational needs of students with disabilities
	Teachers of students with disabilities have better access to expert support
	Through evaluation, education policymakers are informed of effective practice under this initiative and long term policy development occurs in an environment well informed about what works to improve the educational outcomes of students with disabilities
	Through evaluation, parents, carers, school leaders, school administrators, teachers and the wider community are better

	informed about effective practices and strategies that benefit the educational achievement of students with disabilities
Outputs	Providing assistive technology to support the teaching and participation of students with disabilities
	Providing training for teachers to strengthen their skills in the use of assistive technology in the classroom
	Developing support centres as centres of expertise in the educational needs of students with disabilities which provide expert support to other schools
	School coordination with health or other professionals to strengthen support for students with disabilities
	Providing training for pre-service and/or practising teachers to build their skills in special education
	Providing training for all school staff to improve understanding of obligations under the 2005 Disability Standards and how to meet these
	Supporting principals and/or leadership to strengthen teachers' ability to assist students with disabilities
	Supporting school staff to assess current level of students with disabilities and adjust curriculum programs and assessment based on their level of ability
	Supporting teachers to develop or modify lesson plans to suit the needs of students with disabilities
	Supporting teachers to meet the needs of students with disabilities through collaborative teaching practices
	Engaging teacher aides to strengthen skills in supporting students with disabilities
	Providing additional support for students with disabilities to transition effectively between stages of schooling and/or from school

The Agreement provides a framework for greater consistency and focus in the planning and delivery of inclusive schooling for students with disability. While it does not explicitly mention illness or injury, its focus on disability as defined under the DDA means that it is applicable to students whose disability is a significant illness or injury. It identifies a number of approaches to continuing education for such students; for instance, the application of assistive technology, provision of additional support, coordination with health services, professional development, and strategies to promote inclusivity. It also offers scope for flexibility in local implementation by state and territory education departments.

An important aspect of the Agreement is performance measurement. Each output to be delivered in each jurisdiction includes quantifiable performance benchmarks and indicators, and an independent national evaluation of the initiative is planned (COAG, 2012). As well as measuring the impact and outcomes from this effort, this could assist the development of best-practice evidence-based approaches to support the education of students with significant illness or injury.

One of the more visible initiatives resulting from the MSSD is the development of the Nationally Consistent Collection of Data (NCCD). Schools are asked to report annually in August on how many of their students have a disability and what adjustments are being made at school for those students. This relies heavily on the ability of schools to identify students with disability correctly, as defined under the Disability Discrimination Act which includes students with illness or injury; the 2010 review of the Disability Standards for Education made clear that this could not be assumed. Also, data for any particular student may only be included in the Collection if the school holds 10 weeks of documented evidence of disability and adjustment. This means that students whose disability has not been disclosed or documented, students for whom no adjustment is being made, and students who have been absent from school may not be included in the Collection. The NCCD is being rolled out in stages across Australia, and so robust data will not be available for some years. It is to be hoped that refinements to the process over future years will ensure that data for all students is captured and reported².

Current policy and practice supporting the education of students with significant illness or injury

Current practice in Australia to support the continuing education of students with significant illness or injury is difficult to quantify. Support may be provided within the education system either formally, in compliance with legislation, or informally as a result of the goodwill of

² For more information, see: www.schooldisabilitydatapl.edu.au

individuals. Alternatively, it may be provided from outside the system by individuals and charitable organisations. While support provided from outside the education system is particularly difficult to assess, formal and informal practice within the system is – or should be – informed by legislation, policy, processes and evidence-based programs that include robust evaluation.

School-based education

Within a framework of federal legislation and whole-of-government agreements, state and territory governments have the responsibility of setting policy for students with significant illness or injury within their jurisdiction. These are then implemented by education authorities, schools, and other relevant service providers at a local level.

Outlined below are the state and territory education policies, processes and programs applicable to continuing the education of students with significant illness or injury. These have been principally identified through documentation and resources provided on state and territory departmental websites. While every effort has been made to identify and note relevant documentation, these summaries may not be exhaustive nor fully inclusive of every practice being implemented at a local level. It is noted also that this is an outline of the legislative provisions in place, and does not evaluate the extent to which these provisions are observed or practised, or even whether they meet the student’s educational needs.

Table 2: Summary of state and territory education policies, processes and programs

<p>Australian Capital Territory</p> <p>As in many other jurisdictions, the ACT’s approach to supporting students with significant illness or injury tends to be guided by disability and special needs education policies. The Education and Training Directorate adopts a Student Centred Appraisal of Need to look at “the particular needs of each child and the support they require to access school programs and participate in the curriculum” (Education & Training Directorate, 2010). This includes some assessment of personal care needs in relation to health and wellbeing, and dietary and medical conditions. The assessment provides a basis for appraisal meetings between school staff, parents, and any other professionals who work with the student (e.g. carers), during which Individual Learning Plans (and, in some cases, Personal Health Care Plans) will be developed or assessed.</p> <p>In surveying the Directorate’s services and programs for students with a disability, little appears to be of direct relevance to children with significant illness or injury, with the exception of a hospital school based at Canberra Hospital (Education & Training Directorate, 2014). Alternatively, some students may benefit from the Healthcare Access</p>

at School (HAAS) program, which offers nurse-led care for students at school to administer health procedures and use of equipment (ACT Health, n.d.). Other standard procedures (e.g. first aid and asthma medication) may be delivered by trained staff within school.

New South Wales

The NSW Department of Education and Communities has a statement of commitment for the education of 'people with disabilities' (Department of Education and Communities [DEC], 2006). The Department also maintains a policy on Student Health in Public Schools. Similar to disability policy, this states that students are entitled to participate in education regardless of their health needs, that students should be supported to develop independence in managing their own health, and that schools should work cooperatively with parents, GPs and health and community service providers in the process (DEC, 2005).

In general, issues resulting from illness or injury are managed at the school level in collaboration with students, parents, teachers and health professionals. Schools are required to provide first aid through a trained staff member when needed, offer temporary care of unwell children and administer prescribed medications if required. Students can be assessed according to disability criteria and additional assistance and support options will then usually be facilitated by learning and support teams within the school. For students with complex health care needs or diagnosed at risk of an emergency, individual health care plans will likely be developed in order to formalise the most appropriate package of support (Dempsey, 2012; NSW Public Schools, n.d.).

Specific programs and practices in NSW are outlined in a Disability Action Plan 2011-2015. This highlights outcomes from the previous plan (2004-2010), including additional and alternative teaching resources, upgrades to school access, infrastructure and technology, professional learning programs for school staff (e.g. in asthma and health care procedures), development of inclusive curriculum and assessment practices, and updates to student welfare systems (DEC, n.d. (a)). One program noted is the Students with Disabilities in Regular Classes – Funding Support Program. This allows school principals a level of flexibility to apply for and allocate funding for additional teacher training, time, and the engagement of teacher aides based on the identified needs of targeted students. The program is contingent on student needs being identified in a student support plan or individual health care plan, and this being reappraised informally and formally on a frequent basis (DEC, n.d. (b)).

Looking forward, NSW's response to the National Partnership Agreement for More Support for Students with Disabilities appears to form the basis for emerging policies, practices, and programs aimed at inclusion and equity for students with disability, including significant illness or injury. Known as Every Student Every School, this outlines five key areas of activity: professional learning and development in special education; support for students with disability in regular classrooms through a specialist teacher presence in every

mainstream school; establishing special schools as centres of expertise; development of instruments and assessment tools to understand and support individual student learning needs; and information and resources to support teaching and learning (DEC, 2012).

Northern Territory

The Northern Territory Department of Education and Training outlines a philosophy of inclusion for students with disability, which **advocates “adjusting curriculum, assessment practices, teaching styles and the physical environment to provide for the needs of all students”** (DET, n.d.). **Definitions of disability echo those in federal Disability Standards** legislation and thus may relate to some students with significant illness or injury. Otherwise, there appear to be no obvious, clearly delineated policies for these students.

The Territory’s Special Education Support Services (SESS) package is said to offer an extensive continuum of services for students and is the basis from which student need is assessed and adjustments implemented. The service continuum involves collaboration between the school, an Initial Contact Officer and Case Manager, and any additional specialist support providers. Assessment of students for services is based on a Special Needs Profiling Instrument; while heavily focused in the behavioural, intellectual and physical disability areas, this instrument does include an assessment of health care need including aspects such as management of chronic conditions and administration of medication (DET, 2010; 2011a).

In practice, documentation suggests that the approaches adopted in the Northern Territory for students with significant illness or injury are likely to be similar to those in other jurisdictions. Individual Health-care Plans are noted in the Special Needs Profiling Instrument **and templates for these are available on the Department’s website (DET, 2011b)**. Some students may also or alternatively have an Educational Adjustment Plan, which will outline the adjustments necessary for them to continue to be educated. Typically these involve additional classroom support (e.g. teacher aides), modifications to the school environment, and modifications to curriculum delivery and assessment (DET, 2011c).

Queensland

As in other jurisdictions, the Queensland Government provides a commitment to inclusive education for all children (Department of Education, Training and Employment [DETE], 2014a), coupled with a disability policy stating that all schools should make reasonable adjustments to ensure students with disability are able to participate in education on the same basis as students without disability (DETE, 2014b).

Specific procedural guidelines are provided for the Management of Students with Specialised Health Needs (DETE, 2013). This seeks to ensure that all students with specialised health needs have access to *‘a reasonable standard of support’* for their health needs whilst attending school or being engaged in school-based activities. The guidelines offer something of a checklist for principals, school staff and parents, so that a consistent approach to health care management for students in an educational setting can be

provided. Key aspects of the guidelines include:

- clear identification and recording of health conditions on the school management system;
- identification of student health needs and determination of need for an Individual Health Plan (IHP) or Emergency Health Plan (EHP);
- instigation of actions from any IHP / EHP and regular review and updating of plans;
- training for school staff involved with students with health conditions, including for performing specialised health procedures in relation to that student;
- policies for the control and management of equipment or medication; and
- specific guidelines and plans for anaphylaxis and diabetes.

Associated with the guidelines are a number of supporting resources, one of which – a Planning Guide for Students with a Medical Condition – offers a breakdown of medical conditions and the likelihood of this requiring an IHP and / or EHP, along with key contacts for advice related to the condition (DETE, n.d.). Other documents provide procedures for developing and managing IHPs and or EHPs, accessing training and support, and requesting nursing and teacher aide support.

South Australia

Reflecting the Commonwealth Disability Standards legislation, The South Australian Department for Education and Child Development (DECD) promotes a policy of inclusive education which engages every child so that they “achieve at the highest possible level of their learning and wellbeing through quality care and teaching” (DECD, 2006). One of the main vehicles for achieving this for students with health support needs is its Disability Support Program. While this may not apply to all students with significant illness or injury, **eligibility requirements for physical disability do include a “physical condition and/or sustained illness that has significant learning, access and/or care implications”** (DECD, 2007). A related Educational Support Matrix for the Program outlines some of the health care support adjustments that schools may be required to implement to meet student needs (DECD, 2012).

More widely, health care plans and **health support plans are noted on the Department’s** website as instruments for schools to identify needs and implement strategies to support the participation of students with serious medical conditions. The health care plan appears to be initiated by parents and is completed by the student's health professional and submitted to the school.

This documents the student's emergency and routine health care needs and helps the school to determine if a health support plan is needed. The health support plan documents care and procedural responsibilities for all parties in all circumstances in all settings, and includes processes for communication, incident management, medications, staff training, and ongoing review of the plan (DECD, 2014a).

Students who are unable to attend school for prolonged or recurrent periods may qualify for Learning Support. Arrangements for such support appear to be individualised and organised in liaison between schools, parents and students. Two options for continuing schooling come via the Hospital Education Service and Open Access College. The Open Access College provides distance education through a variety of methods (telephone, online, face to face), offers specialised course booklets and customised support materials, and may include visits from teachers (DECD, 2014b).

Finally, a more integrated approach to health and education in South Australia appears to be a key aim of the Child Health and Education Support Services (CHESS). This comprises an interagency agenda focusing on policy development, information provision, training, research, service delivery and education support for children with physical or psychological health care needs. Some of the resources provided through CHESS include health support books, fact sheets, and provision of health training programs for educators (CHESS, 2005).

Tasmania

In its *Policy Driver for Health and Wellbeing*, the Tasmanian Department of Education (DoE) **states that it seeks to “ensure that all learners are provided with a safe and inclusive learning environment which supports them and allows them to strive for excellence and to reach their potential” (Department of Education [DoE], 2012a). Regarding students with disability, this may entail adjustments being made within their school, or placement at a special school in the state. Some students with significant illness or injury may be included under this arrangement, if deemed eligible for the Register for Students with Severe Disability. One criterion for eligibility is a ‘physical disability or health impairment’, which may include “an identifiable, severe medical condition or health impairment which has highly significant learning / educational implications e.g. severe uncontrolled epilepsy, severe head injury etc.” (DoE, 2013).**

The Department’s **Learner Health Care and Safety Policy outlines the responsibilities of schools (and other parties) towards student health. Among other things, this requires schools to “collaborate with parents and medical personnel to make appropriate provision for medical and health care on an individual basis, including when appropriate the development and implementation of Medical Action Plans”. It also notes responsibilities for first aid and administration of medications (DoE, 2012b).**

Other practices and programs adopted in Tasmanian schools for students with significant illness or injury are difficult to gauge from available literature. The Department does provide an overview of procedures, information and contacts for specific health issues including asthma, bleeding disorders, cystic fibrosis, diabetes, and epilepsy. Generally, the procedures for schools to follow involve the development of Medical Action Plans and, presumably, action and adjustments arising from these. However, the documentation appears to provide limited detail on this process (DoE, 2012c).

Victoria

The Victorian Government Department of Education and Early Childhood Development (DEECD) states a commitment to deliver “an inclusive education system that ensures all students have access to a quality education that meets their diverse needs” (DEECD, 2013a). This underpins policies and approaches in the area of disability and special needs education, encapsulated in its Program for Students with Disabilities. Eligibility for the program does include students with a significant physical disability and / or significant health impairment that requires regular paramedical support; however it seems unlikely to apply to all students with significant illness or injury.

The Departmental website details a number of approaches for students with significant illness or injury, stating that all children with a medical condition or illness will have a **health support plan, developed in conjunction between the school, child’s doctor and parents** (DEECD, 2013b). Applicable programs for such students may include:

- **Schoolcare Program, provided in partnership with The Royal Children’s Hospital RCH@Home Program.** This involves specialist training to school staff who deliver interventional medical care to students at school, and is available where the student would otherwise not be able to attend school without such intervention.
- Medical Intervention Support, offering funding to enable trained educational support staff to assist students who require regular, complex medical support at school.
- Accessible Buildings Program, to provide facilities that will enable students, parents and teachers with injuries or disabilities to access mainstream schools (DEECD, 2013c).
- Home-Based Education Programs, supporting schools to provide students with severe disabilities and comorbid fragile health with an educational program when they are unable to attend their enrolled school (DEECD, 2014a).
- Primary School Nursing and Secondary School Nursing Programs (PSNP, SSNP), involving school visits from health professionals to conduct health assessments, provide information and health education, and connect children and their families to community-based health and wellbeing services (DEECD, 2013d).

The Department’s policy on Curriculum **Continuity** (DEECD, 2013e) confirms that “the school in which the student is enrolled retains responsibility for the student’s curriculum when they are in hospital or recuperating at home” and notes that schools must:

- ensure continuity and relevance of the education program;
- design curriculum that allows delivery and assessment for students who need to (i) transition between hospital, home and school, and (ii) attend school part-time or

episodically; and,

- **support the student's connection to school, including** developing and maintaining social networks.

More broadly, strategies to foster inclusive education environments are evident with several resources provided for educators, parents and students, focusing predominantly on students with disability. Many of the approaches advocated would seem appropriate for the inclusion of students with significant illness or injury, although they are not explicitly stated to apply (DEECD, 2014b).

Western Australia

Western Australia's policy of inclusive education for students with disability is manifest in its *Pathways to the Future* report, which sets out recommendations to "build safe, inclusive and engaging learning environments which meet commitments to all students in government schools" (DET, 2004). One practical implementation arising from this report has been Schools Plus, which provides a framework for analysing student need and implementing adjustments in the areas of curriculum differentiation, assessment and reporting, collaborative planning, communication, social competence, health care, mobility and positioning, toileting hygiene, meal management, self-regulation and resilience, and mental health (DoE, n.d.)

With specific regard to students with serious medical conditions, the Department of Education (DoE) maintains a detailed Student Health Care Policy. This outlines procedures for identifying health care need, managing student health care, managing student health care records, dealing with medical emergencies, administration of medication, and managing specific health issues. As in other jurisdictions, the policy includes the determination of the need for a student health care plan, with specific plans available for students with allergies, asthma, diabetes, and epilepsy (seizures), as well as a generic health care plan for all other conditions (DoE, 2011).

Of particular note in the policy is the expectation on principals to "arrange provision of an educational program for students who are absent for more than ten school days due to illness," and "maintain engagement and participation of chronically ill students in an appropriate educational program" (DoE, 2011). This provision may include participation in out-of-school learning and, potentially, engagement with Schools of Special Educational Needs (more details of which are addressed in the hospital school element of this report).

A final consideration in the provision of health services for students in Western Australia is a Memorandum of Understanding (MOU) in place between the Department of Education and Department of Health. This sets out the services to be provided by the Department of Health in schools (principally through school nurses) and is jointly funded with the Department of Education. The MOU offers an example of more integrated and collaborative linkages between health and education not always clearly manifest across jurisdictions (DoE & DoH, 2014).

Reflecting COAG agreements on disability and education there is, on the whole, a high degree of commonality across states and territories in the policies adopted to support students with 'special needs'. In summary, all jurisdictions:

- support and advocate a policy of **inclusive education**, and purport to take an individual needs-based approach to education by implementing reasonable adjustments (such as classroom modifications, teacher aides, curriculum adjustments);
- have **criteria for identifying a student with additional support needs**, typically within a disability or special needs context. While their definitions of disability are consistent with the Disability Discrimination Act, they generally categorise disability as a physical, sensory, or mobility impairment or behavioural issue. Illness and injury are rarely explicitly mentioned and as such may be overlooked in planning and data collection;
- have processes for documenting individual needs and required adjustments using **personalised learning plans**. Plans are intended to be developed and monitored in liaison between affected parties including educators, health care providers and parents;
- provide (as a minimum) **basic health care services in schools**, i.e. first aid and emergency treatment procedures, administration of medication and / or equipment necessary for a student to participate in school;
- outline a consistent policy of establishing **Individual Healthcare Plans** (or similar) for students with specific medical needs; and
- have **additional funding, resources and/or programs** available to support students identified with disability and/or specific health needs. However, funding is usually dependent on whether the disability fits into a set of categories defined under the local legislation, which frequently does not include illness or injury.

Much of the state and territory legislation relating to students with significant illness or injury focuses on health needs in school, and rarely addresses the student's educational needs outside school other than to refer to hospital schools or distance education.

Probably the biggest visible limitation – and variation between states and territories – is the **level to which policy and processes specifically and directly address students who have significant illness and injury**, rather than subsuming illness in disability policy. Some jurisdictions appear to be more advanced in this respect. For instance, New South Wales has a documented public policy specifically for student health in public schools, advocating inclusion

and participation for students with illness, and promoting collaboration between schools, parents and health providers (DEC, 2005). In Queensland, documentation exists for educators to support the management of students with specialised health needs, offering a procedural checklist and guidelines in the approach to adopt for specific medical conditions (DETE, 2013; DETE, n.d.). In Victoria, the State Education Department's policy on Curriculum Continuity notes that when a student is hospitalised then the student's regular school retains responsibility for the student's education; the importance of maintaining connection between the student and the school is asserted (DEECD 2013e). Elsewhere, Western Australia is one of the few jurisdictions which has a student health policy which explicitly states a responsibility for school principals to **"arrange provision for an educational program for students who are absent for more than ten school days due to illness"** (DoE, WA, 2011).

The extent to which these policies are understood and implemented is a separate question. **Research from The Royal Children's Hospital Education Institute suggests that many students** in Victoria who miss school because of significant illness or injury have no support from their regular schools (Barnett, Hopkins, Peters, 2014). This may also be the case in other states and territories.

Programs and resources that are in place to support the learning of students with significant illness or injury within school also vary across jurisdiction, and are likely to differ in implementation at a local level. As a minimum, schools provide first aid and emergency treatment procedures, with most having access to a school nurse. Training is available for school staff to administer first aid and medication or assist in the use of medical equipment. Some jurisdictions also offer programs in which health professionals can support students within the school environment with medication, treatment and care. Access to disability programs and related funding for implementing adjustments (such as classroom modifications) is generally dependent on the student's meeting eligibility requirements for 'disability'. This is problematic for many students with significant illness or injury since most disability criteria focus on physical, sensory or mobility impairment or behavioural issues. Additionally, these are all provisions for supporting the health needs of a student who is attending school, rather than the educational needs of a student who is absent from school.

Hospital-based education

Provision of in-hospital and/or home-based learning may be available for students who experience non-negligible absence from school because of significant illness or injury. A detailed review of education services for hospitalised students has recently been finalised by **The Royal Children's Hospital Education Institute. This includes interviews with managers and**

practitioners at hospital schools across Australia (and New Zealand), to build a picture of current policies and practices in place. An overview of findings to date is outlined here, noting the main limitations and challenges with current provision. Appendix I lists hospital schools around Australia and the numbers of students who attend those schools. Differences in recording processes mean that it is again difficult to obtain firm student data, since some schools record individual students and others record individual attendance days.

Despite the patchy nature of explicit policy attention given to the issue of education support to students in hospital, in practice every state and territory in Australia (as well as New Zealand) has a program of some sort in place to address these specific educational needs. The programs vary widely between and within each jurisdiction, across domains such as age of eligibility for students, location of services, bureaucratic reporting and accountability structures, range of programs offered **and degree of liaison with students' regular schools.**

The current provisions for hospital schooling in each Australian state and territory (as well as New Zealand) are outlined below. These have been identified through documentation and resources publicly available, as well as through consultation with practitioners within a number of hospital education services. While every effort has been made to identify current approaches, these summaries may not be exhaustive nor fully inclusive of every practice being implemented at a local level. It should be noted also 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 review may not be applicable as new settings and services come into operation.

The full report on the provision of education support to students with health conditions across Australia and New Zealand can be obtained by contacting The Royal Children's Hospital Education Institute.

Table 3: Summary of provision of hospital-based education by jurisdiction

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 2.5 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 regular 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, which also provides education support to adolescent patients in 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 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 30th June in year of first enrolment, up to 18 years). Provision may be made for pre-school students on an individual or needs basis. Students enrolled in school (K–12) are eligible to enrol in the hospital school (shared enrolment with regular 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 student's illness or injury may have an impact on their 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, consisting 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 a second or third language, 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 if they are able to display school behaviours (sitting at tables, listening, taking turns to speak).

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 student's regular school.

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. 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. Darwin Hospital School also reported good access to technology, wireless internet and videoconferencing facilities to link the hospital school with the regular school and community.

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 of such a student, 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 working with students who have experienced child abuse.

Teachers in hospitals see school-aged children; however in Queensland children with disability are linked to special schools from birth, so that a pre-school aged child with disability can also be seen by the hospital school during a hospital admission. Teachers in Queensland hospital schools also reported using many more formal assessment tools than teachers in other states and having a closer alignment with state-wide 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 not yet returned to school.

South Australia

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

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), 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 assessment units across three sites, providing educational assessments but not teaching to the children in those clinics.

Education support at the **Women's and Children's Hospital in Adelaide 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 student 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 the regular 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 TRT (temporary relieving teacher) as required.

Tasmania

The Tasmanian e-school 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. E-School 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 student's regular school 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, with some students benefiting from individual tutoring.

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 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 the aim of working 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 student. Participation in education support is not compulsory – parents must opt in to the service and 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 with technology, and students have the opportunity to Skype in to lessons back at their regular 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 in-patients 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 health conditions. Students with mental health condition have a separate education service, provided by four registered schools. One of these schools works with mental health in-patients **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 in-patients and out-patients through hospitals and community 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). The SSEN:MMH provides more than 40 teaching and liaison programs in 18 different locations, one of which provides teaching opportunities to in-patients at the Princess Margaret Hospital, the specialist paediatric hospital in Perth. 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 the students' regular schools, while the school also runs an extensive program of professional learning for teachers in regular schools around common medical conditions. SSEN: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 two times 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) or over in particular circumstances, such as adult rehabilitation. The service is 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. Each student's regular school is responsible for supplying the student's curriculum, as outlined in the school's enrolment policy, while hospital teachers also assess student learning and report back to the regular school on a five-weekly (half-term) cycle.**

New Zealand

NOTE: While not a direct input into assessing 'current effort' in Australia, approaches in New Zealand offer a useful example of delivery of education services for students with serious medical conditions, and are included in the current RCH research.

Education support for students with health conditions in New Zealand is provided through three Regional Health Schools, which cover the entire country geographically. Health schools provide education to students in hospital, as well as at home, in the community 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 student's 5th birthday until the end of the year s/he turns 19). Health School teachers are responsible for liaising with the student's regular 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 the student's regular school for students in years 0-10 early in the student's 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 the student's regular school.

Technology is extensively used by the health schools to connect remote students to regional support centres and facilitate video conferencing of tutorial sessions.

Some characteristics of hospital-based education support are common across all Australian jurisdictions:

- education support is provided in major hospitals (although not necessarily in smaller or regional hospitals) for long-stay hospital in-patients, either in classrooms or through ward-based services; and
- hospital schools are expected to liaise with the student's regular school for curriculum, assessment and reporting purposes, although in practice, and for a variety of complex reasons, this does not always happen.

Other characteristics may vary and include:

- The amount of supervised teaching or class time allocated to students.
- The level of support provided to the sibling of an in-patient. Some siblings may have access to classroom teaching in the hospital school, others may be referred to a local school.
- The length of time for which the hospital school will support a sibling of an in-patient.
- The age at which students are accepted into the school. This is dependent on the state in which the hospital is located and can be problematic for rural or regional students who are referred to a metropolitan hospital in a different State or Territory.

Most of the hospital education services also report that their assessment of students is informal and anecdotal, although provision is made for students to undertake assessment from their regular school if required, or to sit national or state authority testing such as NAPLAN and senior school certificates. This lack of accountability in monitoring student progress is cause for concern, given that this population of students is already at risk of long-term educational disadvantage.

Limitations and challenges

For nearly all the areas covered in this research (though not Western Australia or New Zealand), a major issue for those who work to support the education of students with significant illness or injury 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 exists in this gap, including support from regular and hospital schools, or enrolment in distance education and private tuition, such services are

generally uncoordinated and available 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. Some states will permit a dual enrolment in which two schools **cooperate to meet a student's needs; most do not. Private tuition may be available as an option to those students whose families can afford it.**

The widespread development and implementation of the Australian Curriculum offers an opportunity to increase the consistency of educational content across diverse learning settings. However for hospital schools there remain **discrepancies in approach between schools** which carefully adhere to the Australian Curriculum and those which offer more flexible, individual and personalised approaches, focusing on engagement in education rather than mandated curriculum content.

The **divide between students with mental health conditions and those with significant illness or injury**, and the differing level of education support available to each cohort is also highlighted in several jurisdictions. While the bigger hospital schools 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 a separate school, which operates independently from the education support in the same hospital for students with significant illness or injury. In smaller settings, students with significant illness or injury may be in the same classroom as those with mental health conditions, despite different therapeutic approaches to education for these cohorts. A further discrepancy is clear in the definition of mental health conditions. In some states, for example, students with eating disorders are treated in the mental health unit, whilst in other states they are seen in general medical wards.

Eligibility for service varies by state according to whether the student is enrolled in **education and the level of education at which they are enrolled. At The Royal Children's Hospital in Victoria**, all students are seen, regardless of the level at which they are enrolled. In New South Wales the student must be already enrolled in a K–12 school in either the government, Catholic or independent sector; pre-schoolers, TAFE and university students and young people who have left school early, are not eligible for enrolment. 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.

Almost all providers of education support who operate in hospitals report **difficulties in using new digital technologies** to connect students with their regular schools and peers. 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 are frequently mentioned as obstacles to the more extensive use of internet enabled devices to support both learning while out of the classroom and social connections with friends, peers and classmates.

A further issue for many hospital education services is 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 authority while located in a health department physical space, and in many cases in the absence of any clear policy or documentation to govern the way this is managed.

Distance education

Distance education is sometimes offered as an alternative for students who are unable to attend school because of medical conditions. Provisions have not been catalogued here on a state-by-state basis, but the arrangement generally partners students with teachers who work one-on-one with the student to address academic learning needs. Advances in information and communication technologies have meant that these partnerships are no longer restricted to weekly work packages, but can now be based on a multitude of quick and informal interactions between student and teacher every day.

To be successful, distance education relies heavily on parental involvement and support to maintain continuity. For parents who choose to accept this responsibility, it can be an efficient and effective option. However, for parents who are already managing the responsibility of caring for a child with a significant illness or injury, it becomes another task to be undertaken which may not be of their choosing and which is not required of other parents.

Because of the one-on-one design linking students with teachers, distance education does not usually include opportunities to connect the student with his or her peers in their regular school. Some students may be willing to overlook this limitation, but for students whose school engagement, motivation and emotional wellbeing depend on participation in their learning community, replacing this community with a single channel to teacher assistance is unlikely to generate enthusiasm.

For this reason, distance education is only infrequently adopted as a support measure for students whose illness or injury prevents them from attending their regular school.

Alternative programs and sources of support

Outside the public education and health sector, support for students with significant illness or injury may be available through non-government and charitable organisations. Examples include *Back on Track*, operated by the Fight Cancer Foundation, the *Ronald McDonald Learning Program*, operated by Ronald McDonald House Charities, and RedKite's provision of scholarships and financial assistance to support students with cancer. These programs provide individual tutoring to students who have missed school because of significant illness or injury, but availability is variable; some are provided in hospital, others are provided only once the student has returned to school. All these programs are intended to fill the gap in school-based provision, but they are neither monitored nor evaluated by state education authorities.

There are likely to be many other informal and undocumented approaches that are being implemented with students who face education disruption because of significant illness or injury. Anecdotal feedback suggests parents or carers and other family members often play a role in attempting to 'bridge the learning gap' arising from missed schooling; and also that this can be an overwhelming additional burden on parents who are already managing the stress of dealing with their child's significant illness or injury. Schools and educators themselves may be offering unique, tailored support on top of what is mandated (e.g. additional tuition provided voluntarily by one teacher). Community groups and charities may also play a role in maintaining learning and connections through various programs and schemes related to literacy, reading, numeracy etc., or providing things like transportation, child care for siblings, youth groups and parental support.

All of this 'undocumented effort' is something which is impossible to capture in ascertaining what currently takes place in Australia to support students with significant illness or injury to continue education. However, it strongly indicates a gap in formal provision and the reach and efficacy of legislated and regulatory practices.

How does current effort fare in relation to theoretical models and approaches for effective practice?

The accompanying *How do we know what works?* set out to identify 'best practice' models and approaches towards continuing education participation and connection for students with significant illness or injury. However, with limited robust evaluation of 'what works' in this field, it was not possible to develop a single, strongly-evidenced 'ideal' model. Nonetheless, the report draws on lower-level evidence (e.g. case studies, qualitative research, self-report

surveys) and the weight of literature outlining common approaches and strategies to propose a theoretical framework for practice.

The theoretical framework reflects the emphasis on educational **inclusion and equity**, with this positioned as an overarching, long-term outcome for students with significant illness or injury. While this report shows that inclusion and equity are strongly represented in Australian legislation, this is not always observed in practice for students with significant illness or injury. The question arises as to whether these students really do have equal opportunity of access, particularly if they do not qualify for funding support under 'disability' criteria and are not in a jurisdiction with clear and explicit approaches and interventions for students with significant illness or injury.

The variability in provision for these students across (and within) states and territories leads to a situation of inequity. The cohort seems to have been invariably overlooked in any educational initiative, to the extent that there is no reliable data even around how many students miss school because of significant illness or injury, as noted in the accompanying *Who are they?* In the absence of any detailed knowledge of the cohort, it is impossible to ascertain whether or not the measures which are intended to support them are effective let alone being implemented.

A positive dimension to current practice which reflects that proposed in the theoretical framework developed is the **individualisation** of approaches to supporting students with particular needs (including those arising from significant illness or injury) and the **flexibility** that this entails. This is good teaching practice in any setting, and is embedded in the inclusive education legislation which advocates an individual, needs-based approach. It typically manifests in personalised learning plans and/or medical safety plans. However, while all jurisdictions have policies in place to recommend individual planning arrangements in schools for students with particular learning needs, some researchers have noted limitations with how these have been adopted in practice. Concerns arise around the inconsistent use of plans, and the perception of these as an administrative requirement to keep stakeholders happy, rather than something that actually helps (Dempsey, 2012; Shaddock, et al., 2009).

Medical plans address a student's physical wellbeing, and operate when the student is physically present in the school and the school has responsibility for the student's physical safety. However, risks to a student's mental and emotional wellbeing, which can persist beyond the physical boundaries of the school, are more readily addressed in a personalised learning plan. As a risk management tool, medical plans alone may be insufficient to manage all risks to a student's wellbeing.

Noting the inconsistency in the use of personalised learning plans, the 2012 Commonwealth review of the Disability Standards for Education recommended that they be mandated, rather than optional, for all students with disability; under the DDA, any illness or injury, no matter its nature, severity or duration, is considered to be a disability. The same review noted a widespread lack of familiarity with the Disability Standards for Education and recommended also that all state and territory governments work to raise awareness and understanding of this legislation amongst education users and providers (Department for Education, Employment and Workplace Relations, 2012).

The theoretical framework also advocates for ongoing **collaboration** between various stakeholders; for instance, involvement of health practitioners in developing personalised learning plans and working with students in school settings, and participation of educators within health, hospital and home environments. Current efforts in Australia suggest that this can happen but can also be challenged by discrepant operational parameters, such as having Education Department staff working in a Health Department (e.g. hospital) setting, and vice versa. Developments such as the Memorandum of Understanding between the Education and Health departments in Western Australia (DoE & DoH WA, 2014) and the inter-agency Child Health and Education Support Services in South Australia demonstrate promise in developing more integrated approaches addressing both education and health needs (CHESS, 2005).

However, in general, the linkage between health and education sectors is problematic and often patchy. For example, in NSW, the gap between the health and education sectors is evident in the fact that Ronald McDonald House Charities has funded the appointment of Education Liaison Coordinators **in some major children's hospitals. The role of the Education Liaison Coordinator is to facilitate connection between the Hospital School and the student's regular school**, which, despite nominally falling under the same governmental authority, can struggle to maintain open communication because one operates in a health setting and the other in an educational setting.

A key approach outlined in the theoretical framework is in providing students with significant illness or injury an integrated **continuum of learning and support experiences** when the student is facing a non-negligible absence. In Australia, this is variable and dependent on availability and delivery of alternative education provision. Hospital school services, where they exist in hospitals, vary widely in terms of accessibility and eligibility and the nature of learning **and tuition provided. Maintenance of connection and contact with a student's regular school** occurs in some hospital school programs but appears limited in others. In Victoria, despite the Education Department's policy that the student's regular school retains responsibility for the education of students who are hospitalised, research from the RCHEI confirms that many

students with significant illness or injury have limited to no contact with their regular schools (Barnett, Hopkins and Peters, 2014). Use of technology to maintain connectedness and consistency of learning experiences is also patchy, and subject to operational challenges.

One of the biggest gaps in current practice comes about when a student is neither attending a regular school, nor hospitalised with access to the hospital school, but is recovering at home. At present there is **no nationally standardised provision, nor are there nationally consistent procedures** in place for continuing the learning of a student in this situation. Typically, arrangements are ad hoc, and vary depending on where the student lives (urban, rural or remote), access to charitable support, and how active various parties (parents, teachers, and health care workers) are in setting up and implementing ongoing learning opportunities (Barnett, Hopkins & Peters, 2014).

Similarly, there is wide variability in how transitions between home, regular school and the hospital school are managed. While there is provision for **transition planning** in some state and territory policies, there is limited guidance on what transition planning might require and **how students' needs might be addressed. This report has not considered transition planning in detail, but acknowledges it as a further area of concern for students who miss school because of serious illness or injury.**

Recommendations

Opportunities for greater alignment of effort

It is important to acknowledge the current efforts that do take place in Australia to support students who face education disruption due to significant illness or injury. There is undoubted goodwill and there are some determined efforts made by individuals, organisations, schools and communities to ensure that these students remain connected to education and learning. The principles of good teaching, using a student-centred approach, apply in all settings, whether at a regular school, or in a hospital or community setting.

At a systems level, there is a widely accepted philosophy of educational inclusion and equity, although it is not clear that this transpires consistently in practice. The systems which aim to identify and support students on an individual needs basis are heavily dependent on the **school's ability to identify those students** who need support and the nature of support needed; however, this has already been seen to be inadequate, given the difficulty in establishing metrics on such students (see *Who are they?*).

Through reviewing the current policies and identifying their limitations, observations for improvements can be made. There are many barriers and challenges to be addressed, and this report does not seek to solve these or provide all the answers; rather, it is a means of generating informed dialogue about next steps. Certain areas that should be examined include:

- **National legislation, state / territory policies and procedures**
Having national legislation specific to the needs of students with significant illness and injury, mirrored by policies and procedures developed at the state and territory level to explicate the processes to support such students. These should be clearly communicated to educators, parents, students and other stakeholders, and their implementation monitored through regular review and reporting.
- **A separate policy area**
Developing specific policy for students with significant illness or injury, and not merely subsuming this into disability.
- **Data collection**
Formalising health and education data linkage and collection processes to allow for improved monitoring and research of the number of students with significant illness or injury, the extent of their absence, and to determine support needs and resources

accordingly.

- **Legislated entitlement to ongoing support**
Ensuring that funding, infrastructure, resources and staff development opportunities are available to support the additional needs of students with significant illness or injury as a legislated entitlement. This should recognise that there may be a continuing need for educational and learning support **across the student's school life whether the illness is ongoing, or whether the student has recovered from the illness or injury leading to the absence.**
- **Health initiatives and services in educational settings**
Advancing health initiatives and health services within school settings to support awareness and management of illness, managing environmental barriers to attendance, and enhancing integration of education and health services.
- **Educational initiatives in healthcare settings**
Advancing educational initiatives within medical settings to promote understanding amongst medical staff of the importance of the child's education and learning needs, and wellbeing and identity as a student or learner.
- **Formalise links between healthcare and education sectors**
Formalising linkages between the healthcare and education sectors in order to develop a **cohesive, integrated education model that maintains students' connections with their regular schools, and making explicit the legislated responsibility of schools to support the education of all their students.**
- **Information / communication technology (ICT)**
Incorporating and facilitating the use of information and communication technology as an **integral part of learning, allowing for remote education and 'virtual' presence** within school.
- **Formalise roles and responsibilities**
Formalising the roles and responsibilities of all parties, including parents and carers, in supporting students with significant illness or injury.

Current legislation and policy provides a framework for practice to support students with significant illness or injury to continue their education. However, more – and more targeted – effort is needed to ensure that the students who need this support actually have access to it. Critically, this will mean improving collaboration between stakeholders and jurisdictions, and developing integrated, systemic processes for students with significant illness or injury, so that

all may benefit from appropriate intervention rather than relying on the lottery of people, places and processes available to them at any one time.



Appendix I: Numbers of students seen in hospital schools

School/ education provider	Number of students		
	Students seen per day	Students seen per week	Annual enrolment
ACT:			
Canberra Hospital School	6–8 per day		
NSW:			
Bankstown Hospital School			577 (2012 figure)
Illawarra Hospital School			756 (2012 figure)
John Hunter Hospital School			2314 (2012 figure)
Liverpool Hospital School			678 (2012 figure)
Royal Far West School			1500 (2012 figure)
Royal North Shore Hospital School			803 (2012 figure)
St George Hospital School		Average of 31 per week	
Sutherland Hospital School		Average of 18 per week	
Sydney Children’s Hospital School			Over 4250 in 2013
Westmead Hospital School	Average of 104 per day		
NT:			
Royal Darwin Hospital School			Approximately 1000 students per year
Alice Springs Hospital School	No data available		
Qld:			
Mater Hospital School			1213 (2012 figure)
Royal Children’s Hospital	Average of 73 students per day		
Cairns Hospital Class (Woree State High School)	Average of 6 students per day		
Townsville Hospital Class	No data available		

Logan Hospital Class	No data available		
Robina Hospital Class	No data available		
Southport Hospital Class	No data available		
Toowoomba Hospital Class	No data available		
SA:			
Hospital Education Service	Up to 14 per day in classrooms		
Tas:			
eSchool	Average 10 students per day		
Vic:			
The Royal Children's Hospital Education Institute	60 per day		
Austin Hospital School			468 (2012 figure)
Monash Children's Hospital	8–12 per day		
Travancore School	No data available		
Avenues Education centre	No data available		
Baltara School	No data available		
WA:			
SSEN: MMH			4149 (2009 figure)
NZ:			
Northern Regional Health School			Over 2000 annually
Central Regional Health School	No data available		
Southern Regional Health School	No data available		

Please note that due to differences in enrolment and administrative practices, the figures in this table are not comparable between different educational settings. The table does not take account of significant variation in the size of the hospital and number of paediatric admissions, nor the different services which different students receive (direct teaching and learning, consultation, communication with regular school).

References

ACT Health (n.d.). *Healthcare access at school*. Retrieved from:

<http://health.act.gov.au/health-services/community-based-health-services/women-youth-children-health-services/school-health/healthcare-access-at-school-haas>

Adams, D. (1978). *The Hitchhiker's Guide to the Galaxy*. New York: Random House USA Inc .

Attorney-General's Department (2005). *Disability standards for education*. Canberra: Attorney-General's Department.

Australian Government (1992). *Disability discrimination act 1992*. Act No. 135, 1992.

Australian Government (2013). *Australian education act 2013 – An act in relation to school education and reforms relating to school education, and for related purposes*. Act No. 67, 2013.

Barnett, T., Hopkins, L. & Peters, S. (2014). *What happens when they go home? An investigation of education support for students following discharge from the RCH*. Melbourne: RCH Education Institute.

Child Health and Education Support Services (CHESS) (2005). *Statement of collaborative intent*. Retrieved from: www.chess.sa.edu.au/statement_collab_intent_221106.pdf

Council of Australian Governments (COAG) (2012). *National partnership agreement for more support for students with disabilities*. Retrieved from: www.federalfinancialrelations.gov.au/content/npa/education/more_support_for_student_with_disabilites/national-agreement.pdf

Dempsey, I. (2012). The use of individual education programs for children in Australian schools. *Australasian Journal of Special Education*; 36(1), 21-31.

Department for Education and Child Development, SA (2006). *Students with disabilities policy*. Retrieved from: www.decd.sa.gov.au/speced/pages/specialneeds/policy/?reFlag=1

Department for Education and Child Development, SA (2007). *Disability support program – 2007 eligibility criteria*. Retrieved from: www.decd.sa.gov.au/docs/documents/1/DisabilitySupportProgra-1.pdf

Department for Education and Child Development, SA (2012). *Educational support matrix – adjustments to support student learning and achievement*. Retrieved from: www.decd.sa.gov.au/speced/files/pages/dsp/Final_16611_DECD_Support_M.pdf

Department for Education and Child Development, SA (2014a). *Health issues and health plans*. Retrieved from: www.sa.gov.au/topics/education-skills-and-learning/health-wellbeing-and-special-needs/health-conditions/health-issues-and-health-plans

Department for Education and Child Development, SA (2014b). *Children who are unable to attend school due to illness or injury*. Retrieved from: www.sa.gov.au/topics/education-skills-and-learning/health-wellbeing-and-special-needs/school-services/non-attendance-illness-or-injury

Department for Education, Employment and Workplace Relations (2012). *Report on the review of disability standards for education 2005*. Canberra: Author.

Department of Education, TAS (2012a). *Policy driver for health and wellbeing*. Retrieved from: <https://www.education.tas.gov.au/documentcentre/Documents/Policy-Driver-Health-and-Wellbeing.pdf>

Department of Education, TAS (2012b). *Learner health care and safety policy*. Retrieved from: <https://www.education.tas.gov.au/documentcentre/Documents/Learner-Health-Care-and-Safety-Policy.pdf>

Department of Education, TAS (2012c). *Specific health issues: Procedures, information and contacts*. Retrieved from: <https://www.education.tas.gov.au/documentcentre/Documents/Specific-Health-Issues-Procedures.pdf>

Department of Education, TAS (2013). *Register of students with severe disabilities*. Retrieved from: <https://www.education.tas.gov.au/documentcentre/Documents/Register-of-Students-with-Severe-Disabilities.pdf>

Department of Education, WA (n.d.). *Schools plus*. Retrieved from: www.det.wa.edu.au/schoolsplus/detcms/portal/

Department of Education and Communities, NSW (2005). *Student health in NSW public schools: A summary and consolidation of policy*. Retrieved from:

https://www.det.nsw.edu.au/policies/student_serv/student_health/student_health/PD20040034.shtml

Department of Education and Communities, NSW (2006). *People with disabilities - statement of commitment*. Retrieved from:

https://www.det.nsw.edu.au/policies/general_man/general/spec_ed/PD20050243.shtml

Department of Education and Communities, NSW (2012). *Every student, every school*. Sydney: NSW Department of Education and Communities.

Department of Education and Communities, NSW (n.d. (a)). *Disability action plan 2011-2015*. Retrieved from:

https://www.det.nsw.edu.au/media/downloads/strat_direction/strat_plans/disaplan.pdf

Department of Education and Communities, NSW (n.d. (b)). *Funding support: Students with disabilities in regular classes*. Retrieved from:

www.schools.nsw.edu.au/media/downloads/schoolsweb/studentssupport/programs/disability/supportdocument.pdf

Department of Education and Department of Health, WA (2014). *Memorandum of understanding for the provision of school health services for school students attending public schools during the period 1 July 2010 to 30 June 2013*. Retrieved from:

<http://www.det.wa.edu.au/studentssupport/behaviourandwellbeing/detcms/navigation/wellbeing/student-health-care/?page=10&tab=Main#toc10>

Department of Education and Early Childhood Development, VIC (2013a). *Program for students with disabilities – guidelines for schools 2014*. East Melbourne.

Department of Education and Early Childhood Development, VIC (2013b). *Medical conditions*. Retrieved from:

www.education.vic.gov.au/school/parents/health/Pages/medicalconditions.aspx

Department of Education and Early Childhood Development, VIC (2013c). *Supplementary Programs: Supporting Students with Specific Needs*. Retrieved from:

www.education.vic.gov.au/about/programs/needs/Pages/programsupp.aspx

Department of Education and Early Childhood Development, VIC (2013d). *School nurses*. Retrieved from: www.education.vic.gov.au/school/teachers/health/Pages/nurses.aspx

Department of Education and Early Childhood Development, Victoria (2013e). *School policy and advisory guide: Curriculum continuity*. Retrieved from: www.education.vic.gov.au/school/principals/spag/health/Pages/continuity.aspx

Department of Education and Early Childhood Development, VIC (2014a). *Home based educational programs*. Retrieved from: www.education.vic.gov.au/about/programs/needs/pages/homebased.aspx

Department of Education and Early Childhood Development, VIC (2014b). *Resources*. Retrieved from: www.education.vic.gov.au/school/teachers/teachingresources/diversity/Pages/swdresources.aspx

Department of Education and Training, NT (n.d.). *DET philosophy of inclusion for students with a disability*. Retrieved from: www.education.nt.gov.au/_data/assets/pdf_file/0005/11678/DET_PhilosophyOfInclusion.pdf

Department of Education and Training, NT (2010). *Special needs profiling instrument*. Retrieved from: www.education.nt.gov.au/_data/assets/pdf_file/0007/9799/SpecialNeedsProfilingInstrumentInfo.pdf

Department of Education and Training, NT (2011a). *Special education support services information package*. Retrieved from: www.education.nt.gov.au/_data/assets/pdf_file/0006/16656/SpecialEducSupportServicesInfo.pdf

Department of Education and Training, NT (2011b). *Student's health care plan*. Retrieved from: www.education.nt.gov.au/_data/assets/word_doc/0003/768/StudentHealthCarePlan.docx

Department of Education and Training, NT (2011c). *School guidelines and procedures: Students with disabilities policy*. Retrieved from: www.education.nt.gov.au/_data/assets/pdf_file/0019/26722/StudentsWithDisabilitiesGuidelines.pdf

Department of Education and Training, WA (2004). *Pathways to the future: A Report of the review of educational services for students with disabilities in government schools*. East Perth: Department of Education and Training.

Department of Education, Training and Employment, QLD (2013). *Management of students with specialised health needs*. Retrieved from: <http://ppr.det.qld.gov.au/education/management/Pages/Management-of-Students-with-Specialised-Health-Needs.aspx>

Department of Education, Training and Employment, QLD (2014a). *Inclusive education policy statement*. Retrieved from: <http://education.qld.gov.au/schools/inclusive/index.html>

Department of Education, Training and Employment, QLD (2014b). *Disability policy*. Retrieved from: <http://education.qld.gov.au/schools/disability/index.html>

Department of Education, Training and Employment, QLD (n.d.). *Planning guide for students with a medical condition*. Retrieved from: <http://ppr.det.qld.gov.au/education/management/Procedure%20Attachments/Management%20of%20Students%20with%20Specialised%20Health%20Needs/Planning%20Guide%20for%20Students%20with%20a%20Medical%20Condition.DOCX>

Dockett, S. (2004). 'Everyone was really happy to see me!' – The importance of friendships in the return to school of children with chronic illness. *Early Childhood Australia*, 29(1), 27-32.

Donnan, B. & Webster, T. (2011). *Inquiry into the transition support for students with additional and/or complex needs and their families. Submission to the NSW Parliament*. Westmead: Ronald McDonald House Charities.

Education and Training Directorate, ACT (2010). *Student centred appraisal of need: Booklet for parents, carers and staff*. Retrieved from: www.det.act.gov.au/_data/assets/pdf_file/0012/20127/Student_Centred_Appraisal_of_Need_-_Appraisal_booklet_for_Parents_Carers_and_Staff.pdf

Education and Training Directorate, ACT (2014). *Services for students with a disability*. Retrieved from: www.det.act.gov.au/school_education/disability_education

Lavoipierre, J. (2012). *Strategies to support the learning of students with serious medical conditions in rural areas*. Bathurst: All Saints College

Ministerial Council on Education, Employment, Training and Youth Affairs (MCEETYA) (2008). *Melbourne Declaration on Educational Goals for Young Australians*. Melbourne.

NSW Public Schools (n.d.). *Supporting students: Disability, learning and support*. Retrieved from: www.schools.nsw.edu.au/studentsupport/programs/disability.php

Porter, L. (2008). *Teacher-parent collaboration*. Melbourne: ACER Press.

Shaddock, A., MacDonald, N., Hook, J., Giorcelli, L. & Arthur-Kelly, M. (2009). *Disability, diversity and tides that lift all boats: Review of special education in the ACT*. Chiswick NSW: Service Initiatives.

Shaw, S.R. & McCabe, P.C. (2008). Hospital-to-school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools; 45* (1), 74-87.

Shiu, S. (2001). Issues in the education of students with chronic illness. *International Journal of Disability, Development and Education; 48*(3), 269-281.

Shiu, S. (2004). Maintaining the thread: Including young children with chronic illness in the primary classroom. *Early Childhood Australia, 29* (1), 33-38.

UNICEF (n.d.). *Fact sheet: A summary of the rights under the Convention on the Rights of the Child*. Retrieved from: www.unicef.org/crc/files/Rights_overview.pdf

Whiteford, C.M. (2010). *Children with special health care needs: Social and learning competence in the early years*. Brisbane: Queensland University of Technology.

Wilkie, K.J. (2012). **'Absence makes the heart grow fonder'**: Students with chronic illness seeking academic continuity through interaction with their teachers at school. *Australasian Journal of Special Education, 36*(1), 1-20.



aracy.org.au