Taking Responsibility:

Preventing educational disadvantage for seriously sick kids experiencing school absence

Review of Current Practice
# Document Details

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<thead>
<tr>
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<tbody>
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</tbody>
</table>
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table of Contents</td>
<td>4</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>7</td>
</tr>
<tr>
<td>Acronyms</td>
<td>8</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>9</td>
</tr>
<tr>
<td>Key findings:</td>
<td>9</td>
</tr>
<tr>
<td>Introduction</td>
<td>10</td>
</tr>
<tr>
<td>What is the problem?</td>
<td>10</td>
</tr>
<tr>
<td>What does this review do about the problem?</td>
<td>11</td>
</tr>
<tr>
<td>Absence</td>
<td>13</td>
</tr>
<tr>
<td>Non-negligible absence</td>
<td>14</td>
</tr>
<tr>
<td>Collaboration</td>
<td>14</td>
</tr>
<tr>
<td>Inter-agency collaboration</td>
<td>15</td>
</tr>
<tr>
<td>Educational disadvantage</td>
<td>15</td>
</tr>
<tr>
<td>Good/better/best practices</td>
<td>16</td>
</tr>
<tr>
<td>Illness/injury/disease/health condition</td>
<td>18</td>
</tr>
<tr>
<td>Significant illness or injury</td>
<td>18</td>
</tr>
<tr>
<td>Wicked problems</td>
<td>18</td>
</tr>
<tr>
<td>Method</td>
<td>20</td>
</tr>
<tr>
<td>Evaluation Method</td>
<td>20</td>
</tr>
<tr>
<td>Orientation</td>
<td>24</td>
</tr>
<tr>
<td>What’s currently happening?</td>
<td>26</td>
</tr>
<tr>
<td>Australian and International Examples:</td>
<td>26</td>
</tr>
<tr>
<td>Australia:</td>
<td>27</td>
</tr>
<tr>
<td>International</td>
<td>44</td>
</tr>
<tr>
<td>What is working?</td>
<td>51</td>
</tr>
<tr>
<td>Policy and Standards Hierarchy</td>
<td>51</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>51</td>
</tr>
<tr>
<td>Good and Better Practice</td>
<td>51</td>
</tr>
<tr>
<td>Inter-agency Collaboration</td>
<td>51</td>
</tr>
</tbody>
</table>
Communication .................................................................................................................. 53
Place .................................................................................................................................. 54
Student experience when it works ..................................................................................... 55
What isn’t working? .............................................................................................................. 58
Policy and Standards Hierarchy .......................................................................................... 59
Theoretical Framework ......................................................................................................... 59
Flow-on effects ..................................................................................................................... 59
Absence Management .......................................................................................................... 59
Data collection and evaluation .............................................................................................. 60
Inclusive practice ................................................................................................................... 60
Reliance on outside providers ............................................................................................... 62
Informal arrangements .......................................................................................................... 62
Personalisation ........................................................................................................................ 63
Place .................................................................................................................................... 64
Silos ....................................................................................................................................... 64
Student experience when it doesn’t work............................................................................. 65
What could be improved? ....................................................................................................... 67
Policy and Standards Hierarchy .......................................................................................... 67
Theoretical Framework ......................................................................................................... 67
Other Areas for Improvement ............................................................................................... 68
Collaboration ........................................................................................................................ 68
Data collection and evaluation .............................................................................................. 71
Formal inclusion processes .................................................................................................... 72
National Policy and Standards Hierarchy .............................................................................. 72
Funding ................................................................................................................................. 73
Place-based Programs .......................................................................................................... 73
Practitioner Education .......................................................................................................... 74
Student and parent voice ...................................................................................................... 74
Student experience when systems are improved ................................................................. 75
What is the lived experience of students when all of the elements discussed in this section are improved? ........................................................................................................ 75
What is the lived experience of students when any one of the elements in the theoretical framework is improved?

Conclusion

Appendix One

Definitions and Key Terms

Disability

Engagement

Enrolment/registration/participation/attendance

Regular school

School

Silo Mentality

Appendix Two

Policy and Standards Hierarchies

Appendix Three

Summary of Current Practice by Jurisdiction

ACT

New South Wales

Northern Territory

Queensland

South Australia

Tasmania

Victoria

Western Australia

References
Acknowledgements

ARACY acknowledges with gratitude the important work of MissingSchool in establishing a voice for the cohort of Australian students who experience absence from school due to serious illness or injury. Thanks to the work of MissingSchool there is now a national conversation about the policy and service reforms necessary to ensure these students remain connected to their learning and schooling.

This project builds on the findings of the 2015 report, *School connection for seriously sick kids*, which was commissioned and co-authored by MissingSchool.

ARACY also acknowledges the continued generous contribution of MissingSchool throughout the current project. MissingSchool have shared their Theory of Change, which informs the context and applications of systems architecture used in this project. The methodology to identify the structural gaps in current Australian policy and practice, through the Policy and Standards Hierarchy, was introduced by Megan Gilmour, Cofounder and Chair of MissingSchool.

ARACY thanks the many individuals and organisations who contributed to this work, whether through membership of the Project Advisory Group, as critical friends, or in response to requests for information.
## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Curriculum, Assessment and Reporting Authority</td>
<td>ACARA</td>
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<td>Australian Research Alliance for Children and Youth</td>
<td>ARACY</td>
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<td>Centre for Community Child Health</td>
<td>CCCH</td>
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<td>Department of Education and Child Development, South Australia</td>
<td>DECD</td>
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<td>Disability Discrimination Act</td>
<td>DDA</td>
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<td>Disability Standards for Education</td>
<td>DSE</td>
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<td>Education Queensland</td>
<td>EQ</td>
</tr>
<tr>
<td>Healthcare Access at School</td>
<td>HAAS</td>
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<td>Healthy Schools Campaign</td>
<td>HSC</td>
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<td>Healthy Students, Promising Futures</td>
<td>HSPF</td>
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<td>Individual Education Plan</td>
<td>IEP</td>
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<td>Individual Learning Plan</td>
<td>ILP</td>
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<tr>
<td>Lady Cilento Children’s Hospital School</td>
<td>LCCHS</td>
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<td>Liaison, Education, Transition and Support</td>
<td>LETS</td>
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<td>Memorandum of Understanding</td>
<td>MoU</td>
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<td>Monkey in My Chair</td>
<td>MiMC</td>
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<td>National Collaborative on Education and Health</td>
<td>NCEH</td>
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<td>Nationally Consistent Collection of Data on School Students with Disability</td>
<td>NCCDSSD</td>
</tr>
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<td>National Disability Insurance Scheme</td>
<td>NDIS</td>
</tr>
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<td>On the same basis: Implementing the Disability Discrimination Act Standards for Education</td>
<td>OTSB</td>
</tr>
<tr>
<td>Queensland Health</td>
<td>QH</td>
</tr>
<tr>
<td>Northern Regional Health School</td>
<td>NHS</td>
</tr>
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<td>Regional Health School</td>
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<td>School of Special Educational Need: Medical and Mental Health</td>
<td>SSEN:MMH</td>
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<td>State School Nursing Service</td>
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</tr>
</tbody>
</table>
Executive Summary

Every school day, in any given school across Australia, a significant number of children and young people will be absent. For some of these students, the absences are frequent and/or lengthy due to illness or injury, and their capacity to fully access and engage with their education is compromised. While numerous legislative protections require schools to provide these students with access to education on the same basis as their peers, the barriers to effective participation are many. The education and health systems are not responding in ways that prevent educational disadvantage.

This review provides an overview of current policy and practice in Australia in response to the barriers to educational access presented by chronic or frequent (non-negligible) school absence. In particular, it focuses upon the intersections between the health and education systems, and how jurisdictions are working to build cooperation across and between organisations.

The review maps current legislative responsibilities and the resulting policies, frameworks and procedures that are in place to ensure equity of access to education for all students, including those who are experiencing non-negligible absence due to illness or injury. The appendices include a detailed examination of the policy and standards hierarchies of all Australian educational jurisdictions.

Key findings:

- there is Commonwealth, State and Territory legislation mandating the inclusion of all students in quality education
- there is no consistent data collection regarding the number of children and young people who are frequently or chronically absent from school due to illness or injury
- policies, frameworks and practices are not systematically established to ensure students with significant illness or injury are provided with the educational access and inclusion required by legislation
- some jurisdictions, and within them some organisations, are providing some support for students with significant illness and injury. However, the gap remains wide between current practice and ideal systematic responses to ensure students do not face educational disadvantage due to absence as a result of illness or injury.
Introduction

In Australia, and around the world, the numbers of students who experience significant illness or injury is increasing. Advances in medical science and improved understanding of genetic conditions have contributed to this increase, as has the rise in rates of mental illness and diseases of affluence across the Western world. While accurate figures are difficult to obtain on the numbers of students concerned (Gilmour, Hopkins, Meyers, Nell & Stafford, 2015), some research suggests that up to 30% of school-aged children in developed countries may experience one or more chronic health conditions over the course of a year (Halfon, Houtrow, Larson & Newacheck, 2012). UK figures suggest that 14% of school children have a long term medical condition and an estimated 125,000 UK children miss more than 14 school days per year (http://www.royalfree.camden.sch.uk/page/default.asp?title=Welcome&pid=1).

Excluding students with mental health conditions, an estimated 60,000 Australian students experience school absence which impacts on their academic, social and emotional well-being each year, as a consequence of significant illness or injury (Gilmour et al., 2015). Within the cohort of students who experience significant illness or injury, there are those who experience both intermittent and extended absence from school. These students, for example those with childhood cancers, genetic conditions such as cystic fibrosis, and those who experience significant trauma (Hopkins, 2016), may face long periods of time away from school, or more frequent but shorter-term absences.

In the provision of support for students with significant illness or injury, there is regular cross over between the health and education jurisdictions:

To meet every child at their point of educational need is the responsibility of both healthcare providers and education authorities working collaboratively to support each student and their family in a child- and family-centred way (Hopkins, 2016, p.214).

This point of cross-over is the health-education nexus. The health-education nexus is bi-directional and frequently challenging for individuals to negotiate.

What is the problem?

Students who experience absence from school due to significant illness or injury can experience educational disadvantage (see Educational disadvantage). The cause of this disadvantage is not their illness or injury, nor is it the sum of their absences. The educational disadvantage stems from the fact that their significant absences are neither quantified by the health and education systems, nor appropriately managed and supported.

Health systems attempt to reduce the length of hospital stays because shorter lengths of stay results in better health outcomes for patients, reduced risk of healthcare acquired infections, and improved patient flow through hospital systems.
In general, education systems monitor and act upon ‘unexplained absences’. An unexplained absence is one for which no parental explanation has been provided to the school. The absence of a student who is at home and physically unable to attend school due to illness or injury is explained. In most educational settings, such an absence is not monitored. Few Australian educational jurisdictions have systems in place to ensure that students with extensive, explained absences are in receipt of appropriate educational support. It is interesting to note that under the various jurisdictional Education Acts, parents have a legal responsibility to ensure that their children attend school on every day, and during the times on every day, when the school is open for attendance (ACT Education and Training Directorate, 2011, p.1).

As previously discussed, all jurisdictions allow for absences to be explained through the provision of medical evidence. But, when a student who is unable to physically attend school attempts to retain some level of academic connection to school, the legal obligations of the education systems to facilitate the student’s access to learning are less explicitly understood and acted upon. In the absence of support from the education system, the student experiencing non-negligible, explained absence from school experiences educational disadvantage. The issue of absence is explored further in Absence.

What does this review do about the problem?

Taking Responsibility: Reducing educational disadvantage for seriously sick kids experiencing school absence (Taking Responsibility) seeks to address the ‘wicked’ problem of the educational disadvantage encountered by students experiencing non-negligible school absence due to significant injury or illness. It explores cultures and practices within Australian health and education systems; it examines challenges within the health-education nexus that can create an education experience for some students that fails to uphold the principles of equity and inclusion and provisions in Australian legislation. Australian and international evidence has been drawn upon to examine how and where the health and education systems are working together to ensure students remain connected to their school and education while they are absent due to significant illness or injury, and how and where the two systems are failing to manage that connection.

Taking Responsibility was commissioned by the Australian Government in response to the 2015 report commissioned by MissingSchool1 - School connection for seriously sick kids – who are they, how do we know what works and whose job is it? That

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1 MissingSchool is an advocacy organisation, which aims to have the special learning and social needs of seriously sick kids realised through every day practices in their schools. See http://missingschool.org.au/
report is one the most recent Australian works on school connection for students experiencing non-negligible absence from school due to serious illness or injury. *School Connection for Seriously Sick Kids* provides a detailed overview of the situation in which these students find themselves and whether it is adequately addressed. MissingSchool and ARACY began that 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. *School Connection for Seriously Sick Kids* discovered “rigidly defined areas of doubt and uncertainty” (Adams, 1984).

Among the many recommendations in *School Connection for Seriously Sick Kids* are the following:

- 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;
- development of specific policy for students with significant illness or injury, and not merely subsuming this into disability;
- 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; and
- formalising the roles and responsibilities of all parties, including parents and carers, in supporting students with significant illness or injury (Gilmour et al., 2015).

Through a focus on collaboration in the health-education nexus, *Taking Responsibility* seeks to provide the beginnings of a national response to these recommendations. Before legislation, policies and practices can be developed, linkages can be formalised, initiatives can be advanced or roles and responsibilities can be determined, an understanding of what already exists in this space must be developed. This paper will examine current practice in the health-education nexus in Australia and elsewhere in the world through a Policy and Standards Hierarchy, and
will evaluate that practice against principles of good and better practice including a Theoretical Framework developed in *School Connection for Seriously Sick Kids*. Based upon that evaluation, this paper will discuss what is working, what isn't working and what could be improved.

Other elements of the *Taking Responsibility* project include the development of a Practicum Guide for pre-service teachers and a Good Practice Resource for in-service teachers. A case study of collaboration in the education-health nexus has been conducted. The final report for the project will provide recommendations for action.

There are many significant terms and concepts throughout this document. Definitions are provided in Appendix One, but there are several terms which must be explored up front.

**Absence**

Within Australia, there is a lack of consistency in the definition and measurement of school absence, not only across states and territories but also across government and non-government sectors (Australian Curriculum, Assessment and Reporting Authority, 2011). The most common reason given for school non-attendance is illness (Daraganova, 2012). 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 can be described as prolonged, extended, frequent or recurrent (Gilmour et al., 2015).

Chronic absence can be a measure of how much school a student misses for any reason. In the Australian context, the Australian Government does not define chronic absence. The fact that there is no “safe” threshold for absence which does not impact on academic achievement (Telethon Institute for Child Health Research, 2013) may be one reason for the absence of such a definition. As previously mentioned, education jurisdictions have policies in place regarding unexplained absences. For example, the Northern Territory defines chronic absenteeism as a significant pattern of unexplained absences, whether on consecutive days or otherwise, which adversely affects a student’s progress (Northern Territory Government, 2011). In the ACT, when unexplained absences reach a maximum of seven days in a school year, principals are required to commence official procedures to ensure that students meet the school attendance requirement (ACT Education and Training Directorate, 2011). The challenge for students experiencing significant illness or injury is that their absenteeism is explained, and thus these students’ absences do not reliably receive the attention that is placed on students with unexplained absence. However, the impact of the absences on capacity for learning and school connection continues, despite the reason for the absence.

In the US context, chronic absence refers to student absence from their regular school greater than 10% of school days (Healthy Schools Campaign(a), n.d.). Within the Australian education setting, a school term is generally ten weeks long (50 days). Under this definition an Australian student who was chronically absent
would miss more than 5 days over a term – this could occur through continuous or intermittent absence. The use of a percentage rather than a specific number of days promotes earlier identification of students at risk for chronic absence (Healthy Schools Campaign(a), n.d).

**Non-negligible absence**

The term non-negligible absence is used in this review. This term encompasses chronic absence, but also allows for more flexibility. Non-negligible absence does not require a quantitative limit on the number of days which must be missed, nor is it focused on the explanation or otherwise of the absence. The use of the term non-negligible absence moves the focus away from the amount of absence, and onto the **impact** of the absence on the student and their learning. Non-negligible absence is absence which the student, the family and/or the educators agree has a significant or important impact on the student and their academic, social and emotional well-being. Non-negligible absence is absence which can create educational disadvantage or educational disability; a participation restriction where a student is not appropriately supported in their education because of their absence from school (Gilmour et al., 2015). Overcoming the isolation and marginalisation created by non-negligible absence requires interventions to remove environmental and social barriers (World Health Organisation, 2016).

**Collaboration**

Collaboration is a frequently used word, which is not always well defined. Rosen defines collaboration as working together to create value while sharing virtual and physical space (2007). It is important to recognise the need for diversity in collaboration, as the more diverse the group the greater the potential for brainstorming problem solving and ideation (Granovetter, 1973).

The literature contains a wealth of tools and descriptions regarding the components of successful collaboration. Zohdy, Samali, Laidler-Kylander & Simonin (2016) suggest that key behaviours in successful collaborations include prioritising learning; systems thinking and acting; democratising access to assets, and building long-term, diverse, transformational relationships. Prioritising learning is a focus not just on evaluation, but also on creating knowledge for the betterment of the entire field of endeavour. Systems thinking is thinking that looks at the interactions between people and factors/processes in the environment, because people and processes jointly create the system (Social Care Institute for Excellence, 2012). Systems thinking and acting incorporates understanding and addressing the full chain of factors that contribute to the issue at hand at a systems level, including acknowledging the ecosystems of all those relevant to the collaboration. Successful collaborations involve a focus on equitable access to assets, rather than on individual ownership. Building long-term, diverse, transformational partnerships involves building mutual trust, respect, and complementary activities over time across a wide range of participants (Zohdy et al. 2016).

In the context of students experiencing non-negligible absence due to significant illness or injury, collaboration would ideally involve representatives from all systems.
surrounding the student, engaged in working together to support the student in remaining connected to the regular school community and engaged in their learning. There is no expectation that all collaborators are physically present in the same space at the same time. Because the collaborators are drawn from across the different systems, the collaboration is diverse, and thus has improved potential for problem solving, ideation and brainstorming.

**Inter-agency collaboration**

Inter-agency collaboration is a practice for provision of services and support from a variety of government and community organisations. Inter-agency collaboration is a core principle in systems of care, and focuses on bringing together and engaging critical stakeholders, in a coordinated and integrated effort (https://www.childwelfare.gov/pubs/acloserlook/interagency/). Inter-agency collaboration can be a challenging, highly intense process (ARACY, 2009). Overall, the evidence that exists regarding the benefits of collaboration shows that inter-agency collaboration is beneficial for participating professionals and parents, though there is currently limited empirical evidence to clearly demonstrate that inter-agency collaboration benefits children (Australian Institute of Family Studies, 2011). Commitment, communication and strong leadership are major variables for promoting successful inter-agency collaboration (Johnson, Zorn, Tam, La Montagne & Johnson, 2003).

**Educational disadvantage**

Educational disadvantage comprises inequalities of three dimensions:
- **Opportunities:** the access students have to resources and facilities available to students, as well as to effective teachers.
- **Experiences:** this includes students’ relationships and interactions with teachers and fellow students, their sense of belonging in their school, and their experience of classroom discipline.
- **Outcomes:** how the students turn out, in terms of character, as well as the skills and knowledge they gain. (Perry, 2017).

Students who experience non-negligible absence from school due to significant illness or injury can experience educational disadvantage in all three dimensions. Some results of the educational disadvantage experienced by these students 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).

_Good/better/best practices_

Good practice is defined as habitual and judicious use of communication, knowledge, technical skills, reasoning, emotions, values and reflection in daily practice for the benefit of the individual and community being served (Epstein & Hundert, 2002). Better practice is defined as knowledge produced for the specific aim of supporting practice that is firmly grounded in a deep understanding of practice (Stolterman, 2008). Best practices are defined as statements by providers and other agencies of targeted achievable standards (Ager & O’May, 2001). An evidence base for best practice incorporates a systemic model that has been subject to rigorous evaluation over time and determined to be best practice on agreed outcome measures (Gilmour et al., 2015).

Good practice in inclusive education involves consideration of a range of aspects. The key approaches adopted in Australia focus on whole-school practice and in-class support. At a whole school level good practices include adjustments to cultures, policies, and practices, development of support structures, regimes of funding support, and the provision of and access to equitable learning opportunities. At an in-class level, differentiating curriculum or introducing alternative curricula, the application of universal design, use of information technologies, individual planning through an individual education plan (IEP), and a focus on quality teaching for all students are the most prominent practices (ARACY, 2013). Research suggests that practice in inclusive education for students experiencing non-negligible absence is inconsistent across Australian jurisdictions (Gilmour et al., 2015; Hopkins, 2016; Yates et al., 2010), particularly for those students unable to access education through hospital schools.

There have been a number of papers which provide recommendations for good and better practice in supporting students with significant illness/injury in accessing education. Farrell & Harris (2003) list the following indicators of effective practice:
• Regular school ownership: the student’s regular school maintaining a high profile during the time their student is receiving education in an alternative setting due to illness/injury.

• Partnership and collaboration: the ways in which the hospital school and the education system seeks to establish working relationships with other agencies to ensure that an individual student’s needs are met during the time they are out of their regular school due to illness/injury.

• Flexibility: ways in which the provision of educational support is organised reasonably to fit individual cases and adjusted when required due to changing circumstances

• Responsiveness: the ability of the education system to respond to the needs of all the stakeholders: pupils, parents, service staff, regular schools, medical and other professionals.

• Clarity: education systems and schools developing written policies and procedures that clearly outline all roles and responsibilities of those involved in the education of children/young people with medical needs (Farrell & Harris, 2003).

Building on Farrell & Harris, Hopkins (2016) provides recommendations on effective models of education support for students with illness and injury. These are that education supports must:

• Be child centred and focused on the individual learning needs of the child;

• be flexible, responsive, accessible and able to be delivered in a range of settings, including the hospital, school, home and community spaces;

• provide clear communication channels between healthcare professionals, education professionals, the student and the family;

• provide appropriate academic support to the student

• provide opportunities for social and emotional support, as well as peer connectedness;

• be coordinated by a designated education professional, linked to the mainstream education and healthcare systems, and not rely on the parent to fulfil this role, and

• use technology effectively to keep the student connected to learning and to peers (Hopkins, 2016).
The recommendations from Farrell & Harris, and Hopkins, meet the requirements of better practice. Neither of these recommendations meets the requirements of best practice, as they are not “statements by providers and other agencies of targeted achievable standards” (Ager & O’May, 2001). Neither of these recommendations for practice has been subject to rigorous evaluation over time, and thus cannot be considered to be evidence based. Recent research found no strongly evidence based best practice approaches to continuing the education participation and connection of students with significant illness or injury (Gilmour et al., 2015). Accordingly, Taking Responsibility will seek to identify good and better practices in strengthening school connection through collaboration.

**Illness/injury/disease/health condition**

Illness, disease and health condition are words with many connotations, most of them negative. In this review, illness is used to describe non-communicable medical conditions, which may be transient or permanent. Illness includes mental health conditions, as illnesses such as anxiety, bi-polar disorder, depression, eating disorders, and schizophrenia are increasingly being diagnosed in adolescents and younger children (Rivers, 2009). Mental illness was not included in the School Connection for Seriously Sick Kids report, as the authors considered that investigation of mental illness and school separation required dedicated attention. As mental illness is causing increasing amounts of non-negligible absence from school (Fenely, 2013), it has been included in the definition of illness in this review. Its inclusion in this review does not negate the fact that further investigation of mental illness and school separation remains necessary.

None of the terms mentioned above covers the possibility of an injury which leads to school absence or impacts on the ability of the student to engage with their learning. In this review, injury is defined as damage or harm done to or suffered by an individual.

**Significant illness or injury**

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.

The focus of this review is on neither the nature nor severity of the illness or injury but on the minimisation of the impact of the school absence which results from it. The word significant is used in this review to describe any illness or injury which has a non-negligible impact on school attendance (Gilmour et al., 2015).

**Wicked problems**

Complex problems such as those presented in this review are sometimes described as ‘wicked’ problems — not in the sense of evil, but as an issue highly resistant to resolution. Wicked problems share a range of characteristics — they go beyond the capacity of any one organisation to understand and respond to, and there is often
disagreement about the causes of the problems, whose job it is to solve the problems, and the best way to tackle them.

Head and Alford (2008) suggest that a problem’s *wickedness* is determined by two dimensions:

- **Complexity:** difficulty in acquiring knowledge about the problem and therefore its solution. Complexity is driven by a patchy knowledge base; complex interdependencies of processes and structures; and uncertainties arising from the contingent and dynamic nature of social issues and processes; and
- **Diversity:** the number and variety of stakeholders involved.

The combination of these two dimensions forms a typology of problem types that have different levels of wickedness and require different solutions. In this typology, non-negligible school absence for students with illness or injury has mid to high range diversity and complexity, and is therefore a ‘wicked problem’.

Attempts to address wicked problems are hindered by the uncertainty they generate. The over-arching perspective in this review is that non-negligible absence for students with significant illness or injury is a wicked problem in its nature and would respond best to approaches that are appropriate for these highly complex problems — collaborative approaches. No single stakeholder or sector can fully address the issues of students experiencing non-negligible absence from school due to significant illness or injury, necessitating coordinated action among all relevant stakeholders (Widmer, 2017).

This review acknowledges that systems change to advance collaborative strategies *alone* will not solve this wicked problem. To solve wicked problems, there must be a focus on the conditions that produce the problems rather than only seeking to remedy presenting problems (Moore & Fry, 2011). New and systematic ways of thinking about the problem to identify solutions and drive policy change and the development of evidence-based programs and interventions are also required. While these issues may be beyond the scope of this project, collaboration will enhance the policy-making process (ARACY, 2008).
Method
The approach to this review involved a broad sweep of data and evidence sources around collaboration across the health-education nexus. The exploration of the data was conducted online and through telephone or face to face interviews. The main source areas (within Australia and internationally) comprised:

- National, State and Territory Education administrators, co-ordinators, teaching staff and websites
- Hospital School teachers and networks
- peak bodies and non-government organisations within the education-health nexus
- Previous research on students experiencing significant illness or injury, and their interactions within the education-health nexus.

The audit does not take into account commitments made by education jurisdictions about future action.

Evaluation Method
The key elements in the evaluation of what is and is not working and what could be improved in Taking Responsibility are the Policy and Standards Hierarchy and the Theoretical Framework. ARACY is grateful to Megan Gilmour (Cofounder and Chair of MissingSchool) for introducing the methodology for reviewing systemic practice through the Policy and Standards Hierarchy, and guiding its application.

Policy and Standards Hierarchy
Building on the systems thinking discussed in Collaboration an examination of the hierarchy of policies and standards of educational support and absence management across Australia for students experiencing non-negligible absence due to significant illness or injury is warranted.

Figure 1 provides a visual representation of the hierarchy of legislation, principles, policy and standards. Tier One of the hierarchy is the laws, regulations and requirements, which provide the legal definitions and requirements. Tier Two explores the principles, providing core statements of commitment. Tier Three details the specific policy statements of intent – the political, managerial, financial and administrative mechanisms which provide support for the implementation of Tiers One and Two. Tier Four provides control specification of standards – statements and descriptions of how resources will be used, and details of the data reporting and review requirements. Tier Five explores the grassroots levels of know what, know how and show how. For the purposes of this review, while Tiers One to Four cross over national and state/territory jurisdictions, Tier Five is centred...
at the State/Territory and School levels. At Tier Five we find the school processes and procedures which support or hinder access to education for students experiencing non-negligible absence due to illness or injury.

![Diagram](image)

Figure 1: Policy and Standards Hierarchy, adapted from Performance Resources, 2006.

The provision of absence management and educational support for students experiencing non-negligible absence due to significant illness or injury in each state and territory has been mapped against the Hierarchy provided in Appendix Two. An overlay of educational support and absence management for students with significant illness or injury at the national, state and territory levels on this hierarchy can be found in Appendix Two. At national, state and territory level the laws, requirements and principles are clearly established – Tiers One and Two are adequately populated. Students experiencing non-negligible absence due to significant illness or injury are members of the cohort for which disability laws and standards were instituted. Laws compel and inclusive education principles guide practice in Australian schools. However, gaps in direction at the Tier Three to Five (policy, standards, procedures, processes, baselines, guidelines and practices) levels of the hierarchy are obvious, and deeply concerning. The results of the mapping of jurisdictional support for students are explored in more detail in What’s currently happening?

**Theoretical framework**

The theoretical framework was developed in *School Connection for Seriously Sick Kids*. The framework is based on an overarching desired outcome of educational
inclusion and equity for students with significant illness or injury. The principles which guide the practical implementation of the framework are:

- 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), and

- equitable approaches in which students and their families are treated as equal partners and actively involved in planning, implementation and review (Gilmour et al., 2015).

The framework includes the following elements, which have been used in *Taking Responsibility* to evaluate current practice in addressing the educational disadvantage generated by non-negligible school absence for students with significant illness or injury:

- 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 (Gilmour et al., 2015).

The use of the theoretical framework provides a thought-provoking introduction to systemic challenges and potential solutions around support for educational connection for students experiencing non-negligible absence from school due to significant illness or injury.
Before beginning to explore current practice, in recognition of the students themselves, it is important to encounter their lived experience. The orientation which follows is a phenomenological\(^2\) examination of one student’s experience of the health-education nexus, and the educational disadvantage she experienced. To enter into this student’s experience phenomenologically, readers must encounter the emotions and experiences of the student at a personal level. These emotions and experiences are what “infuses us, permeates us, infects us, touches us, stirs us, exercises a formative affect” upon us (van Manen, 2007, p.11). In addition to the phenomenological orientation provided, the lived experience of students will also be included in later sections of this paper.

\(^2\) Phenomenology is a philosophical approach to the study of structures of consciousness as experienced from the first-person point of view (https://plato.stanford.edu/entries/phenomenology/).
Orientation

You are a 17 year old female student in Year 11 at your local government school. You are a well-beloved daughter, sister, partner and friend. You are a dancer, a musician, a writer, an artist, a baker. You are living with cystic fibrosis (CF) – a terminal genetic disease which affects your respiratory and digestive systems. Complicating life are the other medical conditions which have flowed on from living with CF. You have asthma; gastro-oesophageal reflux disorder; social anxiety; depression and body dysmorphic disorder. You are always tired and have a continuous cough.

Tired really doesn’t begin to adequately describe how you feel. Tired is the word used by people who are getting ready to go to bed after a busy day. Tired is the word used to describe babies who are overdue for a nap. Tired is inadequate. You wake up bone-shatteringly, hair-achingly, stomach churningly exhausted every day. You crawl through each day, desperately fighting to be a normal teenager. You collapse into your bed at night, preparing to face the night terrors, the fear, the sweat, the hopelessness, the feeling of waking up drowning inside your own lungs, the hideousness of the thoughts which swarm in the darkness and force you to acknowledge your own mortality.

And let’s talk about the cough. That cough that your mother uses to track you through the shopping centre. That cough that sounds as though you are tearing the lining of your lungs away from the walls, that echoes through the classroom, the corridor, the bus. That cough that leaves you scarlet faced, sweat drenched and shaking. That cough, which causes complete strangers, new teachers or other students to offer harsh comments on the importance of quitting smoking while you are young. That cough, that you seek so frantically to suppress during class time, so that you don’t distract the other students. And in that concentrated cough-suppression state, once again you have missed what the teacher was saying.

You have recently returned home after 6 weeks in a residential mental health facility where you sought assistance for suicidal ideation and self-harming behaviours. Is it really so surprising, that after spending 16 years caring for your disease, which like a toddler is always demanding your attention and absorbing your time and every shred of energy available, the black dog of depression has reduced you to slicing yourself open with razor blades, just to make sure that you can still feel?

You miss a lot of school. So far this year, you have not had a single week when you have attended for 5 full days. The worst week in Term Two, you only made it to school for 2 half days. It’s currently Week 4 of Term 4. So far this term you have only attended for 3 days, as you have been battling an infection which has now placed you in hospital for at least the next two weeks.

You and your mum have worked hard throughout your school career to keep you connected to your learning. It’s not so bad when you are admitted to the hospital –
because you live in one of Australia’s capital cities, you can access a hospital school. (Aren't you lucky? Imagine what it would be like if you lived in a country area!) On the days when you are well enough to attend, and there isn’t anyone else with CF there, you can go to school for a couple of hours a day. Mum asks the teachers at your regular school for information on what’s happening in your classes, and some of them provide that information to the Hospital School teachers. The Hospital School staff work with you on the work your teachers provide, and on your assessment items. It’s a lot harder when you are at home. Sure, there are days when you are sick at home and you’re not well enough to do any school work. But there are other days when you could get some work done, but you don’t always have a way of accessing the work. What’s happening in your classrooms? What are your friends working on? How much learning will you miss this time? Is there any point even trying to keep up?

When you are at school, you are constantly trying to catch up on what you missed yesterday or last week. Too many times, you discover that despite your best efforts, you have once again fallen asleep in class. Your teachers and your friends are kind, and understanding, and try so hard to help make your learning easier. But how can you begin to do your best at school, when so often your best is simply making it to class on time, and staying awake to the end? This is not learning! This is existing. Your last Maths report pointed out that there were major gaps in your knowledge, which were attributed to your intermittent attendance at school. Many of your report comments include phrases like “makes excellent contributions to class discussions when she is able to attend”. But again, and again, and again, the grades are pro-rated and status is given, because you cannot be assessed on what you have not been present to learn.

You hear the politicians, and the senior administrators in the Education Department, and your school principal talk about the principles of inclusive education, and the supports that are provided for students with disabilities. Your school has ramps and lifts, so that students who use wheelchairs can move around the school. Your teachers are really good at providing ways for students with vision impairments, or intellectual disabilities to access the learning. But it’s like your special educational needs don’t really fit. You need access to education when you’re not physically able to attend school, so that you don’t need pro-rated grades and status. But when you’re not physically there, it’s kind of like you are invisible. There’s nothing in the system that meets your needs.

What does your future look like, when you finish school? Do you know enough; have you learned enough? Is your education good enough to enable you to reach your full potential and maximise your life opportunities? Has all of the hard work and medical treatment to get you to this point been worth it?
What’s currently happening?

Teachers, health professionals and education advisors reported the need for better communication between health professionals, teachers and families and, more broadly, within and across sectors about how to best support individual young people in achieving their broader life and education goals (Yates et al., 2010, p.12).

Despite the good intentions and efforts of some individual educators, parents, policy makers and others in the field, there is a gap in current policy and provision for students with significant illness and injury (ACACY, 2015, p.10).

Teachers in Australia are uncertain about their role in supporting students with chronic illnesses; schools inconsistently provide learning support for home and hospital study; and current communication frameworks between hospitals, parents and schools are inadequate (Gough & Dunlevy, 2017).

It is deeply telling that in the seven years between these pieces of Australian research on non-negligible school absence for students with significant injury or illness, the same issue remains. The data estimate conducted in *School Connection for Seriously Sick Kids* suggests that at least 60,000 Australian students face disadvantage every year because they miss school as a result of significant illness or injury\(^3\). That estimate also indicates that there are currently no definitive measures of either the numbers of students in Australia missing school because of significant illness or injury, the extent to which their schooling is disrupted (i.e. days missed) because of their illness or injury, or which illnesses and injuries are creating the most disruption (Gilmour et al., 2015). Complexities of hard data on the number of students involved notwithstanding, there are examples of current good and better practice around Australia and across the world which may address elements of the problem of school absence for these students.

**Australian and International Examples:**

*School Connection for Seriously Sick Kids* (Gilmour et al., 2015) identified emerging evidence and commonalities in strategies and approaches across Australian and international educational jurisdictions in support of engaging students with significant injury or illness. In *Establishing Australian school re-entry guidelines for children diagnosed with cancer*, Lum, Donnan, Wakefield, Fardell & Marshall (2017) noted flaws in the implementation policies around current legislation; the need to establish better hospital-to-school communication structures; inadequate teacher knowledge of the educational implications of childhood cancers; and a lack of nationwide homebound learning support. *Taking Responsibility* builds on the

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\(^3\) This figure does not include students with mental illness. With the inclusion of mental illness, the figure will increase significantly, but exact numbers remain unknown.
information provided in *School Connection for Seriously Sick Kids* and *Establishing Australian school re-entry guidelines for children diagnosed with cancer* through a focus on the role of inter-agency collaboration and better practice in reducing exclusion. Whenever possible, recent research publications or hospital school documents have been consulted to provide details of the student experience.

**Australia:**

As mapped in Appendix Two there are multiple elements of the Policy and Standards Hierarchy present at the national, state and territory levels. At the national level, Tier One includes the *Education Act 2013* and the *Disability Standards for Education (2005)*.

The Australian Education Act (2013) states that:

> the quality of a student’s education should not be limited by where the student lives, the income of his or her family, the school he or she attends, or his or her personal circumstances (Australian Government, 2013).

Thus, under this Act, illness or injury should not limit the quality of a student’s education.

Access to education in Australia for students with disability is governed by the Disability Standards for Education (DSE) 2005, which clarify the obligations of education and training providers and seek to ensure that students with disability can access and participate in education on the same basis as other students. The DSE were formulated under the *Disability Discrimination Act 1992* (DDA) and came into effect in August 2005.

The DSE are required to be reviewed every five years in consultation with the Attorney-General’s Department. The 2015 Review recognised that progress had been made since the 2010 Review in raising awareness of the Standards with educators through various initiatives and resources (http://www.education.gov.au/disability-standards-education). It also noted that “there remains a need to continue efforts on supporting development of the skills to interpret and apply the Standards in practice” (URBIS, 2015, p.ii). This point is particularly apt when considering students experiencing non-negligible absence as a result of significant illness or injury.

As previously described, inclusive education and equity of access to education are two of the Tier Two principles which determine the national agenda around students experiencing non-negligible absence due to significant illness or injury. At the Tier Three level, there are two major political mechanisms which support these principles.

The *Nationally Consistent Collection of Data on School Students with Disability (NCCD)* requires that schools include students in the data collection when:

- there is evidence that adjustments have been provided over a minimum period of one school term (or 10 weeks of school education (excluding school holiday
periods) in the 12 months preceding 5 August 2016 (the reference date for the 2016 national data collection). Where a student has newly enrolled in the school and has attended the school for less than 10 weeks, schools may include that student if they have evidence of a continuing need for adjustments for the student. For example, evidence from the previous school of long-term adjustments together with evidence that similar adjustments are required in the new school; and

- reasonable adjustments have been provided to the student to access education because of disability, consistent with definitions and obligations under the DDA and the Standards (Education Council, 2016).

Given that many students with significant injury and illness are not reliably receiving appropriate accommodations, adjustments or disability supports from their regular schools, there is a question as to whether or not these students are currently being included in the NCCD.

The National Disability Insurance Scheme (NDIS) is a recent development in the Australian disability landscape. The NDIS is designed to support Australians with a significant and permanent disability and their families and carers, in accessing the support that they need (https://ndis.gov.au/about-us.html). The level of support available under the NDIS for people with significant illnesses and injuries is currently unclear.

To meet the NDIS disability rules you need to have an impairment or condition that is likely to be permanent (lifelong) and that stops you from doing everyday things by yourself (NDIS, n.d.)

The Australian Administrative Appeals Tribunal has found that “children with type 1 diabetes are outside the scope of the NDIS” (O’Donovan, 2017), and people with cystic fibrosis have been told that they are not eligible for support under the NDIS (S. Jackson, personal communication, 12 March 2017). The NDIS funds supports that enable participants to attend school education, where these supports are required by the participant to engage in a range of community activities (NDIS, 2014). The NDIS does not fund supports deemed to be the responsibility of the education system.

A recent Australian initiative in support of inclusive education is the Leading Learning 4 All (LL4A) website. LL4A is based in the DSE and the Australian Professional Standards for Teachers and School Leaders. This resource is intended to initiate changes in thinking and practice regarding students with disability and additional learning needs by promoting a community of inclusive learning practice - a place where all learners have equal opportunities to achieve, and where there is school-wide understanding of what is involved in enabling this to happen. On launch the site did not include direct reference to students with significant illness/injury; as a result of the Taking Responsibility project there are plans to correct this omission in the near future.
Policy and Standards Hierarchy

All Australian educational jurisdictions were approached to verify the mapping of their jurisdiction against the policy and standards hierarchy (see Appendix Two). While Tiers One and Two are adequately populated, there are significant gaps in direction for schools at Tiers Three to Five (policy, standards, procedures, processes, baselines, guidelines and practices). Table 1 provides a visual representation of the results of the mapping process.

In successful systems, all tiers of the policy and standards hierarchy are complete, allowing for the easy flow of information down through the system to the ‘coalface’ of delivery. Realising a successful system requires a focus on the needs of the people within the systems, determining required functionality, and documenting requirements (http://www.incose.org/AboutSE/WhatIsSE). It is within tiers Three and Four that mechanisms around policy, management, finance and administration, and data on standards of compliance are found. Without these elements, schools are limited in their capacity to ensure that students experiencing non-negligible absence due to significant illness or injury are not educationally and socially disadvantaged. This is because it is precisely the existence of such policies, standards, practice guidelines, processes and procedures which drives the school level response. Without the guidance set out in policies and standards, the students rely on the good will of individual school leaders and teachers, rather than consistent provision.

Exploring one jurisdiction can illuminate the impact of gaps in the policy and standards hierarchy further.

Within the ACT there are no rural/remote schools. The Territory as a whole has a higher socio-economic status than the Australian average, as well as higher rates of school retention and university qualifications (http://www.censusdata.abs.gov.au/census_services/getproduct/census/2011/quickstat/SOS80?opendocument&navpos=220). The ACT generally scores highly on NAPLAN in comparison to other jurisdictions (Macdonald, 2015). The Territory has a range of policies and procedures around inclusion, equity and support for students with disability, such as the Disability Policy and Healthcare Access at School (HAAS). The ACT also has a procedure for attendance. It would appear from these facts that the ACT has great potential for equity in access to education, including for students with experiencing non-negligible absence due to significant illness or injury.

However, the ACT Disability Policy contains no reference to illness or injury, and access to HAAS is limited to students who with complex or invasive health care needs which require action on school premises. While the procedure for attendance includes illness or injury as a reasonable excuse for absence, the procedure does not address the issue of educational disadvantage caused by intermittent and extensive absences, such as those experienced by students with significant illness or injury. None of these general policies and procedures provides appropriate educational support or absence for students experiencing non-negligible absence as a result of significant illness/injury.
From the hierarchy of policy and standards in educational support and absence management in Table 1, it is clear that the ACT lacks Tier Three and Four elements in relation to students experiencing non-negligible absence due to significant illness/injury - policy, standards, procedures, baselines and guidelines. Without the support of Tier Three and Four elements, ACT schools will continue to struggle to provide a service that mitigates the educational disadvantage experienced by these students. Without appropriate policies and standards to draw upon, ACT schools cannot develop relevant Tier Five procedures, processes and practice guidelines to ensure that access to education for these students is equitable, and that their educational disadvantage is reduced through educational and social management of their absences.
Table 1 - Policy and Standards Hierarchy Mapping

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<td>Tier Four Standards</td>
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<tr>
<td>Tier Five Procedures, processes, baselines, guidelines &amp; practices</td>
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The policy and standards hierarchies of other states and territories (Appendix Two and Table 1) demonstrate that there are jurisdictions in Australia with less educational support and absence management provisions for students with significant illness/injury than the ACT. The students of those jurisdictions may be experiencing even more substantial educational disadvantage.

Theoretical Framework
Given the clear evidence of substantial gaps in the policy and standards hierarchies of the majority of Australian educational jurisdictions, the theoretical framework has been used as a tool to examine what’s currently happening in each jurisdiction. An audit against a number of elements of the theoretical framework for current education provision and absence management for students with significant illness/injury by jurisdiction is listed in Appendix Three. The information for this audit was drawn from School Connection for Seriously Sick Kids, and the resources, materials and individuals consulted in this Review of Current Practice, including the Policy and Standards Hierarchy. It is important to note that this is an audit of specific policies, standards and practices around access to learning and management of absence for students with significant illness and injury. Unlike the policy and standards hierarchy, general disability policies and services such as provision of first aid or healthcare access at school are not included in this audit. As stated in School Connection for Seriously Sick Kids:

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 (Gilmour et al., 2015, p.8, emphasis added).

Interestingly, when asked to respond to the audit, a number of States and Territories could only provide general disability support policies and procedures. Further, these education jurisdictions were not able to provide data on the numbers of students experiencing non-negligible absence from school due to significant illness or injury accessing the support provisions of those initiatives. It is clear from this response that the recommendation from School Connection for Seriously Sick Kids around the need for specific provisions for students with significant illness/injury has not been adopted.

Table 2 provides a visual representation of the audit result
## Table 2 - Theoretical Framework Audit by Jurisdiction

### Theoretical Framework Audit by Jurisdiction

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- **Policy frameworks managing absence for this cohort**
- **Resources & Professional Learning for regular school staff**
- **Resources for parents**
- **Formalised collaboration between Health and Education Departments**
- **Policy on use of ICT to assist in maintenance of regular school connection**
- **Provision of education support services outside hospital setting**
- **Provision of support services outside major metropolitan settings**
Only Western Australia was able to provide evidence of standardised, documented educational practice designed to address the issue of educational disadvantage caused by school absence for students with significant illness or injury across all elements of the theoretical framework. Four other jurisdictions were able to provide evidence of emerging practice in some of the elements of the theoretical framework. A detailed examination of practice within each Australian jurisdiction follows.

**Australian Capital Territory**

**Policy and Standards Hierarchy**

The ACT has a number of Tier One elements in the Policy and Standards Hierarchy. These include the Education Act 2004, Discrimination Act 1991, Children and Young People Act 2008, Information Privacy Act 2014, ACT Student Disability Criteria 2016, and Students with a Disability: Meeting their Educational Needs Policy and Procedures. Unfortunately, while the Student Disability Criteria includes chronic illness, it does not include the impact of absence on student capacity to access learning. Associated with the Student Disability Criteria is the Student Education Impact Statement which does not include the impact of absence or any reference to access to education outside of school. Students with a Disability: Meeting their Educational Needs Policy & Procedures does not include the words illness, injury or absence. The Children and Young People Act 2008 allows for the creation of Declared Care Teams to promote coordinated and planned services for children, young people and their families and facilitate the sharing of information among its members (Child & Youth Protection Services, n.d.). No evidence was found in this review of Declared Care Teams being utilised in support of students experiencing significant illness or injury.

At Tier Two, the ACT has clearly articulated its principles of inclusive education and compliance with the DSE. There are a number of Tier Three administrative mechanisms which could provide educational support and absence management for students experiencing non-negligible absence due to significant illness or injury. These include the Monkey in My Chair (MiMC) program, Healthcare Access at School (HAAS), the Student Resource Allocation Review and the Attendance at ACT Public Schools Procedure. HAAS does not provide any assistance in mitigating educational disadvantage caused by absence. It is a program to reduce absence, through the provision of healthcare procedures at school, which includes the development of a HAAS Healthcare Plan (ACT Health Directorate, 2013). The Student Resource Allocation Review aims to develop a student needs-based school funding model for Canberra public schools, in line with the Review of Funding for Schooling Final Report (DEEWR 2011). As the Student Resource Allocation Review is ongoing, it has not been evaluated as part of the Taking Responsibility project. The Attendance Procedure contains no definition of chronic absence or management process for such absence. MiMC is only used in primary schools. While there are several monkeys being used in schools, there is no systemic data on how many students would be eligible for the program, nor any evidence of prioritisation of need in determining which students access the program.
There is no evidence of any Tier Four standards through statements and descriptions of how resources around students with significant illness or injury will be used, or details of any data reporting or review requirements. There is some evidence of Tier Five supports in the ACT, through the provision of an Information Pack by the Canberra Hospital School. This resource package includes:

- a brochure about the Hospital School;
- Frequently Asked Questions (FAQ) about the Hospital School
- FAQ about collaborations between regular schools and the Hospital School;
- Fact Sheet: Information for teachers of students with chronic/critical illness;
- MiMC flier and FAQ.

The Information Pack was distributed in hard copy during 2016. There is no data available from the Education Directorate on the use of this resource. It is possible that digital access to the resources, as recommended in the Theoretical Framework, could improve the impact of the Information Pack.

**Theoretical Framework Audit**

It is clear from the audit against the Theoretical Framework in Table 2 and Appendix Three that the ACT has limited policies and practices in place to address the impact of absence from school on students with significant illness or injury.

The ACT has disseminated a fact sheet for teachers in regular schools containing information about teaching students with significant illness or injury. This fact sheet was distributed in hard copy to a limited number of schools and is not yet digitally accessible to teachers in regular schools. There are pockets of good practice in some ACT schools around the use of ICTs to connect students with significant illness or injury to their regular classrooms during periods of absence, but no formal Directorate policy exists. The Healthcare Access at School program involves formal collaboration between the Health and Education Directorates, but this program does not include practices which mitigate the educational disadvantage caused by absence from school.

**New South Wales**

**Policy and Standards Hierarchy**

NSW has a number of Tier One elements in the Policy and Standards Hierarchy. These include the *Education Act 1990*, *Anti-discrimination Act 1977*, *Privacy and Personal Information Protection Act 1998*, *Children and Young Person (Care and Protection) Act 1998*, and the NSW Department of Education *Disability Inclusion Action Plan 2016-2020*. The *Disability Inclusion Action Plan* does not include the words illness or injury.
The NSW Department of Education Tier Two principles are clearly demonstrated in this quote from the Wellbeing Framework:

There is a heightened awareness of, and commitment to, personalised and differentiated learning and support for every student to succeed. There is targeted support at the system and school levels so that where a child or young person lives and goes to school does not shape their learning outcomes (NSW Department of Education & Communities, 2015).

Other Tier Two elements include the Personalised Learning and Support website, and Local Schools, Local Decisions, an education reform giving NSW public schools more authority to make local decisions about how best to meet the needs of their students. The School Excellence Framework has the potential to be a tool to support schools in managing the absence of students with significant illness or injury, as schools are required to are required to assess their practices against the framework including areas such as: "Attendance rates are regularly monitored and action is taken promptly to address issues with individual students" or "The school has an effective plan for student transitions in place" (Department of Education & Communities, 2014, pp.2-4). The Department did not supply any Tier Four data collection and evaluation evidence of the School Excellence Framework being used in this manner, and does not provide specific guidelines around student transitions.

There are a number of Tier Three administrative mechanisms in NSW which could address aspects of the educational disadvantage faced by students experiencing non-negligible absence from school due to significant illness or injury:

- The School Attendance Policy contains no definition of chronic absence or management process for such absence. While it does require Principals to develop strategies to ensure regular attendance at school when frequent absences are being explained as illness, there is no evidence of any Tier Four data collection and evaluation of this requirement.
- The Personalised Learning and Support website contains four elements (assessed individual education needs of the student; provision of adjustments or support; monitoring and review of the impact of the adjustment or support and consultation and collaboration with parents, support staff and other professionals where required) which are clearly highly relevant to students with significant illness or injury. There is no reference to absence management or impact of absence on learning on the website.
- The Personalised Learning and Support and Signposting Tool, also known as the PLASST is a web based tool designed to assist teachers and learning support teams to identify the strengths and functional educational needs of students with disability. PLASST generates a student profile report that signposts where students may benefit from adjustments or support. There is one question in the PLASST regarding attendance and another regarding administration of medications. There is no mention of the impact of absence on learning, engagement, interactions or relations with peers or teachers. It is not possible to determine from the information provided by the Department whether a student profile report would signpost a student experiencing non-negligible absence due to significant illness or injury as benefiting from adjustments or support.
• The *Enrolment Policy* requires the principal to ensure that an appraisal of student educational need is carried out at enrolment for students with disability, but there is no Tier Four data collection and evaluation evidence of the *Enrolment Policy* being used in this manner for students experiencing non-negligible absence as a result of significant illness or injury. (As has previously been mentioned, significant illness or injury is not always recognised as a disability.)

• The *Bridging the Gap* project between Sydney and Westmead Children's Hospitals and NSW DET is an area of emerging practice, seeking to identify key principles to improve collaboration between Health/Education around students with disability, which may include students experiencing non-negligible absence due to significant illness or injury.

• Another Tier Three administrative mechanism available in NSW is the *Thomas Teddison* program, which utilises the same principles as the ACT MiMC. However, *Thomas Teddison* is a pilot program run by Ronald McDonald House Charities, and thus cannot be evaluated as a NSW Education Department initiative.

There is no evidence of standardised Tier Four or Five level practices in support of students with significant illness or injury in NSW schools. Information supplied by NSW Education against these elements of the Policy and Standards Hierarchy referred back to the *Personalised Learning and Support* website, which is a general disability support resource, and contains no reference to absence management or impact of absence on learning. In theory, the Home School Liaison Officers who support tracking of school attendance and assist in monitoring wellbeing issues and the provision of timely support for students could be used to support students experiencing non-negligible absence due to significant illness or injury, but the Department did not supply evidence of this happening in practice.

**Theoretical Framework Audit**

As shown in Appendix Three and Table 2, NSW Education has extremely limited system level policies and practices in place to address educational disadvantage for students with significant illness/injury. The *Bridging the Gap* project may be evidence of emerging practice in formalised collaboration between the Health and Education Departments.

**Northern Territory**

**Policy and Standards Hierarchy**

The Northern Territory (the Territory) has a number of Tier One elements in the Policy and Standards Hierarchy. These include the *Education Act 2016, Disability Services Act 2004, Northern Territory Information Act 2016*, and the Department of Education *Students with Disability Policy 2016*. The only mention of illness or injury in the Disability Policy is in the definition clause. The Territory has a number of documents on its website which clearly articulate its Tier Two inclusion and equity principles.

At the Tier Three level, the Territory has an administrative mechanism in the *Attendance & Participation Policy 2016*. Injury and illness are not mentioned in the
Attendance & Participation Policy; and the policy contains no definition of chronic absence or management processes for such absence. There is no evidence of Tier Four or Five level practices in Northern Territory schools.

Theoretical Framework Audit

When approached for their input into the Theoretical Framework audit, Northern Territory Department of Education staff were unable to identify any system level policies and practices in place to address the impact of absence from school on students with significant illness/injury. (This information is reflected in Table 2 and Appendix Three).

Queensland

Policy and Standards Hierarchy

Queensland has a number of Tier One elements in the Policy and Standards Hierarchy. These include the Queensland Education (General Provisions) Act 2006, Queensland Anti-Discrimination Act 1991, Queensland Privacy Act 2009, the Department of Education and Training Disability Policy, and Inclusive Education policy statement. The Disability Policy and the Inclusive Education policy statement do not contain the words illness, injury or absence. Queensland has a number of documents on its website which clearly articulate its Tier Two inclusion and equity principles.

At the Tier Three level, Education Queensland (EQ) has a number of administrative mechanisms which could address the educational disadvantage encountered by students experiencing non-negligible absence due to illness or injury. These include the Every Day Counts resources; Management of Students with Specialised Health Needs resources; Learning and Wellbeing Guidelines; Managing Student Absences and Enforcing Enrolment Guidelines, and the State School Registered Nursing Service (SSNS).

Illness is listed as an acceptable reason for absence in the Every Day Counts resources; there is no mention of illness or injury in the 'Provide intervention and support' Every Day Counts resource. There is no mention of absence due to illness or injury in the Specialised Health Needs resources. There is no mention of absence due to illness or injury or risks for educational disadvantage for this cohort in the Learning and Wellbeing Guidelines. The Managing Student Absences & Enforcing Enrolment Guidelines state that early identification of students whose attendance is not regular is crucial to minimising student absences (Department of Education & Training Queensland 2017), but the guidelines do not comment on management of irregular attendance which is explained by medical certificates. These guidelines contain no definition of chronic absence or management process for such absence. The SSNS does not provide any assistance in mitigation of educational disadvantage caused by absence. It is a program to reduce absence, through the provision of healthcare procedures at school including Individual Health Plans. There is no evidence of Tier Four or Five level practices in Queensland.
Theoretical Framework Audit

It is clear from the Theoretical Framework audit in Appendix Three and Table 2 that Queensland has extremely limited system level policies and practices in place to address the impact of absence from school on students with significant illness/injury.

Previously, EQ had a policy in relation to education for students attending hospital schools, but the Delivery of educational services in hospital settings procedure was decommissioned. Staff at the Lady Cilento Children’s Hospital School (LCCHS) have created resources for regular school staff on some health conditions, and Queensland Ed-Linq health staff can provide training for teachers on mental health related issues on request. While LCCHS Guidance Officers and the Leadership team work with families to assist them in negotiating appropriate education supports for their students, this service is not guaranteed for students outside the hospital school.

There is evidence of collaboration between EQ and Queensland Health (QH). There are the Regional Working Parties which include representatives from both Health and Education Departments and the EQ led Advisory Group for Students with Mental Health Conditions. This group has representatives from Education (all sectors), QH, HSAC, Child and Youth Mental Health Service, and the Queensland Mental Health Commission. The LCCHS Advisory Council includes teachers, parent groups, health representatives and the Lady Cilento Hospital Foundation. There is also an education representative on the Mental Health, Substance Misuse and Residential Care Settings initiative. While these collaborations are to be commended, there remains a gap in collaboration around the students experiencing non-negligible absence due to significant illness or injury.

Queensland does provide support services outside of Brisbane for students with significant illness or injury. There are 12 settings in regional areas which include teachers in hospital schools. However, these teachers are limited to engagement with students in hospital settings. EQ has no formal policy on the use of ICTs to keep students connected with their regular classrooms, though there are pockets of such contact taking place.

South Australia

Policy and Standards Hierarchy

South Australia has a number of Tier One inclusions in the Policy and Standards Hierarchy, including the Education Act 1972, and the Disability Services Act 1993. At the Tier Two level, it is clear that South Australian children and students with a disability or special needs must be given the same opportunities for education as other children and students.

At Tier Three, South Australia provides a number of relevant administrative mechanisms including On the same basis: Implementing the Disability Discrimination Act Standards for Education (OTSB) and procedures for Attendance and Absenteeism (http://www.sa.gov.au/topics/education-and-
learning/schools/school-life/attendance-and-absenteeism ). OTSB includes the words illness, injury and absence. Illness appears in definitions and resources; injury appears once in the Options Co-ordination section, and absence appears in a case study in regard to employee work-related stress. The attendance and absenteeism webpage contains no definition of chronic absence or management process for such absence. There is no evidence of Tier Four or Five level practices in South Australia.

**Theoretical Framework Audit**

When approached for their input into the Theoretical Framework Audit, South Australian Department of Education and Child Development (DECD) staff were unable to identify any system level policies and practices in place to address the impact of absence from school on students with significant illness/injury. In terms of emerging practice, DECD staff identified the Oncology Education Group, which is a collaborative group that meets monthly to discuss the educational needs of oncology students to ensure they do not fall through the gap. There is currently no equivalent for any other illness or injury group. (This information is reflected in Table 2 and Appendix Three.)

**Tasmania**

The Tasmanian Department of Education was contacted on numerous occasions seeking input into this review of current practice. The responses to those requests were limited. *School Connection for Seriously Sick Kids* details the following on Tasmanian support for students experiencing absence from school due to significant illness or injury:

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 (Gilmour et al., 2015, p.143).

The Tasmanian Department of Education conducted a review of support for students with disability in 2015. The report from that review, while detailing five key areas for improvement, does not include the words 'injury', 'illness' or 'disease' (Department of Education Tasmania, 2015).

**Policy and Standards Hierarchy**
Tasmania has a number of Tier One elements in the Policy and Standards Hierarchy. These include the *Guidelines for Individual Education Planning – Students with Disability*, and the *Learners First - Supporting All Students with Disability Focus FAQ*. The *Guidelines for Individual Education Planning - Students with Disability* do not include the words illness, injury or absence. The *Learners First FAQ* does not contain the words absence or injury - illness occurs once in relation to the NDIS. There is clear evidence of Tier Two level principles around inclusion.

At Tier Three, there are two significant documents: *Specific Health Issues: Procedures, Information and Contacts* and *School Attendance Procedures*. The *School Attendance Procedures* state that students are excused from attending school when ill, and may be eligible for part-time attendance when a student has a ‘particular medical condition or is affected by medical treatment’ (Department of Education Tasmania, n.d, p.6). They do not include any reference to significant illness or injury, nor do they address ongoing or intermittent absence, nor is there a definition of chronic absence. The Specific Health Issues document contains no reference to management of absence caused by illness/injury. No evidence of Tier Four or Five elements of the Policy and Standards Hierarchy were identified in Tasmania.

**Theoretical Framework Audit**

As the responses to requests for information from the Tasmanian Department of Education regarding the Theoretical Framework audit were limited, the information included in this audit was sourced solely from the Departmental website. It appears from the audit against the Theoretical Framework in Table 2 that Tasmania has extremely limited system level policies and practices in place to address the impact of absence from school on students with significant illness/injury.

There are some resources available for parents through School Nurse Program on specific conditions only. No other resources were identified against any elements of the Theoretical Framework.

**Victoria**

The Victorian Department of Education conducted a review into education provision for children and young people with serious medical and mental health conditions in 2015. The Department did not provide a copy of the results of that review to the *Taking Responsibility* project; the review report is not a public document. The Consultation Paper from that review, *Strengthening education for children and young people with serious health conditions*, suggested that hospital school services be extended state-wide and into the home, citing Western Australia and New Zealand as pre-eminent services (Queensland Department of Education and Training, 2015). At the time of the review, there were no service providers of hospital school services in regional areas throughout Victoria. There was a focus on in-hospital service with limited input post-discharge.
Policy and Standards Hierarchy

Victoria has a number of Tier One elements in the Policy and Standards Hierarchy. These include the Education and Training Reform Act 2006, the Disability Act 2006, and the Privacy and Data Protection Act 2014. At the Tier Two level, the Briefing Pack for Principal Applicants for the Monash Children’s Hospital School states that “Students with serious health conditions are a small cohort who need additional support because of the absences and disengagement from education their conditions cause” (Education and Training Victoria, 2016a, p.2).

Tier Three mechanisms exist in Victoria at the political and administrative level. At the political level, there is the establishment of the Monash Children’s Hospital School in response to Strengthening education for children and young people with serious health conditions. At the administrative level, there are the Program for Students with Disabilities operational guidelines and the Strategies to improve a student’s attendance - Attendance Improvement Plan or Return to School Plan procedures. The Program for Students with Disabilities operational guidelines do not include the words illness, injury or absence (Education and Training Victoria, 2016b). The Strategies to improve a student’s attendance document includes a requirement for follow up and improvement for absences over 5 days, including absences with a medical certificate (Education and Training Victoria, 2016c). The document does not include any definitions of follow up and improvement.

It is possible that the process of establishing the Monash Children’s Hospital school may result in some Tier Four elements in Victoria’s Policy and Standards Hierarchy. No evidence of Tier Five elements of the Policy and Standards Hierarchy were identified in Victoria.

Theoretical Framework Audit

From the audit against the Theoretical Framework in Table 2, it is clear that Victoria is developing some system level policies and practices to address the impact of absence from school on students with significant illness/injury.

There are resources available for teachers and parents on the Royal Children’s Hospital Education Institute website. These resources are not publicised on the Department of Education website, so may not be generally accessible to teachers and parents outside of the Royal Children’s Hospital circle of influence. It is possible that the process of establishing the Monash Children’s Hospital School may result in further elements of the Theoretical Framework being provided. For example, there are plans to facilitate video conferencing between students in the hospital and their regular classrooms (Andrews, 2016).

Western Australia

There are several major differences between the approach in Western Australia and many other Australian states and territories to education for students experiencing non-negligible absence due to significant illness. In Western Australia, the School of Special Educational Need: Medical and Mental Health (SSEN: MMH) operates under a
Memorandum of Understanding (MoU) between the State Ministers for Health and Education (Department of Education & Department of Health, 2014). The MoU was established through the State Solicitor.

While the SSEN: MMH is located in the Princess Margaret Hospital, it provides educational services in 18 different locations (including locations outside of the metropolitan area) and includes a home-based education service (Gilmour et al., 2015; Wheatley, 2016). The SSEN: MMH has affiliations with government and non-government agencies. The teachers in the programs work with the regular schools to ensure that the students are accessing the regular school curriculum. The SSEN: MMH uses a model governed by the principles of Liaison, Education, Transition and Support (LETS). The LETS model encourages the staff of SSEN: MMH to place the student and the regular school in the centre of their practice. The SSEN: MMH provides a wealth of information to students, parents and teachers through the school web page.

Western Australia recoups money from the Catholic and Independent education systems, via an agreement with the Western Australia Department of Education. Through affiliations with non-government agencies, the SSEN: MMH has accessed alternative funding sources, which have allowed greater flexibility in service delivery in comparison to other states.

Policy and Standards Framework
Western Australia has a number of Tier One elements in the Policy and Standards Hierarchy. These include the School Education Act 1991, and the Equal Opportunity Act 1984. The SSEN: MMH contains a number of Tier Two level statements in relation to students experiencing non-negligible absence due to significant illness or injury, including the specification of the expectation of a partnership between the regular school, hospital school, health services, family and student.

There are a number of Tier Three administrative mechanisms in Western Australia specifically for students experiencing non-negligible absence due to significant illness or injury. These include the Memorandum of Understanding between Departments of Education and Health and the Home and Hospital Teaching Referral Process. At Tier Four, the SSEN: MMH requires that there are individual service level protocols in place wherever dedicated staffing is provided. At Tier Five, the procedures, processes, baselines, guidelines and practices are all available on the SSEN: MMH website.

Theoretical Framework Audit
From the audit in Table 2, it is clear that Western Australia is the only jurisdiction in Australia to have system level policies and practices in place to address the impact of absence from school on students with significant illness/injury against every element of the Theoretical Framework. This is a clear reflection of the significant difference between the approaches taken in Western Australia to those in the rest of the country.
As previously discussed, information for regular classroom teachers and parents of students with significant illness or injury is available on the SSEN: MMH website. There are formal policies for this cohort, such as the Home and Hospital Teaching Referral Process. Formalised collaboration between the Health and Education Departments is set out in the Memorandum of Understanding, and SSEN:MMH has a policy on use of ICT to assist in maintenance of regular school connection. Also as previously discussed, there is provision of education support services outside hospital settings and outside the major metropolitan areas, with educational services delivered in 18 different locations (including locations outside of the metropolitan area) and including a home-based education service.

**International**

Two international examples have been included in this review. These examples have been selected for several reasons. The Netherlands approach was cited in School Connection for Seriously Sick Kids as a well-regarded, working example of a model established to support students with significant illness or injury to continue education participation and connection. The New Zealand model has significantly influenced the outcome of the Victorian Strengthening education for children and young people with serious health conditions review, and thus the establishment of the new Monash Children’s Hospital School.

**New Zealand**

The New Zealand approach to addressing the challenges associated with non-negligible absence for students with significant illness or injury includes Regional Health Schools (RHS), which were established in following a review of special education in the late 1990s. Rather than solely providing in-patient education in hospital schools, New Zealand has three RHS: Northern, Central and Southern. The RHS system is founded in inclusive practice. The schools maintain the education of students in Years 0-13 (Australian system Pre-School to Year 12), who are too ill to attend regular school. Irrespective of their geographical location, this access to education may happen in hospital, student homes, or other locations. The teaching may be one-to-one, or students may work in small groups. The students may also access correspondence material (Regional Health Schools, 2010). Students access the New Zealand Curriculum, every student has an Individual Plan and ideally they complete work as at their regular school. The RHS have agreements with the various institutions where the teachers are working (hospitals, other schools and community facilities) in terms of access to space, WHS etc, but there are no formal system level agreements between the Ministries of Health and Education.

In addition to the Hospital School sites, there are also itinerant teachers who travel to work with students. The teaching might happen in the student’s home, or alternative venues such as the local library, or at the regular school. This is 1:1 teaching for 2-3 hours per week. The goal is to keep the students connected to school and up to date with their learning. On some occasions, the students return to school academically ahead of their peers (Hamilton, 2011). Northern Regional Health School teaches in 17 different locations, Central Regional Health School across 14 sites.
Since 2002, there has been a major increase in the numbers of students enrolled in RHS due to mental health conditions. Central Regional Health School City is a transition site for students with chronic mental health issues. In addition to the teaching staff, there is a health funded occupational therapist and a mental health nurse. The program is one of combined health and education topics and students attend every day. There is a 30 minute review with/for each student every 3 weeks. The high school students can work on transition to vocational education and/or the workplace, as an alternative to transition to the home school.

The Central Regional Health School also provides teaching in the Acute Mental Health Unit, the Forensic Intellectual Disability Unit, the Forensic Mental Health Unit, and within the Youth Justice and Care and Protection systems. Within the Youth Justice and Care and Protection systems, there are health issues in areas such as Alcohol and Drug Use and Mental Health. Southern Regional Health School works with young people experiencing the challenges of substance abuse.

There is a new program running in the Central Regional Health School as a result of research completed by Pamela Snow of Monash University involving speech and language therapy. This is focused on communication difficulties around receptive language and also skills for students involved in narrative therapies in the mental health area. This project has particular relevance for the students in the Youth Justice and Care and Protection cohorts.

Northern Regional Health School (NHS) conducted a review in 2011, after 10 years of operation in this system (Hamilton, 2011). Students interviewed during this review identified four main areas in which the RHS program assisted in their re-integration into their regular school:

- Development of confidence through encouragement
- Keeping up with the work from the regular school
- Taking small steps as required
- One to one teaching

The review determined that the families who had been involved with NHS were strongly supportive of the staff and the service provided. Areas identified for improvement included speed of transition from NHS to the regular school, and the need for the voices of the students to be heard in the process of transition planning and implementation. Communication between medical and education teams, particularly in relation to medical certificates and medical exemptions was another area of concern. Extended follow up of students transitioning from NHS to their regular school was recognised as potentially problematic (Hamilton, 2011).

Partnerships with students, families and schools are a significant element of the New Zealand Regional Health Schools.
The School Team includes students and their families, the teaching team across 14 sites, a Board appointed by the Minister of Education, Government and Non-government agencies, and schools. Working in real and functioning partnership, focused on the individual student, is the key to the School’s success (Central Regional Health School, 2015).

**Policy and Standards Hierarchy**

New Zealand has a number of Tier One elements in the Policy and Standards Hierarchy. These include the *Education Act 1989*, *Public Health & Disability Act 2000*, and the *National Teaching Standards 2010*. The *Education Act* and *Teaching Standards* were under review at the time of writing of this review. Similarly to Australia, inclusive education is a major component of New Zealand’s Tier Two elements

Inclusive education is where all children and young people are engaged and achieve through being present, participating, learning and belonging (https://education.govt.nz/framework/main.php/running-a-school/inclusive-education/?url=/school/running-a-school/inclusive-education/)

At Tier Three, there are two key political mechanisms which are directly relevant to the educational support of students experiencing non-negligible absence due to significant illness or injury – the self-determining schools model, and the Regional Health Schools. The *Attendance Matters Guidelines* provide an administrative mechanism. The self-determining schools model has the potential to significantly impact on policy and practice around students experiencing non-negligible absence due to significant illness or injury - there are differences between the Regional Health Schools in practice. The *Attendance Matters Guidelines* discuss justified and unjustified absences. There is no clear direction from the Education Ministry on how the *Attendance Matters Guidelines* apply to students who are inpatients in hospital and have access to Regional Health Schools.

Unlike some Australian jurisdictions, New Zealand has a Tier Four element, through the Education Review Office. This office conducts reviews of all schools in New Zealand – an external validation process. The reviewers work with the management and board of each school to design the review. The nature of the Regional Health Schools allows the audits of those schools to be focused on quality of educational support for students with significant illness/injury.

Tier Five elements in New Zealand are supplied on the Regional Health School websites.

**Theoretical Framework**

From the audit in Table 3, it is clear that New Zealand has system level policies and practices in place to address the impact of absence from school on students with significant illness/injury against every element of the Theoretical Framework.
New Zealand has clear policy frameworks for managing the absences of students with significant illness and injury, through the Regional Health Schools. The model includes formalised, joined up education and health services, and extensive collaboration between the parties involved in the care and education of students with significant illness or injury. There are resources for parents and regular school staff on the RHS websites and policies on the use of ICTs to keep students connected to their regular classrooms. The Regional Health Schools work to ensure that students do not face educational disadvantage based on where they live, providing educational support services outside of hospital settings and major metropolitan areas.
Table 3 – International Audit Theoretical Framework

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<th>Jurisdiction</th>
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<td>Resources &amp; Professional Learning for regular school staff</td>
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The Netherlands

As discussed in School connection for seriously sick kids, the approach taken in the Netherlands offers a well-regarded, working example of a model established to support students with significant illness or injury.

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. The original consultants were hospital school teachers, after the hospital schools were disbanded.

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 elements of good and better practice. There is regular application of real-time interactive, two-way audio-visual links between student and classroom for students unable to attend school due to their medical circumstances (Gilmour et al., 2015).

Policy and Standards Hierarchy

The Netherlands has a number of Tier One elements in the Policy and Standards Hierarchy. These include the Primary Education Act, Secondary Education Act, Compulsory Education Act, and the Equal Treatment (Disability and Chronic Illness) Act. At Tier Two, the principle of Education that fits is of particular interest for the provision of services for students experiencing non-negligible absence from school due to significant illness or injury. Under this policy, every school board has the responsibility to provide adequate education for every pupil that enrolls, regardless of their specific educational needs and the kind of support that they need. By cooperating with other school boards at a regional level, schools are required to arrange educational provisions in such a way that every child can be educated, taking into account their special educational needs.

At the Tier Three level, the Netherlands has a number of managerial, administrative and financial mechanisms to assist in reducing educational disadvantage for students with significant illness or injury. A financial mechanism is demand-oriented financing. This policy is known as the 'back-pack' policy: pupils take the funding with them to the school of their choice. If a student meets the criteria for this so-called 'pupil-bound budget', parents and pupils can choose a school – special or mainstream – and take part in decision making on the best way to use the funds in order to meet the student’s special needs. An administrative mechanism is the increasing use of video conferencing to support students who are absent from school connect with
their classroom. A managerial mechanism is the previously mentioned use of consultants placed at Education Centres or Education Advisory Bureaus.

**Theoretical Framework**

The Netherlands model incorporates all the elements of the theoretical framework. The model ensures the development of a culture of inclusion in schools, which improves the knowledge in the regular school of the needs of the student with significant illness or injury. The model uses ICTs to allow students to maintain connection with the regular school. Parents and students are highly engaged in the planning, implementation and review of education and care arrangements. Practitioner support for both medical and teaching professionals is provided. The Netherlands approach ensures joined up education and health services. Collaboration and formalised links between all parties involved in the education and care of students with significant illness or injury is present and consistent across the 12 provinces of the Netherlands.
What is working?
Before the question of ‘What is working?’ can be answered, there must first be a definition of what ‘working’ entails. For the purposes of this review, if something is working to mitigate the educational disadvantage of students with significant illness or injury, it involves some or all of the following elements:

- The system in which it is operating has an appropriate hierarchy of policies and standards for this cohort.
- It fulfils multiple elements of the theoretical framework.
- It demonstrates evidence of good or better practice.

Policy and Standards Hierarchy
As demonstrated in Table 1, the only jurisdiction in Australia which has an appropriate hierarchy of policies and standards to minimise educational disadvantage for students experiencing non-negligible absence due to significant illness or injury is Western Australia.

Theoretical Framework
As demonstrated in Table 2, the only jurisdiction in Australia which fulfils multiple elements of the Theoretical Framework is Western Australia. There is the potential for Victoria to join Western Australia, through the follow up to the 2015 review and the process of establishing the Monash Children’s Hospital School.

Good and Better Practice
While investigating provisions within Australian and international educational jurisdictions for students experiencing non-negligible absence due to significant illness or injury, a number of programs were identified which incorporated good and better practice. Within these programs, three major themes have become apparent. These themes are inter-agency collaboration, communication and place.

Inter-agency Collaboration
Participants realise that to achieve the desired outcomes, they have to agree to radically alter the way they think, behave and operate. Collaboration is not about making adjustments at the periphery; it is about systems change and as such, participants are involved in a high-risk, high-stakes and volatile environment that can produce results significantly different from those originally intended...Collaboration demands participants forge new relationships and learn new ways of dealing with each other (ARACY, 2009).

Building networks and working collaboratively makes a lot of sense and can deliver many things that are not possible by working alone. But they don’t always happen organically or by magic. Most are hard to create and even
harder to sustain. They are also not business as usual and require new ways of thinking, behaving, managing, leading and evaluating (Keast, 2016).

Successful collaboration across government and non-government agencies is clearly possible, and is occurring in a range of environments including supporting students experiencing non-negligible absence due to significant illness or injury.

One component of the collaborations explored in this review is an understanding of the relationships of power. Such understandings can only be achieved when participants have both a high level of trust and extensive dialogue (ARACY, 2009). In collaborations such as the West Australian School of Special Educational Need: Medical and Mental Health (SSEN: MMH), and the Queensland State School Nursing Service (SSNS), the people involved in establishing the collaborations were able to determine where the power lies, and the relationships between those exercising that power.

Once the power relationships are understood, strategies can be developed to impact the power structure and share power. These strategies will vary, depending upon the environment in which the collaboration is occurring. New Zealand has not required Ministerial level agreements to establish the Regional Health Schools (RHS). It has been posited that NSW Education has not yet been successful in establishing a MoU between Health and Education in that state, because the relationship structure is simply too complex. The ACT is currently establishing a program which targets collaborations at multiple levels within the power structure simultaneously⁴. These include the Directors-General, community sector leaders on a Human Services Taskforce, and the frontline workers and managers in a Core Design Team.

A clearly articulated theory of change can be useful in developing successful inter-agency, place-based collaboration.

People need to be supported in the process of change, and place-based initiatives have the capacity to facilitate change by giving people the tools they need to plan, collaborate and execute change (Centre for Community Child Health (CCCH), 2012, p.14).

Theory of change is a comprehensive description and illustration of how and why a desired change is expected to happen in a particular context (http://www.theoryofchange.org/what-is-theory-of-change/). In both the New Zealand and Western Australian examples, the requirement for more flexibility in meeting the needs of students experiencing non-negligible absence due to significant illness or injury drove the development of the change process, and has resulted in systems which are highly collaborative and place-based. In the United

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⁴ The Human Services Blueprint (the Blueprint) is a whole of system reform agenda to better utilise government investment in social outcomes. It seeks to enable community, health, education and justice systems to work in alliance to join up support to people and families (ACT Government, 2014).
States of America, the Healthy Schools Campaign (HSC) strongly advocates the use of theory of change in developing collaborative relationships (HSC, n.d. (b)).

**Communication**

Unsurprisingly, successful inter-agency collaboration requires successful communication between the partners and with communities. Lack of communication creates situations where errors, such as lack of provision of education for students experiencing non-negligible absence due to significant illness or injury, can occur. Thick communication flows (Keast, 2013) are one of the points of difference between coordinative and collaborative arrangements. Communication is a key element of successful inter-agency collaborations.

In Queensland, the SSNS has a significant communication strategy. Through collaboration with leading non-government agencies in the health arena, SSNS has created guidelines for school-based management of major health conditions such as anaphylaxis, asthma and diabetes. The guidelines include models of delivery of health care interventions. In addition to the communication between SSNS and the non-government agencies, SSNS also provides resources to schools. These resources range from electronic documents, to the training courses provided by SSNS staff, which provide support and up-skilling for education professionals. SSNS also communicates with the Ministerial Offices in Health and Education, in ensuring that the MoU which governs the organisation remains relevant and current.

HSC in the USA also has a major focus on communication. This includes high level governmental communication, as the recent joint letter launching Healthy Schools, Promising Futures toolkit (HSPF) to state education and health officials signed by the Secretaries of Health and Human Services and Education bears witness. The communication campaign for HSPF also includes a detailed digitally downloadable tool kit. Within programs, HSC communicates the shared vision of program members visually, verbally and through metrics. For example, in the Green Schoolyards project the metrics are used to assist in selecting sites for the program, and include aspects such as school income level, the amount of public green space in the community and water provision.

Communication is pivotal to the ACT Blueprint, whether in its development, establishment and ongoing actions. In the development process the consultation phase involved submissions to a public discussion paper, an online survey, an intensive design workshop, and focus groups. Whether in the co-design process, the Lead Worker role, or other elements, there are numerous online supports available to participants in the networks.

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5 The Healthy Schools Campaign is a non-profit organisation dedicated to ensuring that all students have access to healthy school environments where they can learn and thrive (https://healthyschoolscampaign.org/about/who/).

6 Green Schoolyards is a program to improve student access to multi-purpose, environmentally beneficial spaces which include outdoor classrooms, gardens, play equipment and ample greenery (https://samples.3dissue.com/colly/greenschoolyards/index.html).
School in Australia is recognised as a place of social inclusion as well as cognitive development (Closs, Stead, Ashad & Norris, 2001). The social element of engagement is a significant component of school connection. The importance of the regular school as the primary place of connection for students with significant illness or injury is well documented (Gilmour et al., 2015; Yates et al., 2010). A sense of community or connection between learners can be affected by the level of social presence felt by the learners (Barbour, McLaren & Zhang, 2012). Garrison and Anderson (2003) define social presence as “the ability of learners to project themselves socially and emotionally into a community of inquiry through the mediums of communication being used” (p.49). Students with significant illness or injury who are absent from school for extended periods, or who do not retain a sense of connectedness to their school community may be at risk of developing a low level of social presence. There are examples of successful Place-based programs which support students experiencing non-negligible absence due to significant illness or injury in education systems.

Australian Capital Territory

As previously discussed, the ACT Education Directorate utilises the Monkey in My Chair (MIMC) program to support junior students with significant injury or illness in maintaining connection to their school community, friends and teachers (Education Directorate, n.d.). While this program does not meet all of the requirements of better practice on combating social exclusion, it does focus on the issue of place, by maintaining a presence in the classroom through having a large plush monkey take the seat of the student when they are unable to attend school. A 2014 report from the trial of MiMC found that:

The Monkey is a focus for social engagement, and students feel better knowing that the Monkey has been holding their place in the class while they are absent. They comment on the activities in which they know the Monkey has participated, such as school assemblies, class excursions, and lunchtime with their friends. However, the Monkey is not used as a means of maintaining academic continuity or connection to formal learning, and this gap has still to be bridged (MissingSchool, 2014).

New Zealand

The RHS model is an example of a successful Place-based program, with modifications to accommodate the special educational needs of students living with significant injury or illness. Rather than students experiencing extended absence from their regular environment, the RHS itinerant teachers travel to work with the students. While students remain too unwell to attend their regular school, they can receive education at home, or in their community.

With regard to the principles of combating social exclusion, the RHS model meets the requirements of place, personalisation, choice and responsibility, and collaborative governance. The teachers take on the Lead Worker role. The model is flexible to the needs and lives of the students and their families. There are elements
of co-design in the location chosen for the teaching, and the accommodations and adjustments made to the work provided by the regular school. The program is sensitive to the needs of the students. In terms of collaborative governance, the RHS was established due to a cultural shift in the health system, away from extended admissions. The RHS is an example of the education system collaborating with the health system to ensure appropriate access to education for students.

Queensland

The SSNS is also a Place-based program, as the School Nurses work with students and schools in the school environment. The SSNS meets the requirements of the virtues of place, personalisation, choice and responsibility, and collaborative governance. The School Nurses take on the Lead Worker role. The model is flexible to the needs and lives of the students and their families, and the capacity of the school. There are elements of co-design in the creation of Individual Health Plans. The program is sensitive to the needs of the students. In terms of collaborative governance, the SSNS was established through a MoU between Health and Education, which has been reviewed and renewed since its original inception.

Western Australia

The SSEN: MMH provides programs in 18 different locations and includes a home-based education service (Gilmour et al., 2015). As in the New Zealand model, the SSEN: MMH meets the requirements of place, personalisation, choice and responsibility and collaborative governance. The major difference to the New Zealand model is the nature of the collaborative governance, which like the SSNS was established through a MoU rather than less formal processes.

Other Place-based Collaborations

Place was significant in the development and implementation of the Blueprint. The Local Services Network at West Belconnen is road testing important elements of place-based service delivery to determine what works in this area, as the “first law of place is that you should not make the assumption that what will work with one target group will necessarily work with another” (Evans, 2013, p.2). Strong Kids, Strong Centre also involves a strong element of place.

Student experience when it works

What is the lived experience of a student with significant injury or illness when collaboration, communication and place are working?

In the SSEN: MMH evaluation (Crosby, Bauer, Hughes & Sharp, 2008), the student responses acknowledged the significance of:

- SSEN: MMH teachers' persistence

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7 Strong Kids, Strong Centre is is a whole of community initiative to work together to make sure all Alice Springs kids have access to the best opportunities in life (http://www.strongkidsstrongcentre.com/).
• one to one teaching and communication with SSEN: MMH teachers
• keeping up with work from the regular school
• career guidance/future planning/ goal setting
• the "distraction" of school work (from being focused on their medical needs/their absence from their regular school)
• motivation and encouragement to stay focused on learning
• increased confidence
• alleviating anxiety associated with returning to their regular schools (Crosby, Bauer, Hughes & Sharp, 2008, pp.60-61).

That review also states that the collaborative practice in the Western Australian system “enhances outcomes for students by maintaining both educational and social links with their school community” (Crosby et al., p.62).

More recently, the SSEN:MMH have instituted a comprehensive evidence-based approach to assessing outcomes for clients of SSEN:MMH to increase the scope for informed decision-making regarding effective service delivery (G. Wheatley, personal conversation, 7 June 2017). This approach incorporates analysis of datasets available from the West Australian Department of Education including enrolment, attendance, caregiver information, teacher grades, NAPLAN test scores, judgements of attitude, behavior and effort (ABE), vocational education and training (VET) outcomes, on-entry assessments and tertiary entrance scores. The databases include all students enrolled in a government school at any point between 2008 and 2016 (inclusive). These data span the entire educational journey of students over this time.

These datasets have been matched with the database of students in the SSEN:MMH, which has collated information over time about the number of times students have been engaged with the school (number of ‘enrolments’), the duration of those enrolments, the main program associated with the enrolment (e.g. Oncology, Respiratory, Mental Health, Neurology, Burns, General Surgical, General Pediatrics etc), the number of service hours received with each enrolment, and number of liaison hours (e.g. teacher liaison with students’ regular school). These datasets have been linked and analysis is underway to examine longitudinal trends for students before, during and after their engagement with the SSEN:MMH. Results from the first year’s analysis will be in the SSEN:MMH 2017 Annual Report.

Aaron and Emma’s stories come to us through the New Zealand Health School system.
Aaron was 16 years old when he came to the attention of his local Health School Unit. He had stopped attending school 18 months before, due to chronic anxiety and had not left the house for all of that time, even though he was supported by CAMHS.

He was assigned to a teacher who started visiting the home as part of an education support programme. Initially she communicated with him through his father, as he was too anxious to talk to her directly. The Health School protocol is for 2 contacts a week and after several such contacts he was able to start talking to his teacher, who planned a programme for him, supporting his learning with continued home visits. With support from CAMHS and his teacher he started a gradual process of re-engaging with the outside world. The steps were small but incremental.

Leaving the house with his father was followed by a drive by of the local Health School support centre on the weekend when nobody was there. This progressed to entering the support centre when other students were not present. Home education visits were then replaced with meetings at the support centre with his teacher, outside usual student hours. The next logical step was to attend when with a couple of students, building up to attendance with up to 10 health school students.

All this took nearly 12 months of steady progress, during which he continued to complete his school work and gained a number of credits towards his National Certificate of Educational Achievement (NCEA) level 2 qualification. The teacher had carefully selected NCEA standards which did not require external examinations, so he was able to make progress without the challenge being overwhelming. The flexible nature of the New Zealand qualifications system assisted in this regard, as he could submit work towards a series of standards at his own pace. It allowed him to complete his level 2 certificate and earn some level 3 credits as well, giving him University Entrance and therefore access to tertiary courses.

Aaron continued to progress and one of the milestones he achieved was to attend the screening of a movie at a local theatre; quite an achievement for a person who could not leave his home 12 months before. Aaron went on to leave the school system and enrol in a University computing course.
Emma was a teen age cancer patient, who presented at Auckland’s Starship children’s hospital for treatment and was placed on the Northern Health School (NHS) roll by the school staff who are based there. She was from out of Auckland and enrolled in her local High School. The New Zealand system allows dual enrolment and Emma was admitted to the NHS roll, while remaining on her High School roll. The High School retained her funding and her place on their roll.

Emma was assigned to a NHS teacher who contacted her school of enrolment, ascertained where she was up to in her programme there. She also discussed with Emma, her medical team and her family what would be a realistic programme for her to undertake and they settled on just 3 subjects, selecting the key standards she would need to gain Level 1 literacy and numeracy minimum requirements. These standards were from maths, English and Classical Studies.

While she was in hospital, her teacher worked with her daily, fitting in sessions around her treatment. The treatment regime for her cancer included time in Starship as well as time at home, a 60 minute flight from Auckland. Her NHS Starship teacher liaised with her NHS Gisborne teacher. Her record of learning was accessible to both of her teachers, who added to her learning programme, updated her records and liaised with each other as she moved between Starship and her home. Her Gisborne teacher visited her at home twice a week and at times visited her at her grandparents’ home as she spent time there to allow her parents to continue to work.

As her treatment came to an end and she was given clearance to start to return to her High School, the Gisborne teacher reduced her visits to once a week, while Emma attended her regular school firstly for one subject and then built up to 4. By the end of the year she was attending often enough to come off the NHS roll, having gained enough credits for literacy and several for numeracy.
What isn’t working?
Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have (New Zealand Ministry of Health, 2001, p.1)

The disability service system has been described as discontinuous, inconsistent, redundant, fragmented and disintegrated (Porter, 2008, p.86).

Both *Keeping Connected* (Yates et al., 2010) and *School Connection for Seriously Sick Kids* (Gilmour et al., 2015) have provided details of what isn’t working for students experiencing non-negligible school absence due to significant illness or injury. The Policy and Standards Hierarchy, the Theoretical Framework and the recommendations from *School Connection for Seriously Sick Kids* provide a starting point for an exploration of what isn’t working. Further areas of challenge have been identified from other sources examined during the writing of this review.

Policy and Standards Hierarchy
Given that Western Australia is the only Australian educational jurisdiction with elements in all the tiers of the Policy and Standards Hierarchy, it is clear that the governance frameworks of the other jurisdictions are not working in this regard, and require remedial action.

Theoretical Framework
Given that Western Australia is the only Australian educational jurisdiction which fulfils multiple elements of the Theoretical Framework, it is clear that the practices of the other jurisdictions are not working in this regard and require remedial action.

Flow-on effects
There are a number of flow-on effects from the gaps in practice identified through the Policy and Standards and Theoretical Framework audits, which highlight areas of inadequate practice.

Absence Management
Schools and parents both have legal responsibilities to ensure that a student is attending school. Most States and Territories require attendance of students under the age of 17 in full-time school, and this requirement is made clear in attendance and absence policies. For example, the Queensland policy states that “Parents may be prosecuted if they do not fulfil their legal obligations in regard to enrolment and attendance of their child at school” (Department of Education and Training, 2017).

Very few States and Territories have policies and procedures in place that require action on the part of schools to manage non-negligible school absence for students with significant illness/injury. This failure of process creates a situation where...
students with significant illness or injury may experience educational disadvantage. It may also stop parents from being able to uphold their legal obligations in regard to the education of students with significant illness or injury.

**Data collection and evaluation**

“In order to ensure an evidence-base for intervention, more reliable data is needed” (Gilmour et al., 2015, p.8).

As articulated in *School Connection for Seriously Sick Kids* while there is a substantial amount of data relating to school attendance, and another collection relating to health and illness, there is very little to link the two.

Despite the existence of the National Standards for Student Attendance Data Reporting there is no clear policy or direction regarding collection of data in schools in relation to students experiencing non-negligible school absence due to significant illness or injury. Despite clear statements in attendance policies regarding requirements for schools to “monitor the regular attendance of students and develop and implement strategies to support students with identified attendance issues” (NSW Education, 2015), schools do not reliably have the data with which to develop and implement strategies for students experiencing non-negligible school absence due to significant illness or injury.

Very few of the jurisdictions which sourced programs discussed in this review could provide data on the impact of those programs, or the demographic breakdown of students accessing the programs. Thus, it is difficult to prove what is happening in practice. This lack of evidence based practice is unfortunately not usual in the Australian education sector:

- Programs run in Australia are plagued by the use of simplistic evaluation methodologies that use low quality and subjective data such as surveys. Evaluations often do not measure the impact on the children. A lack of follow-up means the endurance of any effects are impossible to determine. This makes it difficult to definitively ascertain whether there is a model that works to effect long-lasting change (Jha, 2016).

Without solid data on how many students are experiencing non-negligible absence from school due to significant illness or injury, or the level of support that they are receiving, or the impact of the support initiatives, it is very difficult for policy makers and providers to ensure that the needs of these students are being met, or that policy and practice comply with legal requirements.

**Inclusive practice**

“development of a culture of inclusion in schools which improves knowledge of the needs of students with significant illness or injury” (Gilmour et al., 2015, p.9)
What troubled Nicola, in particular, was the lack of understanding and interest on the part of the teacher at her former school who also told Nicola that her continued absences, due to hospitalisation, meant that she would be unable to produce the necessary folio for Visual Communications and that she should choose an alternative subject (Yates et al, 2010, p.34.)

“the woodwork teacher was really worried that he wasn’t going to get a mark because he hadn’t finished building a car” (Jackson, 2017).

While inclusion is the clear and legislated policy of all Australian education jurisdictions, both Keeping Connected (Yates et al., 2010) and School Connection for Seriously Sick Kids have documented the fact that students experiencing non-negligible school absence due to significant illness or injury are not reliably accessing appropriate and equitable accommodations and adjustments across all educational jurisdictions.

The extent to which inclusive policies are understood and implemented within school communities is a significant concern. Research from The Royal Children’s Hospital Education Institute suggests that over 60% of Victorian students recovering at home after hospitalisation have no support from their regular schools (Barnett, Hopkins, Peters, 2014). This may also be the case in other states and territories (ARACY 2015).

Students living with invisible conditions such as cystic fibrosis, epilepsy or sickle cell anaemia often struggle to achieve appropriate supports. Some educators query whether significant illness or injury ‘qualifies’ as disability, despite the clear statements within the DDA (1992) and the DSE (2005). As described in the student and parent stories shared above, there are teachers in Australian schools who are simply failing to provide accommodation and adjustments. Far too often, through communication breakdown, lack of clarity regarding policies or the roles of school staff, or lack of interest, teachers are uninformed about the special educational needs of their students with significant illness or injury, and their responsibilities under the DDA and the DSE (Jackson, 2012). In dealing with significant illness, there is frequently a level of scepticism from teachers which students must overcome (Njoku, 2008). Given this lack of understanding, it seems probable that students missing school because of significant illness or injury are not reliably being included in the NCCD (see data collection and evaluation).

The inequity in access to inclusive support may flow in part from the reliance on individuals within schools and families for advocacy. There is no clear national policy or direction regarding access to supports such as ILPs or Healthcare Plans for this cohort. Even the paperwork required to access inclusion support can be a roadblock for students experiencing non-negligible school absence due to significant illness or injury. For example, in the ACT, the Student-Centred Appraisal of Need forms do not cater for these students.
Reliance on outside providers

There are charities which provide education support services for students with significant illness. Organisations such as the Ronald McDonald Learning Program and Back on Track provide tuition for students who have non-negligible absence due to some significant illnesses. These programs do not provide support to students with mental health conditions. In contrast to the ACT experience of the Education Directorate implementing a support system for primary school students to improve school connection during period of absence, (the Monkey in My Chair program), in NSW this process has occurred only through the intervention of a charity.

When charity support is available, and parents and students wish to access such support, they are of course entitled to do so. However, it is inappropriate and possibly illegal for education practitioners to outsource their legal obligations under the DDA and the DSE to private providers. First and foremost, it is the responsibility of staff in the regular school to make the necessary accommodations and adjustments to ensure that a student experiencing non-negligible absence from school due to significant injury or illness is able to access education on the same basis as their peers. If such adjustments and accommodations are properly applied, then students experiencing non-negligible absence from school due to significant injury or illness should not be suffering from extensive educational disadvantage, nor requiring support from external providers such as charities.

Informal arrangements

“formalising the roles and responsibilities of all parties, including parents and carers, in supporting students with significant illness or injury” (Gilmour et al., 2015, p.11).

“while responsibility for their health and wellbeing lies with everyone, accountability currently rests with no one.” (Gates, 2016, p.5).

Because of the gaps in Policy and Standards Hierarchies, much current practice in educational accommodations and adjustments for students experiencing non-negligible school absence due to significant illness or injury relies on informal arrangements within schools. This results in inequity across and within jurisdictions. Some examples include:

Advocacy: The extent to which a student’s needs are addressed is heavily reliant on the disposition and capacity of individuals within the school and the family, and thus there is widespread variability and inequity in the educational access afforded (Lavoipierre, 2012; Wilkie, 2012). Many parents find themselves responsible as main advocate for the needs of the student with significant illness or injury, and they often lack support and expertise to do this well (Yates et al., 2010). Parents of students experiencing significant illness and injury can experience ‘management fatigue’, in which case there is no-one to advocate for their child.

Student Voice: or student impact are phrases which describe the capacity of students to participate in and contribute to decision-making about their health and
education (Shaddock, 2016). Partnering with students experiencing significant illness and injury to identify the problems they are experiencing with their education and possible solutions (Savrock, 2008) is not a formalised practice across all Australian education and health jurisdictions.

**School processes:** and rules for claiming special consideration tend to focus on identifiable absences or markers of physical incapacity. They do not deal adequately with the experience of significant illness or injury as an uneven and continuing process over time (Yates et al., 2010).

**Transition** (change of year level, change of school, return to regular school, introduction of major medical treatments): The literature is replete with examples of challenges in transition for students experiencing significant illness or injury (Gilmour et al., 2015; Lindsay et al., 2015; Shaw & McCabe, 2008; Yates et al., 2010). This is most clearly apparent when students transition from hospital to home, prior to returning to their home school. The period of transition at home can be extensive, particularly for students with critical illnesses such as cancer. Current practice in many Australian educational jurisdictions does not address the challenges of access to education for students experiencing non-negligible absence due to extended transitions at home. There are many suggestions on possible formal transition arrangements, such as those found on the National Association of School Nurses site.

It is important that a balance be found which allows for the development of formal processes for transition that retain sufficient flexibility to meet the individual needs of students experiencing non-negligible absence as a result of significant illness or injury. This cohort is extremely diverse, and we know from the literature on policy learning that the first law of place is that you should not make the assumption that what will work with one target group will necessarily work with another (Evans, 2010).

**Personalisation**

Five sets of barriers …: lack of belief in participants by service providers; limited help in negotiating services; lack of trust by participants in service providers; competing demands from social services; and, poor communication (Evans, 2013, p.3).

Parents find that having an advocate from within the system amplifies their own voices and adds an objective view to their personal perspective on their child’s needs (Porter, 2008, p.85)

effective models of education support for students with health conditions must … be coordinated by a designated education professional, linked to the mainstream education and healthcare systems, and not rely on the parent to fulfil this role (Hopkins, 2016, p.217).
Human connection—personalisation through the Lead Worker role—is not reliably present in the supports available for students experiencing non-negligible absence due to significant illness or injury. In the absence of personalisation through a Lead Worker, there are many challenges faced by students and families in attempting to engage with multiple, potentially competing services across multiple locations. Human connection is significant in ensuring positive experiences for those using support services (Institute of Child Protection Studies, 2015). It is important to acknowledge that parents’ frustration over their struggle to secure services for their child can spill over into their interactions with each new practitioner that they meet (Porter, 2008). Families value professionals’ advocacy resources; the privileged status of professionals can boost families’ voices across services (Kasahara & Turnbull, 2005).

**Place**

It is important that, as far as possible, school provides a venue for (students experiencing non-negligible absence due to serious illness or injury) to be ‘normal’ (Porter, 2005, p.89)

The significance of the regular school as a place of academic and social connection for students experiencing non-negligible absence due to significant illness or injury is well documented in the literature (Dockett, 2004; Porter, 2008; Shiu, 2004). Also well documented in the Australian literature is the disconnection from regular school experienced by this cohort (Gilmour et al., 2015; Jackson, 2012; Shiu, 2004; Yates et al., 2010).

The majority of Australian education jurisdictions do not currently provide opportunities for mobile, place-based education at home or in community for students experiencing non-negligible school absence due to significant illness or injury.

**Silos**

Silo Mentality in organisations encourages localized, disconnected decision-making. In this culture everyone is making decisions based on their own local context and personal requirements. They see no incentive to make their own changes in order to solve another’s problem (Perception Dynamics, 2016).

Operating as a whole rather than in parts or silos allows us to achieve the best for our children and young people (Milich, 2016).

Many of the individuals interviewed for this review spoke of the frustrations and potential damage that silos cause for attempts at collaboration.

Silo mentality may contribute to the current lack of collaboration between the health and education systems in Australia in relation to students experiencing non-negligible school absence due to significant illness or injury. Silo mentality is also apparent in the challenges facing students with significant illness or injury accessing NDIS supports. The barriers encountered by this cohort demonstrated in the
literature (Gilmour et al., 2015; Yates et al., 2010) have some similarities to those barriers experienced by other vulnerable groups in relation to the provision of government services. Evans (2013) describes the creation and maintenance of these barriers through a lack of genuine collaborative practice and poor communication.

**Student experience when it doesn’t work**

What is the lived experience of a student with significant injury or illness when these elements are not working? It is the experience of disconnection, isolation and exclusion which dominates the conversations of the students and parents who are living with the physical, social and educational impact of non-negligible school absence.

Some examples of the experiences of the students in the *Keeping Connected* report (Yates et al., 2010) are included below.

And yeah, it’s hard at school...like I’m a step behind because I’m constantly, you know, I can’t pay attention in class because I’m tired and stuff and I miss days that I’m sick. So it’s like at school I’m playing from behind at the moment just trying to catch up, constantly trying to catch up. When I had the operation I missed a lot of subjects and the teachers didn’t really follow it up or anything yeah and they didn’t give me any work to do or anything.

For Hilary, the physical manifestation of her condition led to bullying. Initially her former friend started calling her a ‘hunchback’, and other students at the school joined in. The school did not address the issue adequately despite repeated reports by the young person and her family. Eventually this was resolved by changing schools.

Kylie was bullied at school and on MySpace, and when she was physically threatened (with her leg held together with a brace and pins) the school responded by wanting to put Kylie and her tormentor together in the same room to ‘sort it out’. The denial of a teacher aide meant that Kylie was reliant on the goodwill of her fellow students for assistance and this dependence had a profound effect on her friendship group. Kylie expressed gratitude for the support of two girls who wheeled her into class and were themselves late as a consequence. She described a culture of fear and intimidation, which permeated her school.

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

Young people who experienced long term stays and more frequent returns to hospitals spoke about the loneliness and isolation, yet they also remembered the comfort they gained from the simple everyday occurrences such as receiving gifts, cards and visits from classmates. For young people whose
families lived in outer urban or rural areas, hospital visits were less frequent. Once at home and away from the hospital environment the young people stressed the need for friends and how significant their presence or loss had been on their identity and wellbeing. Lisa, before her stroke, had been a student who was taking an academic VCE course and excelled as an ‘A’ grade hockey player. Her sense of social exclusion began with the school administration who told her family that perhaps this school was no longer the place for her. Moving on and getting a fresh start in a new school interstate was a major step for Lisa. When asked what she was looking forward to in her new school she did not mention educational opportunity. The desire to be connected socially was her first priority.
What could be improved?

Where are the levers for change, and how can we make the greatest difference to the largest number of people? (CCCH, 2012, pp. 9-10).

Nurture networks of connection and communication, create climates of trust and mutual support, encourage questioning and reward innovation (Center for Ecoliteracy, 2011).

Diversity is a fact, inclusion is a practice and equity is a goal (Alikan, 2016).

For many students experiencing non-negligible absence due to significant illness or injury, their parents, their teachers and their medical teams, the question of what could be improved is rather like the question of how to eat an elephant. It is a daunting task, and it is difficult to choose where to start. In this review, the Policy and Standards Hierarchy, the Theoretical Framework and the recommendations from School Connection for Seriously Sick Kids provided the starting point. Further areas of improvement have also been identified from other sources examined during the writing of this review.

Recommendations on potential actions which can be taken across each strata of the health-education nexus will be provided in the final report of the Taking Responsibility project.

Policy and Standards Hierarchy

It is clear from Table 1 that the elements of Tiers Three, Four and Five of the Policy and Standards Hierarchy are least frequently evident. As a result, across most Australian educational jurisdictions there is limited support available to reduce the educational disadvantage experienced by students experiencing non-negligible absence from school due to significant illness or injury.

The first steps to developing good policy is to ensure that policies, standards and procedures fit within the overall hierarchy, and that there are no gaps within the hierarchy. Clearly, there is much scope for change in the governance frameworks of most Australian education jurisdictions.

Theoretical Framework

Achieving sustainable change to the curriculum, school organization and outreach has been proven difficult for many schools that may not fully share or understand the ... goals and objectives that have driven this reform (St Ledger & Nutbeam, 2000, p.46).

The elements of the theoretical framework which are met least frequently are:

- policy frameworks managing absence for this cohort;
• resources for parents,
• formalised collaboration between Health and Education Departments;
• policies on the use of ICT to assist in maintenance of regular school connection;
• ensuring provision of education support services outside of hospital settings, and
• ensuring that provision is consistent across jurisdictions so that students do not face discrimination based on where they live.

**Other Areas for Improvement**

**Collaboration**

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 (Gilmour et al., 2015, p.67).

Health and education systems are inextricably linked, yet they are missing key opportunities to work together to support student health and learning (HSC, 2015).

Drawing upon Bio-ecological Systems Theory (Bronfenbrenner, 1977), it is clear that collaboration within and across micro-, meso- and macro-levels is required (Figure 2). In the context of students experiencing non-negligible absence due to significant illness or injury, these systems can be represented as:

**Figure 2 Bio-ecological Systems Theory**

Each of the levels interacts with and influences the others. For example, students respond to the processes of health care and education. Likewise, health care and education organisations and communities are responsive to policies that in turn influence students. When micro-, meso- and macro-systems work effectively within themselves, health care and education are efficient; students experience appropriate care and have opportunities for learning on an equal basis to their peers. Dysfunction within and between the systems creates waste and ineffectiveness (World Health Organisation, 2002).
In the health field, collaborative care has long been seen to improve health care outcomes, is cost effective, and increases patient satisfaction (Keleher, 1998). Collaborative practice is common in Australian schools. Several examples of successful collaboration between government and non-government agencies across health, education, and other social services are provided elsewhere in this paper. It is clear that nationally and internationally, within both health and education, collaboration is occurring across macro-, meso- and micro-systems.

To work effectively for and with students experiencing non-negligible absence from school due to significant illness or injury, it is essential that “we engage with stakeholders across the health, education ... and other sectors. We must ensure the marginalised have access to opportunities” (Ki-moon, 2016, p.3). Without effective collaboration, we cannot begin to ensure that provision is consistent across jurisdictions so that students do not face discrimination based on where they live.

**High level government commitment**

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 (Gilmour et al., 2015, p.10).

A common feature of successful inter-agency and cross-sector collaborations is clear leadership and direction from levels of government.

Regional Health Schools (RHS) were established by the New Zealand Ministry of Education under Special Education 2000, as a flexible and responsive solution to the challenge of students missing school due to significant illness or injury. Since the introduction of the RHS, the Ministry of Education has continued to demonstrate its commitment to this model. In Australia, the MoUs which exist in Queensland and Western Australia have enabled the establishment of cross-sector, flexible, responsive programs. The United States Surgeon General set up a Working Group which led to the establishment of a National Collaborative on Education and Health (NCEH). Also in the United States, the Healthy Schools, Promising Futures (HSPF) program was launched with a policy letter signed by the Secretaries of Health and Human Services and Education.

This is an area of the health-education nexus in Australia which has great potential for improvement. It is also an area which will be required for success in ensuring that provision is consistent across jurisdictions.

**Cross-sectoral, public and private partnerships**

“greater collaboration and formalised links between all parties involved in the education and care of students with significant illness or injury” (Gilmour et al., 2015, p.9).

Successful collaboration to support students experiencing non-negligible absence from school due to significant illness or injury requires more than high level
government agreement. When attempting to meet the needs of this cohort, they must be placed fully within their micro-, meso- and macro-environmental levels, and not necessarily restricted only to the systems of support provided in government agencies.

SSNS provides an Australian example of the value of working across government and non-government systems. There is potential for the ACT Defined Care Teams to be used in cross-sectoral, public and private collaboration around students with significant illness or injury, as Chapter 25 of the Children and Young People Act 2008 provides the legal framework for government agencies to ask for, receive and give information to specified people and agencies including all ACT Health staff and Education staff. (For further discussion on this issue, see the Taking Responsibility Case Study report.) Collaboration with the leading non-government agencies in the health arena has provided a depth of resources for schools. In Western Australia, involvement with the non-government sector has provided funding opportunities which have allowed for much greater flexibility in approaches. Further investigation of cross-sectoral public and private partnerships in the health-education nexus may be appropriate, particularly in terms of ensuring practitioner support and up-skilling for both medical and teaching professionals.

**Learning Collaboratives**

“ensuring that provision is consistent across jurisdictions so that students do not face discrimination based on where they live” (Gilmour et al., 2015, p.102)

The issue of ‘silos’ was raised by many of those interviewed for this review. In overcoming silos, direct action must be taken to develop a culture of collaboration and communication across agency and state or territory boundaries.

In the United States, the National Collaborative on Education and Health (NCEH) involved the bringing together of state teams to enable states to learn from one another and share the lessons learned from their work with others across the country. Within NCEH, participating state teams include representatives from the Education and Health Departments and at least one school leader. The state teams are encouraged to include state-level partners, such as advocacy organisations, and representatives from philanthropy organisations, health and education unions and associations, and other stakeholders (HSC, 2015). This level of inter-agency collaboration may be achievable in the Australian context, and could be significant in providing opportunities for practitioner support and up-skilling for both medical and teaching professionals, as well as assisting in ensuring that provision is consistent across jurisdictions.

**Creation and dissemination of resources**

“practitioner support and up-skilling for both medical and teaching professionals” (Gilmour et al., 2015, p.67.)
Given the absence of policies, procedures or frameworks across Tiers Three and Four of the Policy and Standards Hierarchy for students experiencing non-negligible absence from school due to significant illness or injury, it is unsurprising that the quality and quantity of Tier Five resources for schools, medical practitioners, students and parents vary across jurisdictions.

EQ provides extensive resources for schools and parents in support of students with specialised health needs. HSPF incorporates a detailed digital toolkit. SSEN: MMH provides a wealth of information to students, families and regular schools through its website. There are opportunities for most education and health jurisdictions to improve their services in this area, which would assist in ensuring that provision is consistent within and across jurisdictions and in practitioner support and up-skilling for both medical and teaching professionals.

**Communication**

“greater collaboration and formalised links between all parties involved in the education and care of students with significant illness or injury” (Gilmour et al., 2015, p.101).

The need for better communication, advocacy and protection of rights for this group must be recognised and addressed. Better avenues of communication are required between institutions, families and young people, and greater clarity about rights, entitlements and means of access to support are also sorely needed (Yates et al., 2010, p.13). Communication is significant to many of the Theoretical Framework elements which were least likely to be achieved in the audit (Table 2).

**Data collection and evaluation**

“Gathering data makes the invisible visible, and analysing it helps us discover what works and what doesn’t” (Gates, 2016, p.5).

“engaging schools and state and territory education departments to obtain access to any detailed school-level records of attendance and causes of absenteeism” (Gilmour et al., 2015, p.9).

Tier Four of the Policy and Standards Hierarchy is where the systemic data collection and evaluation controls should sit. As demonstrated in Table 1, the majority of Australian educational jurisdictions do not have Tier Four elements which can provide data on the implementation of actions to reduce educational disadvantage for students with significant illness or injury.

In addition to data in relation to how these students are supported, *School Connection for Seriously Sick Kids* stated that there are a number of areas for improvement in the collection of data about this cohort of students. It is currently difficult to determine reasons for absence from school, or cross-correlate reasons for absence with duration of absence. While the *Nationally Consistent Collection of Data (School Students with Disability)* may improve this situation, there still remains the
challenge of teachers recognising that significant illness or injury meets the definition of disability under the DDA (1992) and the DSE (2005).

The lack of data around students experiencing non-negligible absence as a result of significant illness or injury contributes to an environment where there is an absence of rigorous data evaluation. For example, given the absence of data to interrogate it is difficult for schools or systems to measure motivation and engagement for this cohort, or the impact of school absence. It is extremely difficult to evaluate the impact of policies and practices when there is no understanding of the baseline.

**Formal inclusion processes**

Development of a culture of inclusion in schools which improves knowledge of the needs of students with significant illness or injury (Gilmour et al., 2015, p.67)

The right to be included at every level of society is a goal worth pursuing, as it is central to what our society believes (Powell, 2012, p.16).

Inclusive education is the stated policy of all Australian educational jurisdictions (ARACY, 2013). It is important to remember to look at inclusive education through more than a disability lens. Rather than establishing special educational programs for students experiencing non-negligible school absence as a result of significant illness or injury, Shaddock, Giorcelli & Smith (2009) suggest that it is better practice to expand mainstream thinking, structures, and practices so that all students are accommodated. Formal inclusion processes for students experiencing non-negligible absence due to significant illness or injury should assist in the support and up-skilling of teaching professionals, and the *Good Practice Resource and Practicum Guides* produced as a component of this research aim to be a step in that direction.

**National Policy and Standards Hierarchy**

“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” (Gilmour et al., 2015, p.10).

“ensuring that provision is consistent across jurisdictions so that students do not face discrimination based on where they live” (Gilmour et al., 2015, p.10).

As demonstrated in the audit against the Policy and Standards Hierarchy, there is currently no Tier Three national policy which addresses the challenges of accessing education for students experiencing non-negligible absence from school due to significant illness or injury. Filling the gaps in the National Policy and Standards Hierarchy could be an appropriate tool to ensure that health and education professionals and officials have the knowledge, and the appropriate assistance and professional development they require to successfully provide access to medical treatment and learning, for all children, well (Powell, 2012). In addition, a Tier Four national standard could address the current lack of quantitative data on this cohort,
through providing direction on data collection and evaluation. Such a practice could address questions of consistency of provision across jurisdictions, and practitioner support and up-skilling.

**Funding**

“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” (Gilmour et al., 2015, p.10).

This funding will need to have some flexibility, which allows individual schools to accommodate the needs of their own student population (Powell, 2012). Critical to the success of place-based initiatives is public funding, a commitment to long-term investment and a preparedness to review and redesign services (CCCH, 2012, p.11).

Commonwealth, State and Territory governments in Australia have committed themselves to the principle of inclusive education, and to the support of principles of inclusive societies. National priorities and reforms have been agreed to by all governments through the Council of Australian Governments (Gonski, Boston, Greiner, Lawrence, Scales & Tannock, 2011). Appropriate funding is needed to ensure that these commitments are appropriately applied to students experiencing non-negligible absence from school due to significant illness or injury. Without such funding, it will be extremely difficult to ensure the development of a culture of inclusion in schools which improves the knowledge of the needs of students with significant illness or injury, or implementation of ICT into school environments to allow students to maintain connection with school.

**Place-based Programs**

“development of a culture of inclusion in schools which improves knowledge of the needs of students with significant illness or injury” (Gilmour et al., 2015, p.9)

Place-based programs only work well if they have full strategic and political support. Place-based programs work well because they simplify the complexities associated with joining-up several services (system change) and the participants’ interactions with those systems (system navigation) (Evans, 2013, ix-x).

As a lens through which to drive change, place should be defined locally with children and families at the core. Because localities differ, each will raise unique solutions but building on a universal platform, nurturing local leadership, sustaining commitment, delivering high quality services and using existing resources effectively are critical to positive outcomes. (CCCH, 2012, p.5)
The significance of the regular school as the place which allows students experiencing significant illness and injury to retain a sense of normalcy and a connection to their peers and their learning cannot be overstated. The regular school can be the pivot point around which the educational, medical and social supports required by these students and their families can rotate. A focus on the regular school, and an awareness of the impact of non-negligible absence from that school on the student, could contribute to the development of a culture of inclusion which improves knowledge of the needs of students with significant illness or injury, and encourage the implementation of ICTs into school and home environments to allow students to maintain connection to their regular school.

Practitioner Education

“practitioner support and ‘up-skilling’ for both medical and teaching professionals” (Gilmour et al., 2015, p.67).

Ensuring that teachers are well prepared to teach diverse student populations and meet the needs of all learners requires an understanding of the principles and practices that underpin inclusive education environments...Additionally, teachers need to have access to ongoing professional development, which will assist in their being able to adapt to changes in both what they teach, and how they teach, for all students (Powell, 2012, p.15).

Inclusive education is already a compulsory component of pre-service education for Australian teachers. However, the issues highlighted in Keeping Connected and School connection for seriously sick kids clearly demonstrate that current practice in pre-service and in-service teacher education and professional development is inadequate to ensure appropriate access to education for students experiencing non-negligible absence from school due to significant illness or injury. The Good Practice Guide and Pre-Service Guide produced as part of Taking Responsibility are an attempt to address some of these inadequacies, through provision of practitioner support and up-skilling for teaching professionals. The challenge of appropriate practitioner support and up-skilling for medical and allied health professionals remains.

Student and parent voice

“Engagement of parents and students as equals in the planning, implementing and review of education and care arrangements” (Gilmour et al., 2015, p.67)

Ensuring that the voices of the students and their parents are heard is increasingly being recognised as an important component of shared decision making (Savrock, 2008) in both health and education environments. It is good practice to involve young people themselves in the creation of the solutions to the challenges they face. By including them and making sure that their voices are heard, we can empower them to drive change (Gates, 2016). Participatory or co-design of accommodations and adjustments for students experiencing non-negligible absence from school due to significant illness or injury ensures the inclusion of student and parent voices.
One example of good practice within education in ensuring that student and parent voices are heard can be the use of ILPs and Healthcare Plans. The consultative process of establishing, implementing and reviewing an ILP or a Healthcare Plan by the student, the parent(s) and the school is a clear example of providing opportunities for student and parent voices, and the engagement of parents and students as equals in planning, implementing and reviewing education arrangements. However, as discussed earlier, there is currently no requirement for students experiencing non-negligible absence due to significant illness or injury to have an ILP or a Healthcare Plan.

**Student experience when systems are improved**

*What is the lived experience of students when all of the elements discussed in this section are improved?*

The theoretical framework provided in *School Connection for Seriously Sick Kids* describes what the student experience could look like:

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 (Gilmour et al., 2015).

*What is the lived experience of students when any one of the elements in the theoretical framework is improved?*

An evaluation of the services provided in Western Australian (Crosby, Bauer, Hughes & Sharp, 2008) included several case studies of student experience. Some of the outcomes described in that evaluation include:
• Reintegration to enrolled school was very successful, particularly after her second stay in hospital.

• Student was confident on her return that she had maintained work standards during her hospital admission.

• Enrolled teachers were more aware of helpful strategies to support student with her health issues.

• An established routine is in place for her continued participation in an educational program although affected by ongoing health related issues.

• Successfully returned to regular daily activity, including study.

• Significantly improved in socialisation and skills, active in college and community sport.

• Achieved positive increases in self-esteem, confidence and mood based on reinforcement of successes and achievements.

• Developed confidence and greater independence appropriate for her stage of adolescence which will allow her to be active in her life decisions, planning and actions.

• The student returned to school full time in the last 2 weeks of fourth term. He was very tired and found it difficult to keep up with a busy classroom schedule.

• Accommodations were made for him to be able to lie down and rest in the classroom when necessary which enabled him to resume classroom activities afterwards.

• His regular school teacher commented on factors contributing to his successful return to school: "We all had the same goal and were prepared to do whatever it took to get there. Because the school community, and particularly his teachers, have been so involved in his journey over the last year, accommodations are made to help him participates fully in school. "(Crosby et al., 2008, pp.65-68).

Recent research into the implementation and integration of ICT into school and home environments to allow students to maintain connection with school via video conferencing (Jackson, 2017) has provided the following responses:

**Engagement**

• from a student: “I probably wouldn’t have done half the work that I did” [if there had not been a video conferencing connection].
• from a parent: “It’s one thing to be putting notes into school and saying: She’s sick and can’t be at school. It’s another thing when the teachers can see them at home. The teachers can see what’s happening for her and can see that she’s still trying to engage. She’s still trying to learn. The teachers don’t write her off.”

Connection
• from a teacher: “If we hadn’t had the connection, we might have lost her completely”

• from a student: “I actually have a friend who knows me talking about the class work as well. Helping me” [in real time, across the video connection].

Hope
• From the parents: “its hope for her future.”
Conclusion
This review of current practice has demonstrated that there are gaps in the Policy and Standards Hierarchies of most Australian States and Territories, in relation to students experiencing non-negligible absence due to significant illness or injury. While there are pockets of good and better practice in the health-education nexus which provide support for these students, current provision of education support to reduce educational disadvantage is fragmented (Barnett et al., 2014). This fragmentation is unsurprising, as the gaps in Tiers Three to Five of the policy and standards hierarchies create a lack of systemic guidance and direction.

This review has also demonstrated that there are gaps in practice across most Australian States and Territories against a Theoretical Framework for better practice in relation to students experiencing non-negligible absence due to significant illness or injury. These gaps are most apparent in regard to policy frameworks for managing the absence of this cohort; resources for parents; formalised collaboration between Health and Education Departments; policies on the use of ICTs to assist in the maintenance of regular school connection, and provision of educational support services outside of hospital settings.

Like the reports before it (School Connection for Seriously Sick Kids and Keeping Connected), this review of current practice has demonstrated the need for action to ensure that another generation of Australian students do not face discrimination and disadvantage, through being denied access to education on the same basis as their peers.

A reduction in educational disadvantage will not happen on its own. Like any ambitious goal, it requires a comprehensive and innovative strategy. Continuing the status quo will not reduce disadvantage, and over time may even increase it (Perry, 2017).

The time for action is now. The time for system change is now. It is not acceptable to leave the way open for yet another investigation into the same issues to be called at some time in the near future (Wild, 2016). If Australia does truly believe that children are our future, then we must teach them well (Creed & Masser, 1977). In order to teach them well, we must ensure that the health and education systems understand and meet their joint responsibilities for students experiencing non-negligible absence from school due to significant illness or injury. We must ensure that the policies and standards required are in place, and that the fulfilment of those policies and standards is appropriately evaluated.
Appendix One

Definitions and Key Terms

Disability

Medical conditions and illnesses are clearly included under definitions of disability in the Commonwealth legislation:

"disability", in relation to a person, means:

(a) total or partial loss of the person's bodily or mental functions; or
(b) total or partial loss of a part of the body; or
(c) the presence in the body of organisms causing disease or illness; or
(d) the presence in the body of organisms capable of causing disease or illness; or
(e) the malfunction, malformation or disfigurement of a part of the person's body; or
(f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
(g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour (Disability Discrimination Act, 1992).

In more general usage, disability may be understood to mean vision, hearing or mobility impairment or behavioural issues, 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 review, we accept medical conditions, illnesses and injuries as disabilities as defined under the Commonwealth Disability legislation (Commonwealth of Australia, 2016).

Engagement

Engagement can be defined as the evidence of time, energy and resources that students devote to activities which are designed to enhance learning (Corbin, Burns & Chrzanowski, 2010). For education to be successful, student engagement is vital: “Education is not a spectator sport; it is a transforming encounter. It demands active engagement, not passive submission; personal participation, not listless attendance” (Corbin, Burns & Chrzanowski, 2010, p.43). Attendance (listless or otherwise) can be a major challenge for students with significant illness or injury.

Enrolment/registration/participation/attendance

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 review, participation is defined as a student engaged in meaningful activities which support his or her social or academic development (Gilmour et al., 2015).

**Regular school**
The school that 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 this review) (Gilmour et al., 2015).

**School**
School is defined as including 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 review (Gilmour et al., 2015).

**Silo Mentality**
‘Silo Mentality’ is defined as a mindset present when certain departments or sectors within systems do not wish or do not know how to share information with others. This type of mentality will reduce efficiency in overall operation and reduce confidence in the individuals and systems involved (http://www.businessdictionary.com/definition/silo-mentality.html). Silos are the opposite of collaborative practice.
Appendix Two

Policy and Standards Hierarchies
Appendix Three

Summary of Current Practice by Jurisdiction

ACT

Policy frameworks:

Resources & Professional Learning for regular school staff: FAQ in The Canberra Hospital School Information Pack – hard copy distributed to schools in 2016, not yet available online.

Resources for parents:

Formalised collaboration between Health and Education Departments:

Policy on use of ICT to assist in maintenance of regular school connection: No formal policy – pockets of practice in this area e.g. use of video-conferencing between individual students and their regular school classrooms; Canberra Hospital School teachers check online learning environments at student induction.

Provision of education support services outside hospital setting:

Provision of support services outside major metropolitan settings:
**New South Wales**

Policy frameworks:

Resources & Professional Learning for regular school staff:

Resources for parents:

**Formalised collaboration between Health and Education Departments**: Bridging the Gap project – initiated by Sydney and Westmead Children’s Hospitals, seeking to identify key principles to improve collaboration between health and education around students with disabilities.

**Policy on use of ICT to assist in maintenance of regular school connection**:  

**Provision of education support services outside hospital setting**:  

**Provision of support services outside major metropolitan settings**:  

Northern Territory

Policy frameworks:

Resources & Professional Learning for regular school staff:

Resources for parents:

Formalised collaboration between Health and Education Departments:

Policy on use of ICT to assist in maintenance of regular school connection:

Provision of education support services outside hospital setting:

Provision of support services outside major metropolitan settings:
**Queensland**

**Policy frameworks:**

**Resources & Professional Learning for regular school staff:** LCCHS teachers have prepared targeted digital resources about educational connection for regular school teachers of students with some chronic health conditions (i.e cancer and Cystic Fibrosis). Queensland Ed-Linq health staff providing training for teachers on mental health related issues.

**Resources for parents:** LCCHS Guidance Officers and the Leadership team work with families to assist them in negotiating appropriate education supports for their children/young people.

**Formalised collaboration between Health and Education Departments:** Regional Working Parties which include representatives from both Health and Education Departments. DET led Advisory Group for Students with Mental Health Conditions. This group has representatives from Education (all sectors), Health, HSAC, CYMHS, Qld Mental Health Commission. Hospital School Advisory Council – includes teachers, parent groups, health representatives and the Lady Cilento Hospital Foundation. Education representative on the Mental Health, Substance Misuse and Residential Care Settings initiative.

**Policy on use of ICT to assist in maintenance of regular school connection:** No formal policy – evidence of pockets of practice in this area e.g. Telepresence robot at Ferny Grove State School; trial of the iConnect program in the LCCH Burns Unit connecting to LCCH School classrooms only.

**Provision of education support services outside hospital setting:**

**Provision of support services outside major metropolitan settings:** Approx. 12 settings where teachers are based in regional hospitals.
South Australia

Policy frameworks:

Resources & Professional Learning for regular school staff:

Resources for parents:

**Formalised collaboration between Health and Education Departments:** Oncology Education group that meets monthly to discuss the educational needs of oncology students to ensure they do not fall through the gap – nothing for other members of the illness/injury cohort.

Policy on use of ICT to assist in maintenance of regular school connection:

Provision of education support services outside hospital setting:

Provision of support services outside major metropolitan settings:
Tasmania

Policy frameworks:

Resources & Professional Learning for regular school staff:

Resources for parents: Resources for specific conditions only – through School Nurse Program; Medical Action Plans (via community service organisations).

Formalised collaboration between Health and Education Departments:

Policy on use of ICT to assist in maintenance of regular school connection:

Provision of education support services outside hospital setting:

Provision of support services outside major metropolitan settings:
Victoria

Policy frameworks:

**Resources & Professional Learning for regular school staff:** Resources only for specific conditions – Royal Children’s Hospital Education Institute website.

**Resources for parents:** Resources only for specific conditions – Royal Children’s Hospital Education Institute website.

**Formalised collaboration between Health and Education Departments:** Potential for future – Monash Children’s Hospital School

**Policy on use of ICT to assist in maintenance of regular school connection:** Potential for future – Monash Children’s Hospital School

**Provision of education support services outside hospital setting:** Potential for future – Monash Children’s Hospital School

**Provision of support services outside major metropolitan settings:** Potential for future – Monash Children’s Hospital School
Western Australia

Policy frameworks: ✓

Resources & Professional Learning for regular school staff: ✓

Resources for parents: ✓

Formalised collaboration between Health and Education Departments: Defined in MOU.

Policy on use of ICT to assist in maintenance of regular school connection: School of Special Educational Need: Medical and Mental Health policy on using ICT to assist connection.

Provision of education support services outside hospital setting: ✓

Provision of support services outside major metropolitan settings: ✓
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**Australian Research Alliance for Children and Youth**


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**Australian Research Alliance for Children and Youth**


