Taking Responsibility:

Preventing educational disadvantage for seriously sick kids experiencing school absence

Final Report

ARACY

Australian Research Alliance for Children & Youth

Collaboration • Evidence • Prevention

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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.

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Acronyms

Australian Research Alliance for Children and Youth	ARACY
Council of Australian Governments	COAG
Disability Discrimination Act	DDA
Disability Standards for Education	DSE
Individual Learning Plan	ILP
National Disability Insurance Scheme	NDIS
Nationally Consistent Collection of Data (School Students with Disability)	NCCD
Northern Regional Health School	NHS
School of Special Educational Need: Medical and Mental Health	SSEN:MMH
State School Nursing Service	SSNS

Executive Summary

Every school day, in any given school across Australia, a significant number of 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 report provides an overview of current knowledge, 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 if or how jurisdictions are working to build cooperation across and between organisations.

The report 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.

Key findings:

The key findings identified through this project include:

- there is Commonwealth and state 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 existing 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 illness or injury.

Key recommendation

The key recommendation of this report is for a number of actions across all levels of government to ensure absence from school due to illness or injury does not lead to educational disadvantage. To achieve this, we recommend:

Australian Government

- Establish policies and standards mandating all jurisdictions to fulfil their obligations and responsibilities under the *Australian Education Act* (Commonwealth of Australia, 2013) and the *Disability Standards for Education* (Commonwealth of Australia, 2005) (DSE) as they pertain to students experiencing absence due to illness or injury.
- Provide reporting guidelines outlining the requirements under the *Nationally Consistent Collection of Data (School Students with Disability)* (NCCD) process for students experiencing absence due to illness or injury. These guidelines should include

stipulations around consistent standards for recording and reporting on absence, and the required responses.

- The Australian Government Departments of Education and Health and the Australian Bureau of Statistics formalise health and education data linkage and collection processes to allow for improved monitoring and research into the numbers of students with significant illness or injury, and the extent of their absence, and to determine support needs and resources accordingly.
- Convene a working group on health and education, through the auspices of the Council of Australian Governments' (COAG) Education Council, to build consensus and understanding of the roles and obligations of health and education services at the jurisdictional level to prevent educational disadvantage for students who miss school due to illness or injury.

State and territory governments

- Education and Health Directorates or Departments review their Policy and Standards Hierarchies to ensure adequate provision of policies and standards to support this cohort
- Education and Health Directorates or Departments contribute to agreed data collection strategies to ensure absences and the reasons for them are recorded systematically and inform policy development and service delivery for students experiencing non-negligible absence from school due to illness or injury.
- Education and Health Directorates or Departments establish Memoranda of Understanding at the Ministerial level, which detail their joint responsibility for and commitment to education for this cohort, and arrangements for improving health and education collaborative practice in relation to this cohort.

Education and healthcare providers

- As required by state or territory policy (see above)
    - collect and report data on school absence due to illness and injury for all students
    - make reasonable adjustments to ensure students have access to education

A number of more detailed recommendations are also included in this report, recognising that the process of transforming policy in to practice involves efforts at all levels from legislative change through to classroom and clinical practice.

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?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.

The current project, *Taking Responsibility: Preventing educational disadvantage for seriously sick kids experiencing school absence (Taking Responsibility)* was commissioned by the Australian Government in response to the 2015 report commissioned by MissingSchool - *School connection for seriously sick kids – who are they, how do we know what works and whose job is it?* (Gilmour et al., 2015). The project is comprised of a mixed methods approach to better understanding the current practices supporting school engagement for students who experience chronic, repeated or lengthy absence due to ill health.

This report summarises the outcomes of the project. It outlines the key findings from the review of current practice and a case study of network based collaboration between students, parents, and health and education providers. These key messages have been incorporated into a good practice guide and a pre-service practicum resource to support educators and schools to build effective engagement with students who miss school due to illness or injury.

The primary aim of this project was to investigate the 'wicked' problem of how to mitigate educational disadvantage for students experiencing non-negligible school absence due to significant injury or illness. Beyond exploring current practice within the Australian health and education systems, it has identified key points of policy and governance that can support powerful shifts in educational engagement and outcomes for these students.

With a focus on systems level change, *Taking Responsibility* seeks to provide the beginnings of a national response to this issue.

Background

Students who experience absence from school due to significant illness or injury can experience educational disadvantage. The cause of this disadvantage is neither their illness nor injury, nor is it the sum of their absences. Rather, educational disadvantage stems from the fact that across the health-education nexus their absences from school are not treated as important.

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 (Information Services Division Scotland, 2010). However, the shortening of hospital stays creates a situation in which the student is no longer in receipt of hospital based educational support, nor well enough to attend their regular school.

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.**

Under current legislation in most Australian jurisdictions, 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 (Australian Capital Territory (ACT) Education and Training Directorate, 2011). As previously discussed, all jurisdictions allow for absences to be explained through the provision of medical evidence. 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 stated. In the absence of support from the education system, a student experiencing non-negligible, explained absence from school will experience educational disadvantage.

Inclusive practice

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 *Disability Discrimination Act 1992* (DDA) and the DSE (2005). As described in student and parent stories shared in *Taking Responsibility: Review of Current Practice*, there are teachers in Australian schools who are not providing accommodation and adjustments for this cohort. 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). Given this lack of understanding, there is a question whether or not students missing school because of significant illness or injury are reliably being included in the NCCD.

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 regarding access to supports such as Individual Learning Plans (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.

Student experience when it doesn't work

So, what is the lived experience of s student when the systems are not working effectively to counter the educational disadvantage caused by non-negligible absence from school? Disconnection, isolation and exclusion dominate the conversations of students and parents living with the physical, social and educational impact of non-negligible school absence. Dysfunction within and between the health and education systems can cause educational disadvantage through:

- 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 (Gilmour et al., 2015).

Project methodology

This project involved development of four key deliverables. For the length of the project, ARACY has been assisted by a group of critical friends who have provided expert feedback on content and reporting. The project has also been supported by a Project Advisory Group, who provided guidance and feedback for the project.

Review of current practice

The *Taking Responsibility: Review of Current Practice* undertook to address the 'wicked' problem of the educational disadvantage that students experiencing non-negligible school absence due to significant injury or illness encounter. It explored cultures and practices within Australian health and education systems; it examined the gaps and inconsistencies apparent within the health-education nexus that all too often contribute to educational disadvantage for children experiencing chronic, lengthy or repeated school absence due to illness or injury (Savage, 2016). Australian and international evidence was reviewed to examine how and where 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, as well as how and where the two systems are failing to manage that connection.

ARACY conducted consultations with:

- Australian national, state and territory education and health administrators, co-oordinators, and teaching staff.
- International education administrators, co-oordinators, and teaching staff.
- Hospital school teachers and networks.
- Australian and international peak bodies and non-government organisations within the education-health nexus.

Primary research: case study

An increased sense of connectedness with school is a significant factor in a future sense of well-being for children and young people (Jose & Pryor, 2010; Yates et al., 2010). In order to facilitate this sense of connectedness, ARACY and MissingSchool have proposed a framework for educational inclusion and equity for students with significant illness or injury. This framework includes "greater integration and alignment of health, education and social support provision, and methods to ensure that students have continuing connection with their regular school when absent from it" (Gilmour et al., 2015, p.7).

In this case study, elements of the ARACY framework were tested, through a study of facilitated collaboration between the network of players involved in the education of children and young people with significant illness and injury. This network included the student, their parents/carers, school staff, school leaders, medical practitioners and other Health and Education Directorate staff.

The aim of the case study was to facilitate a focused, participatory process to strengthen collaboration between students with chronic illness or injury, their

parents and carers, teachers, school staff and medical professionals. The major objective of this case study was to demonstrate how health and education professionals can work together with students and their families as a network, to ensure students remain connected to their school and education while they are away due to significant illness or injury.

The research questions guiding the case study were:

1. Can the introduction/facilitation of collaboration between network members improve the school connection and academic engagement of children and young people living with chronic illness/injury?
2. Is the direction of any changes in collaboration consistent across the different members of the network?
3. Do attitudes about trust and collaboration processes change as the network evolves? If so, what changes are evident, and what can be learned from these changes?

Good Practice Resource

A resource for in-service teachers has been developed. This resource is informed by the *Review of Current Practice* and the *Case Study.* The resource has been created in the format of the School Support Cards on the Leading Learning 4 All website.

Practicum Guide

A guide for pre-service teachers has been developed. This resource is informed by the *Review of Current Practice* and the *Case Study.* The resource is framed through the Australian Professional Standards for Teachers and the principles of Universal Design for Learning.

Findings – Review of current practice

What works?

According to current research evidence in this area, the most effective responses to mitigate the educational disadvantage of students with significant illness or injury involve some or all of the following elements:

- Education and health systems that have an appropriate hierarchy of policies and standards for this cohort.
- Education and health systems that fulfill multiple elements of the theoretical framework.
- Education and health systems that demonstrate evidence of good or better practice.

Systems are in place ensuring clear pathways from legislative governance to service level response

In successful systems, a series of strategic and operational requirements are met. These can be envisaged as a policy and standards hierarchy, in which obligations and responsibilities are articulated from the level of legislation through to the practices of individuals at the point of service delivery.

For this project, we have utilised the Policy and Standards Hierarchy shown in Figure 1. The hierarchy is comprised of five Tiers: Laws, regulations and requirements (Tier 1); Principles (Tier 2); Policies (Tier 3); Standards (Tier 4); and Procedures and processes, Baselines, and Guidelines and practices (Tier 5). This hierarchy provided a guide for an audit of current levels of educational support and absence management provided across Australia's states and territories as well as two comparable international systems, New Zealand and The Netherlands.

Action aligns with a theoretical framework for effective performance

A theoretical framework was proposed in the 2015 ARACY and Missing School report, *School Connection for Seriously Sick Kids* (Figure 2). The framework was developed to incorporate promising common or emergent practices relating to inclusion and participation of students in education.

This framework is based around three common guiding principles:

1. *Individualisation*: approaches 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;
2. *Collaboration:* relationships are 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);
3. *Equity:* students and their families are treated as equal partners and actively involved in planning, implementation and review.

Further, four main underpinning elements were identified as likely to be necessary for strategies and approaches to be implemented effectively:

1. *Legislative policy and accountability:* approaches are mandated as a norm, can be funded, promoted and supported, and are subject to scrutiny and accountability;
2. *Financial, infrastructure and time:* resources required to develop, implement and review strategies and approaches such as teaching staff, medical equipment;
3. *Leadership:* advocacy, promotion and implementation of approaches and strategies. This may manifest at a local level with school principals driving their school strategy and actions to support students with significant illness or injury or at a wider community, social, or political level; and
4. *Human capacity and capability*: training of educators and health practitioners to implement approaches, provision of additional time to perform certain roles, information for parents and families so that they are best placed to advocate for their child and access appropriate support etc.

The review of current practice also involved mapping of Australian and international performance against this theoretical framework.

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 are apparent. These themes are inter-agency collaboration, communication and place.

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

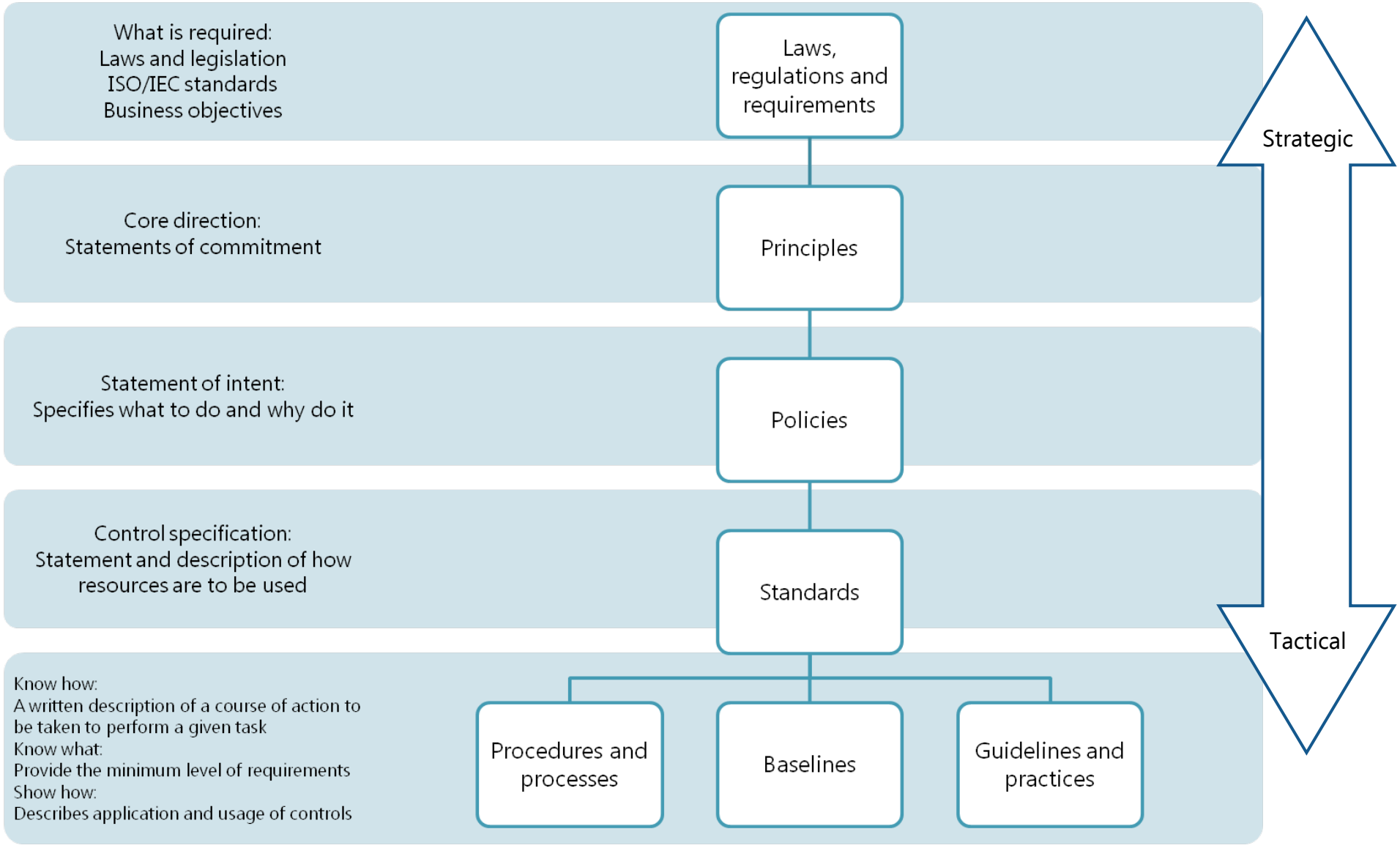

Figure 2 – Theoretical Framework (Gilmour et al., 2015)

DESIRED OUTCOME

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

Example pre-conditions of this outcome

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

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

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

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

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

Potential strategies and approaches to address the pre-conditions

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

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

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

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

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

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

1. Maintaining dedicated teacher contact and instruction throughout the course of absence
2. Alignment of school curricula with hospital or homebound education environments
3. Adopting effective technology to provide 'real time', virtual participation in the classroom
4. Ensuring a transition plan and suitable measures are in place to support absence management and a return to school

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

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 School of Special Educational Need: Medical and Mental Health (SSEN: MMH) evaluation (Crosby, Bauer, Hughes & Sharp, 2008), the student responses acknowledged the significance of:

- SSEN: MMH teachers' persistence
- 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).

The following case studies were provided by the New Zealand Health School system.

Emma

Emma was a teenage 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.

Aaron

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.

What's happening?

Tables 1 and 2 provide visual representations of the results of the hierarchy and framework mapping process. All Australian educational jurisdictions were approached to verify the mapping of their jurisdiction against the policy and standards hierarchy and the theoretical framework (for details see the *Review of Current Practice*).

Policy and Standards Hierarchy

There are multiple elements of the Policy and Standards Hierarchy present at the national, state and territory levels. Across all jurisdictions Tiers One and Two are adequately populated, however, there are significant gaps in the provision of support at Tiers Three to Five (policy, standards, procedures, processes, baselines, guidelines and practices).

Tiers Three and Four include mechanisms around policy, management, finance and administration, and data on standards of compliance. Without these elements, it will be difficult for schools to ensure that students experiencing non-negligible absence due to significant illness or injury are not experiencing educational disadvantage. This is because it is the existence of such policies and data requirements that drives the Tier Five school-level response. Without the guidance, encouragement and reporting requirements of policies and standards, the students are reliant on the good will of individual school leaders and teachers, rather than standard practice.

Tier One – Laws, regulations and requirements

At the national level, Tier One includes the *Australian Education Act* 2013 and the DSE (2005). These provide that illness or injury should not limit the quality of a student's education. The DSE (2005) clarifies 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. As the Education Act states, "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).

Tier Two – Principles

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.

All states and territories have adequate Tier One and Two provision, through their respective Education Acts and other legislation. However, it is notable that many of the regulations that are in place around inclusion and equity in education are focused solely on disability, with significant illness and injury not specifically identified.

Tier Three – Policy

At the Tier Three level, there are two major policy mechanisms in place at the federal level.

The 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 disability supports from their regular schools, there is a question as to whether or not these students are currently being included in the NCCD.

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. While the site did not originally include direct reference to students with significant illness/injury, there are plans to correct this omission in the near future.

There is substantial variability across the states and territories at the Tier Three Level. Western Australia is the only jurisdiction with established Tier Three mechanisms 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.*

Tier Four – Standards

There is no national provision at the Tier Four level. Once again, there is substantial variability across the states and territories at the Tier Four level. In Western Australia the SSEN: MMH requires that there are individual service level protocols in place wherever dedicated staffing is provided. 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.

Tier Five – Procedures and processes; Baselines; Guidelines and Practices

There is no expectation of Tier Five provision at the national level. In Western Australia Tier Five provisions include the procedures, processes, baselines, guidelines and practices available on the SSEN: MMH website. Both the ACT and Victoria have emerging provision at this level. The process of establishing the Monash Children's Hospital School may result in some Tier Five elements in Victoria. The provision of

an Information Pack by the Canberra Hospital School is the beginning of Tier Five practice, but the pack has had limited distribution and was only provided in hard copy.

Currently, there are no national Tier Three policy nor Tier Four standards that explicitly address the challenges of accessing education for students experiencing non-negligible absence from school due to illness or injury. Across most Australian educational jurisdictions there is limited support available through policies and standards to reduce the educational disadvantage being experienced by this cohort. Filling the gaps in Tiers Three and Four of the hierarchies would build the capacity of health and education professionals to provide systematic support to improve outcomes for students experiencing non-negligible absence due to illness or injury. A national standard in Tier Four could address the current lack of quantitative data on this cohort by providing direction on data collection and evaluation.

Theoretical Framework

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 provided in the *Review of Current Practice*. The information for this audit was drawn from *School Connection for Seriously Sick Kids*, and the resources, materials and individuals consulted in the *Taking Responsibility* project, including the Policy and Standards Hierarchy. It is important to note that this is an audit of specific policies 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, p8).

When approached for feedback on the audit, a number of States and Territories attempted to insert general disability support policies and procedures into the table. None of the educational jurisdictions who referred the researcher to initiatives designed for students with disabilities were able to provide data on the numbers of students experiencing non-negligible absence from school due to significant illness or injury accessing the provisions of those initiatives. It is clear from this response that the message from *School Connection for Seriously Sick Kids* around the need for specific provisions for students with significant illness/injury has not successfully reached its target audience.

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

The elements of the theoretical framework most commonly missing in the audit of current practice across Australia 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 barriers to access and inclusion based on where they live.

Table 1 - Policy and Standards Hierarchy Mapping

	National	ACT	NSW	NT	Qld	SA	Tas	Vic	WA
Tier One	√	√	√	√	√	√	√	√	√
Tier Two	√	√	√	√	√	√	√	√	√
Tier Three	√		?					?	√
Tier Four								?	√
Tier Five	N/A	?						?	√

Table 2 - Theoretical Framework Audit by Jurisdiction

Jurisdiction	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
ACT		?		?	?		N/A
NSW				?			
NT							
Qld		?	?	?			√
SA							
Tas		?					
Vic		?	?	?	?	?	?
WA	√	√	√	√	√	√	√

√ Adequate provision
? Emerging provision
Blank No provision

Good and better practice

Through the *Taking Responsibility: Review of Current Practice*, three important elements were found to occur in effective practice. These were: inter-agency collaboration, communication and place.

Inter-agency Collaboration

Successful collaboration across government and non-government agencies is currently occurring in a range of environments where health and education professionals are supporting students experiencing non-negligible absence due to significant illness or injury. Due to the interpersonal nature of collaboration, for collaborative efforts to be successful there are a number of necessary elements in the relationships between the professionals in a team. These include a willingness to collaborate, trust in each other, mutual respect and communication. In addition to the above conditions, which are necessary but not sufficient, organisational determinants play a crucial role (San Martin-Rodriguez, Beaulieu, D'Armour & Ferrada-Videla, 2005).

One component of the collaborations explored in this report 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 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 but may include establishing Memoranda of Understanding or other formal agreements to govern collaboration.

A clearly articulated theory of change can be useful in developing successful inter-agency, place-based collaboration. Theory of change is a comprehensive description and illustration of how and why a desired change is expected to happen in a particular context (Center for Theory of Change, 2016). 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 States of America, the Healthy Schools Campaign[1] (HSC) strongly advocates the use of theory of change in developing collaborative relationships (HSC, n.d. b).

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

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.

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 Memorandum of Understanding which governs the organisation remains relevant and current.

Communication across agencies is assisted by formalised information sharing arrangements, such as those detailed in Chapter 25 of the *ACT Children and Young People Act 2008* or laid out in Memoranda of Understanding such as those around the SSNS and SSEN:MMH.

Place

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. 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. Further details on examples of successful Place-based programs which support students experiencing non-negligible absence due to significant illness or injury in education systems are explored in the *Taking Responsibility: Review of Current Practice*.

Other findings: flow-on effects from system gaps

There are a number of flow-on effects from the systemic gaps in identified through the Policy and Standards and Theoretical Framework audits, which highlight areas that require responses at the level of policy and standards.

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).

However, 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.

Data collection and evaluation

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

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" (New South Wales 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 report could provide data on the impact of those programs, or the demographic breakdown of students accessing the programs. This lack of evidence based practice is unfortunately not unusual 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 ongoing 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.

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 provide tuition for students who have non-negligible absence due to some significant illnesses. The program does not provide support to students with mental health conditions. In contrast to the ACT experience of the Education Directorate implementing the Monkey in My Chair program (a support system for primary school students to improve school connection during period of absence), in NSW this process has been piloted 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 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.

Informal arrangements

Because of the gaps in Policy and Standards Hierarchies, much current practice in education 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 available, 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

Human connection is significant in ensuring positive experiences for those using support services (Institute of Child Protection Studies, 2015). Families value professionals' advocacy resources; the privileged status of professionals can boost families' voices across services (Kasahara & Turnbull, 2005).

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. It is important to acknowledge parents' frustration over their struggle to secure services for their child can spill over into their interactions with each new practitioner they meet (Porter, 2008).

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 (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 educational 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

Many of the individuals interviewed for this report 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. 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. Silo mentality is also evident in the challenges around NDIS support for students with significant illness or injury.

Findings: Case Study

Many of the findings from the Case Study echo previous research. In particular, the case study reaffirmed the evidence indicating collaborative practice across health and education systems requires deliberate action –collaboration is difficult to sustain without leadership, or without support from systemic policy and practice.

The participants in the case study recognised their interdependence and the areas where their practice overlapped. However, that recognition alone was insufficient to ensure successful collaboration. The participants demonstrated a high level of trust, mutual responsibility, and open lines of communication. They articulated the need for an agreed administrative structure to support collaborative operations and regular training and interaction opportunities to allow partners in the collaboration to share knowledge.

Successfully including the voices of the students with significant illness proved challenging in the Case Study. Capacity to utilise participatory research design methods were limited by the research approval process.

Case study participants drew attention to the fact that different practices for areas such as confidentiality and information sharing can be barriers to inter-agency collaboration. Despite the best intentions and goodwill, the proposal to develop a shared understanding and process document was not realised due to the time constraints of the research project. A contributing factor to this particular barrier to successful collaboration is well documented in the literature - collaboration generally takes more time than non-collaborative work and timelines for collaborative projects must be flexible. (ARACY, 2007). The participants rated the face-to-face collaborations as the most effective, again reflecting findings in the literature that barriers to collaboration can be made more manageable through clear, open and regular communication between collaborators at face-to-face meetings (ARACY, 2007).

In summary, one of the key barriers to effective collaborative practice between health and education systems, is the lack of appropriate policies and standards to support it. A lack of structure and direction for cross-sectoral collaboration is one element of a broader lack of policies and standards to minimise the educational disadvantage experienced by this cohort of students. Interprofessional collaboration can benefit, in particular, from the availability of standards, policies, and interprofessional protocols; unified and standardised documentation; and sessions, forums or formal meetings involving all team professionals (San Martin-Rodriguez et al, 2005).

Recommendations

The findings of this project indicate there is a substantial amount of systems level change required if children and young people experiencing non-negligible school absence due to illness or injury are to receive the educational access and opportunities to which they are legislatively entitled. These findings demonstrate that the recommendations of the School Connection for Seriously Sick Kids report have generally not been implemented by Australian education jurisdictions. The following recommendations build on the recommendations made by Gilmour et al in the School Connection for Seriously Sick Kids report, and articulated in the Missing School 2015 request to the Commonwealth Government (Missing School 2015).

The evidence from the many lines of enquiry that have informed this project supports a key high priority recommendation, calling for action to:

Transform the systematic management of student absence from school due to illness or injury.

Australian Government

- In consultation with the State and Territory Directorates or Departments of Education define chronic absence in the Australian context.
- Establish policies and standards mandating all jurisdictions to fulfill their obligations and responsibilities under the *Australian Education Act* (Commonwealth of Australia, 2013) and the *Disability Standards for Education* (Commonwealth of Australia, 2005) as they pertain to students experiencing absence due to illness or injury.
- Provide reporting guidelines outlining the requirements under the *Nationally Consistent Collection of Data (School Students with Disability)* process for students experiencing absence due to illness or injury. These guidelines should include stipulations around consistent standards for recording and reporting on absence, and the required responses.
- The Australian Government Departments of Education and Health and the Australian Bureau of Statistics formalise health and education data linkage and collection processes to allow for improved monitoring and research into the numbers of students with significant illness or injury, and the extent of their absence, and to determine support needs and resources accordingly.
- Convene a working group on health and education, through the auspices of COAG's Education Council, to build consensus and understanding of the roles and obligations of health and education services at the jurisdictional level to prevent educational disadvantage for students who miss school due to illness or injury.

State and territory governments

- Education and Health Directorates or Departments review their policy and standards hierarchies to ensure adequate provision of policies and standards to support this cohort
- Education and Health Directorates or Departments contribute to agreed data collection strategies to ensure absences and the reasons for them are recorded

systematically and inform policy development and service delivery for students experiencing non-negligible absence from school due to illness or injury.

- Education and Health Directorates or Departments establish Memoranda of Understanding at the Ministerial level, which detail their joint responsibility for and commitment to education for this cohort, and arrangements for improving health and education collaborative practice in relation to this cohort.
- State and Territory Directorates or Departments of Education:
    - Amend their School Attendance and Absence policies to address educational disadvantage caused by chronic absence, through inclusion of a definition of chronic absence and procedures to manage such absence for students with significant illness or injury.
    - Include provision in their standards requiring school to track and report absence management processes and procedures.

Education and healthcare providers

- As required by state or territory policy (see above)
    - collect and report data on school absence due to illness and injury for all students
    - make reasonable adjustments to ensure students have access to education
    - ensure that their attendance and absence policies include procedures, processes, baselines, guidelines and practices to manage the impact of chronic absence for students with significant illness or injury.

In addition to these key actions to ensure a systematic response to the issue of absence management, the findings of this project indicate a number of specific undertakings will support access to schooling for students who are absent due to illness or injury. These include:

- State and Territory Directorates and Departments of Education and Health provide and promote digital and hard copy access to the frameworks, policies, procedures and standards which support access to schooling for students who are absent due to illness or injury to schools, health providers, families and students.
- Education and Health services establish Learning Collaboratives to encourage health and education practitioners and officials to learn from one another and share the lessons learned from their work with others across the jurisdictions.
- Providers of tertiary education qualifications review the inclusive education programs within pre-service teacher education to ensure that accommodation of the needs of all students, whether or not they are physically present in school, is appropriately addressed.
- Providers of tertiary education qualifications review the pre-service education of medical and allied health professionals, to ensure that collaboration with education providers in support of this cohort is appropriately addressed.
- Educational jurisdictions ensure that in-service professional development for all school staff includes awareness raising of the eligibility for this cohort to access the accommodation and adjustment provisions of the Disability Standards for Education (2005) and the appropriateness of considering these students in the NCCD process

- Education jurisdictions mandate ILPs and Healthcare Plans for this cohort
- Education jurisdictions mandate age appropriate co-design of school based accommodations and adjustments for this cohort.
- Education jurisdictions review their provision of education support for this cohort, and if necessary, investigate the possibility of adopting more regional and mobile education support
- Education jurisdictions review their policies and procedures regarding access to funding for educational support and accommodations, to ensure that the needs of students experiencing non-negligible absence from school due to significant illness or injury are accommodated.

Conclusion

As stated in *School Connection for Seriously Sick Kids*, there is "undoubted goodwill and there are some determined efforts made by individuals, organisations, schools and communities to ensure that these students remain connected to education and learning" (Gilmour et al., 2015, p. 153). But goodwill alone is insufficient to ensure that every student experiencing non-negligible absence from school as a result of significant illness or injury is accessing appropriate levels of educational support in every school, every day. Australia-wide change is required to ensure that these students, their families and their teachers receive appropriate assistance and support.

This report 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 collaborative practice that 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 report 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 regards 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.

The health and education systems in Australia have a number of responsibilities they are legislatively required to deliver for students experiencing non-negligible absence from school due to significant illness or injury. The first step in ensuring these responsibilities are met is to ensure awareness of the obligations, and provision of guidance as to how best these obligations can be realised through policy and practice.

Policies and standards are required and fulfilment of those policies and standards should be monitored, measured and evaluated.

Collaboration is needed between the health and education systems at every level, and this will involve facilitation, support and appropriate resourcing.

These changes at the systems level are necessary in order to confidently say that the Australian education and health systems are effectively reducing educational disadvantage for students experiencing non-negligible absence from school due to significant illness or injury.

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