



## Public submission made to the Review to Achieve Educational Excellence in Australian Schools

Submitter: Missing School Inc.  
Submitting as a: Parent or community organisation  
State: ACT

### Summary

Students with significant illness or injury are protected under Australian disability legislation, but are invisible because they are absent from school often, or for long periods.

1. State and territory census processes – as well as national survey processes such as the Nationally Consistent Collection of Data, the ABS Profiles of Disability, and the ABS Survey of Disability, Ageing and Carers – should be amended, or new processes developed, to specifically identify school-age students who are absent from school because of significant illness or injury, and to assist in monitoring their progress.
2. State and territory education authorities need to develop legislation and policies which explicate where the responsibility lies for supporting students who miss school because of significant illness or injury, whether they are in hospital, recovering at home or receiving treatment interstate. Currently, there is widespread confusion around the roles of all parties.
3. State and territory education authorities need to ensure that legislation and policies are consistent across jurisdictions, as many of these students have short- and long-term treatment interstate. This, along with improved data collection and other measures, should be raised at the COAG Education Council for discussion and agreement.
4. State and territory education authorities should consult with all stakeholders (including families and students) to develop best practice and processes consistent with their legal responsibility. These should uphold the principles of access, inclusion and equity, offer two-way digital connection with the regular classroom and home teaching. Policies, processes and practice should be supported by reporting and monitoring mechanisms for compliance and accountability.

5. State and territory health and education authorities must formalise collaborative arrangements. Explicit policy and model, funding, Memorandums of Understanding, education outreach staff in hospitals, operational arrangements between hospital schools, hospitals, the students' regular schools and their home, and cross-departmental (and interstate) documentation and communication.

## Main submission

Thank you for taking submissions to the Review to Achieve Educational Excellence in Australian Schools.

What should educational success for Australian students and schools look like?

Flexible, adaptive and progressive to enable all students to reach their productivity potential in adulthood. School quality and education success should be measured by the extent to which all students are equitably included and supported to meet their potential.

What can we do to improve and how can we support ongoing improvement over time?

MissingSchool is a national parent advocacy organisation established to raise awareness of the educational needs of students who miss school because of significant illness or injury, and to work for inclusive and equitable access to quality education for these students via connection to their regular school. This was born out of the personal experience of numerous students and families, and a desire to see evidence-based practice firmly established in our schools through the state and territory education systems.

The Disability Discrimination Act 1992 (DDA) and the Disability Standards for Education 2005 (DSE) define disability to include illness. The rights of students with significant illness or injury are thus protected under that legislation.

With funding provided by a grant from the St George Foundation, MissingSchool partnered with the Australian Research Alliance for Children and Youth (ARACY) to investigate three questions fundamental to understanding how our schools respond to the needs of students who miss school because of significant illness or injury :

- How many students miss school because of significant illness or injury? (Who are they?)
- What are the best practice models for supporting their needs? (How do we know what works?)
- What legislative framework supports their access to education? (Whose job is it?)

The results of this 2015 report, entitled School Connection for Seriously Sick Kids, are summarised here. The report resulted in Commonwealth funded research, through ARACY, finished in June 2017 and pending release by Government.

(a) Current levels of access and attainment, and impact associated with inadequate support

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

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

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

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

During a hospital admission, a student may have access to a Hospital School. The stated mission of most Hospital Schools is to work with the student's home school to maintain continuity of learning. In practice, and for a variety of reasons, this is often not successful (Wilkie, 2012).

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

The school experience of many students with significant illness or injury is one of isolation and marginalisation. We estimate that this is the experience of around 60,000 students who experience frequent or extended absences from school because of illness. This number is likely to be much higher if one includes these students' siblings, who all miss school because of the energy devoted by the family to caring for a student with significant illness.

The burden of advocating for these isolated and marginalised students falls to families. These are families who are already overstretched physically, mentally, emotionally, and financially, may be separated from each other if the student has been admitted to hospital, and may be displaced from home if the admission has been to a specialist paediatric hospital in a different city or state. Failure to provide inadequate support means that the family faces the additional burden of having to work between two silo-ed systems – medical and educational – and attempt to identify and implement support measures on their own.

(b) Social, economic and personal benefits of improving outcomes

It is well recognised that connection to education is important to maintaining student engagement in learning. During a period of illness, it provides connection to normalcy, a respite from medical intervention and boredom. It helps to ensure academic continuity, and – critically – gives the student the message that they are expected to recover and that they are worth educating.

MissingSchool subscribes to the widely-endorsed understanding that “health” is not characterised by the absence of disease, but incorporates physical, mental and social wellbeing. MissingSchool also supports a social and ecological approach to healthcare which recognises the contribution of behavioural and environmental factors in maintaining health.

In the case of children and young adults, access to appropriate education is fundamental to health and wellbeing (The NEST Project, 2012; Blum et al, 2012). Addressing the educational needs of students with significant illness, and the social and emotional consequences of managing that illness, is thus an important

component of healthcare. Access to appropriate educational support is thus a protective factor in a context of ongoing multiple risks, and schools play a vital role in providing that access.

Today, thanks to medical advances, many children and young people who might once have died because of acute life-threatening illness or injury are surviving. Those with chronic illness are able to manage their illness better. To enable them to lead fulfilling and productive lives, at school and eventually in the workforce, these children and young people need access to education on the same basis as all other students. This offers broader social and economic benefits to their communities and to society as a whole.

(c) More Support for Students with Disabilities and Needs-based funding

The School Connection for Seriously Sick Kids report found very little research or evidence to support any single “best practice” model to support the needs of students who miss school because of significant illness. However, precepts of inclusivity and equity should underpin all policies and practice, and access to education.

An inclusive approach to education would indicate that students with significant illness or injury should be able to continuously participate in, or remain connected to, their regular school. Practices which facilitate continuing education participation and connection, whether in hospital or at home, include :

- continuing formal provision in multiple locations and environments;
- personalised needs-based learning, and flexibility to account for the nature of illness;
- communication between families, schools and health care practitioners;
- alignment with education authority curriculum requirements; and
- connective technologies (telepresence) in addition to face to face teaching in all locations.

Neither MissingSchool nor ARACY has undertaken any analysis of funding requirements to develop these practices, but we believe that the necessary infrastructure is largely in place in schools. A critical first step is to ensure that all parties are aware of their rights and responsibilities under the DDA and the DSE, which define disability to include illness. Specific (health-ed) policy measures and standards specific to this group are needed, and implementation of a funded model of best practice would follow. Appropriate standards, independent monitoring and measurement will support this, along with guidelines for managing, administering, and training to translate policy into practice.

(f) The Nationally Consistent Collection of Data on School Students with a Disability

Currently the Nationally Consistent Collection of Data (NCCD) focuses on adjustments made in school to accommodate students with disability rather than on the number of students with disability. It relies on schools' understanding of the nature of significant illness and injury and their student populations; Shiu (2004) observes that many schools fail to maintain adequate data on their students' health needs. Additionally, many schools, students and families are aware of neither the DDA and DSE definition of disability to include illness, nor of their legislated rights and responsibilities. This means that many students with disability, including those with significant illness or injury, may be overlooked.

While the NCCD does not preclude collection of data for students who are absent from school, they are not explicitly included. The failure to consider students who are not actually present in schools when collecting data means that their needs are not known or addressed, and it is this "invisibility" which gives rise to broader systemic failures. No agency in the country has data on the numbers of students who miss school because of significant illness; the Australian Bureau of Statistics (ABS) Profiles of Disability survey specifically excludes students who were not at school at the time of the survey.

Students who are attending hospital schools or who have spent lengthy periods recovering at home may be overlooked as their enrolment status at their regular school may not be clear, and they may not be reported by either school.

Currently, data for any particular student may only be included in the NCCD if the school holds 10 weeks of documented evidence of disability and adjustment. This means that students whose disability has not been disclosed or documented, students for whom no adjustment is being made, and students who have been absent from school may not be included in the NCCD.

The NCCD is being rolled out in stages across Australia, and so robust data will not be available for some years. Refinements to the process over future years must ensure that, as a matter of routine, it captures data on students who experience frequent or prolonged school absence related to significant illness or injury.

(g) Changes informed by evidence-based best practice

Until the NCCD is able to capture data on students who are absent from school, it will be unable to offer findings or recommendations of any sort to address their needs.

The report has not been able to identify any evidence-based best practice for a consistent framework of inclusive support. MissingSchool is calling for state and territory education authorities to collaborate within a national agenda to develop a

systemic model of education provision which ensures equitable access to education for students in all jurisdictions. This should be an inclusive model which upholds the students' right (under the DDA and the DSE) to maintain enrolment in their regular school, to participate in education on the same basis as other students, and to have access to appropriate curriculum, assessment and student services. This model should be rigorously monitored, evaluated and refined, in consultation with all stakeholders, to develop best practice.

(h) What should be done to better support students with disability in our schools

To ensure that we are meeting the needs of the group of students who miss school because of significant illness or injury, they need to be recognised as a group. Currently, they are overlooked by most data collection processes, and sometimes explicitly excluded. Census and survey processes such as the NCCD, the ABS Profiles of Disability, and the ABS Survey of Disability, Ageing and Carers should be amended, or new processes developed, to identify school-age students who miss school because of significant illness and to assist in monitoring their progress.

State and territory health and education authorities need to formalise communication channels which will assist them to collaborate in the care of a student who misses school because of significant illness.

State and territory education authorities need to develop legislation which explicates where the responsibility lies for supporting the education of students who miss school because of significant illness or injury, regardless of whether they are in hospital or recovering at home. MissingSchool asserts that the DDA and the DSE protect the right of students with significant illness or injury who miss school because of that illness or injury to :

- maintain enrolment in their regular school;
- participate in education through connection to their regular school; and
- have access to appropriate curriculum and assessment procedures, as well as student support services.

States and territories should ensure that legislation is consistent across jurisdictions, as many students who seek specialist medical care for significant illness must travel interstate. It should also recognise that there may be a continuing need for educational and learning support across the student's school life whether the illness is ongoing, or whether the student has recovered from the illness or injury leading to the absence.

While some states already have such legislation in place (e.g. Victoria), research shows that non-compliance is common (Barnett, Hopkins & Peters, 2014). Education authorities should thus also develop monitoring processes to ensure compliance and accountability.

Schools need to develop policies and practices which enable students with significant illness to be identified, and their absences managed. They should enable students to maintain academic continuity when they miss school as a result of illness, and should nurture the student's social and emotional wellbeing through connection into the learning community. These policies should be clearly communicated to teachers, students and their families, and their implementation monitored through regular review and reporting. All practices should be evidence-based and should involve consultation with the students and their families.

(i) Early education of children with disability

The recommendations outlined in (h) have been developed with reference to primary and secondary schools, but are equally applicable to other educational settings. Early childhood educational arrangements appear to be completely lacking in systemic support. This is important given the national recognition of the importance of early intervention in addressing disadvantage.

(j) Related matters

New information and communication technologies (ICT) are one of the most promising prospects for continuing education participation and connection of students with significant illness or injury – particularly in a real-time, virtual environment. Small-scale trials of ICT in the classroom suggest that this can be beneficial for students, although some challenges need to be overcome (such as teacher confidence, privacy issues, technology capability etc). These are being used at scale, along with a range of specific governance attributes, in the Netherlands and Belgium (Flanders) for example. MissingSchool is about to commence a national telepresence robot pilot to demonstrate this solution (through up to \$600,000 over three years from St. George Foundation). We are working through education systems for proof of concept, using the technology as a catalytic mechanism for system reform.

Conclusions and key recommendations

The complete list of key recommendations in the full report (referred to) is lengthy, and is indicative of the extent of work still to be done in order to ensure that students with significant illness or injury have equitable access to education despite missing school. The most significant of them have been outlined above.

Tens of thousands of students every year face disadvantage because they miss school as a result of significant illness or injury. Failure to take proactive measures to keep these students connected to education and their learning communities when they are absent from school gives rise to a suite of educational challenges to be addressed upon the student's return.



Principles of inclusivity and equity, as well as discrimination legislation, support the right of students to maintain academic continuity and participation in education despite illness or injury. In order to inform practice, reduce barriers and mitigate disadvantage, much more work is needed. This includes continued development of data collection systems, research into effective practice, and formal explication of the roles and responsibilities of all parties.

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

We thank the Committee for its consideration of this submission, and will be very happy to provide further information or clarification if appropriate.