

Don't wait until they're well

School support systems for students with serious illness

Summary

In schools across developed countries, up to 30% of students have an illness serious enough to affect their attendance^{1,2,3}, with millions in homes and hospitals experiencing isolation from their schools, teachers and peers⁴. But we don't have to leave our sick kids behind. We have the legislation and technology, now we just need the policy to get sick kids in Australia back into their classrooms.

Background

Good health and education place third and fourth in our global Sustainable Development Goals⁵. Yet in schools across Australia, up to 1,185,000 students⁶ may face an illness serious enough to affect their education and attendance. Within this cohort, tens of thousands are missing months to years of school and are cut off from their classrooms and community⁷. They're not getting a complete education, and thanks to incomplete data, we don't know the full extent of the problem⁸.

Unseen, these students face an increased risk of academic failure, social isolation and poor mental health^{9,10,11,12,13,14,15,16}. Combined with illness, social side effects can lower school completion rates and compromise career attainment, factors putting estimated lifetime costs in lost productivity close to \$1 million per student, and the potential price tag of inaction into the billions¹⁷.

An increasing number of students¹⁸ from all walks of life are confronting this double disadvantage. Advances in healthcare mean more are surviving serious illnesses (e.g. cancers), living longer with life-limiting illnesses (e.g. cystic fibrosis), and gaining clearer diagnoses (e.g. anxiety)^{19,20}. As they brave medical trauma, these kids are spending less time in hospital and more time at home^{21,22}.

Unsurprisingly, it's parents who find themselves carrying the burden of their child's learning and loneliness^{23,24,25}. Too often the student's education is left to charity or chance, or they're segregated to distance education^{26,27}. In hospital, students may access hospital schooling, but this too lacks what is vital: continuous connection with their peers, teachers, curriculum, and community²⁸. The outpouring of anxiety over education in COVID-19 lockdowns makes the need for connection extraordinarily clear^{29,30}.

In 2012, after experiencing my own son's two-year medical isolation, I co-founded advocacy group MissingSchool. The organisation has engaged in several audits of Australian law, policy, standards, and guidelines for these students^{31,32,33}. The findings concluded that sick kids across Australia *are* educationally disadvantaged because of critical gaps in governance, an absence of formal education and health agreements, and a lack of specialised support between school, medical settings and home^{34,35}.

Incomplete governance explains why schools find supporting students beyond the school gates a significant challenge, and hospitals don't see education as their role³⁶. Without clear policy, standards and practice guidelines, coordinated systematic support for these students, wherever they are, is impossible³⁷. We can do better.

As it stands, the consequence of coding "authorised absence"³⁸ for everything from a common cold upwards, results in automatically suspending school support for students with serious illness during absence. While still enrolled, these students slip into a policy wilderness, unable to attain the equity and inclusion in their education on the same basis as others, as enshrined by Australian law³⁹, Disability Standards⁴⁰ and ministerial declarations⁴¹.

We can't afford to wait until they are well. School connection keeps sick students in sync socially, helping to nurture their resilience and their identity as learners, and to ease deep anxiety about school absence and belonging^{42,43,44,45}. Critically, it offers hope by proving to sick kids that they are worth educating.

For Australian taxpayers, investments in students' healthcare and education—that continue even when they are absent from school—must yield equivalent personal, social and public returns⁴⁶ by giving these kids the opportunity to reach their potential.

The value of urgent action to these young lives is immeasurable. Our policymakers have the power of evidence to make effective, cost-neutral change. In fact, we don't even need new legislation. We simply need to apply support systems and technology to give these unseen students presence in their schools.

Issues

On the world stage, countries invested in their future workforce are doing things differently. In 2017, my Churchill Fellowship highlighted long-standing models of school support in Finland, Sweden, the Netherlands, Belgium, the United Kingdom (UK) and Canada. Common to all these countries—and New Zealand, which has long practised home teaching for kids in this context—were strong legal frameworks guiding school support for sick kids in practice, and a responsibility of governments to reduce educational isolation⁴⁷.

Australia does not lack legislation⁴⁸. The national *Disability Discrimination Act 1992* includes illness as a protected attribute⁴⁹. Under the Act, the Disability Standards for Education (DSE) require schools to give students with illness access to school facilities, accredited curriculum, and learning alongside their peers⁵⁰. The Standards provide for learning adjustments, use of assistive devices, and delivery of specialised support by schools. Essentially, they prohibit restrictive and gatekeeping practices in education settings.

However, non-compliance in this context continues because of a blind spot in which schools fail to connect illness with the Disability Standards in order to trigger action⁵¹. Still, the DSE do not limit equality to physical presence, signalling that students who miss school with a serious illness still have a right to access their schools with assistive devices and to receive ongoing support⁵². In fact, the current pandemic confirms the role of schools and technology in continuing education for students homebound in a health crisis⁵³.

Australia has the legislation, now we urgently need the policy to scale up school support for sick students during absence. Here is an opportunity for education and health policymakers to establish an integrated policy framework^{54,55}. The first step is in establishing standard operating procedures between education and health authorities and identifying resourcing options, so that regular schools can manage continuity of education for sick students, wherever they are and throughout transitions between places of care^{56,57,58,59}.

"MissingSchool data from ~160 students identifies that almost 40% of students had an expected absence of more than 12 months, and 70% of students did not have an individual education plan from their school." - Sarah Jones, MissingSchool Impact Manager⁶⁰

To ensure Australian schools and healthcare settings are fit-for-purpose, explicit standards for professional practice must be set for school and hospital operations, and come with mandatory specialised training for educators and paediatric health professionals^{61,62}. State and territory authorities should work with tertiary institutions and relevant professional associations to develop training and to establish accountability measures and monitoring to ensure compliance.

"When you're lying in a hospital bed, to be able to engage with your peers, to be able to join in with the learning, is what the student wants to be able to do." - Mercedes Wilkinson, Principal⁶³

An underpinning objective is to establish data collection and monitoring at school, state and national levels. In the Flanders region in northern Belgium in 2017, real-time public-school attendance data tracked students with chronic illness and observed absence at 1.7% of the student population⁶⁴. Closely matching unofficial estimates, this would equate to ~70,000 students in Australia^{65,66}. But this number may misrepresent reality if chronic illness affects over a million students, and hundreds of thousands of kids are experiencing "mental health disorders"⁶⁷.

Surveys conducted through the *Nationally Consistent Collection of Data* (NCCD)⁶⁸ and Australian Bureau of Statistics (ABS)⁶⁹ must be geared towards identifying how many kids are chronically absent due to illness, how much school they miss, and what effect it has. Currently, students who are absent through serious illness are overlooked by most data collection processes, and sometimes explicitly excluded⁷⁰. Without the right data, we can't understand or address their needs⁷¹.

Guidelines on absence related to serious illness should specify an explicit absence code (or flag) to track prolonged and cumulative absence⁷². It turns out that there's 'no safe threshold for absence'⁷³, and missing more than 10 school days per school semester increases the likelihood of negative effects on education outcomes^{74,75}. Data on absence will aggregate to the *National Standards for Student Attendance Data Reporting*⁷⁶ to inform top-line decision making.

We must also formally define a chronic absence threshold. Along with medical diagnosis, a breach of the threshold would oblige schools to intervene early and collaborate with health settings for specialised support, and individual plans for students^{77,78}, ultimately counting as adjustments through the NCCD.

To support social connection, schools should be required to offer telepresence for classroom attendance, within a coordinated service, to ensure that students can connect with their schools from hospital and home⁷⁹. It is then vital to bridge any learning gaps through one-to-one videoconferencing with their teachers⁸⁰. Education authorities and schools must publish their policies for serious illness, and specify technology and support options, so students and families know what to do⁸¹.

"While missing large periods of time off school due to having a flare up, I had virtual learning to help keep up with school work; this helped a lot." - Student⁸²

The Netherlands led the world in education technology for sick students, building on legislation from 1999. In Belgium (Flanders), technology provided for sick students by a social enterprise drove education policy. Now schools are required to offer two-way digital connection to every sick student who needs it, and government funding has followed⁸³. Similar approaches are underway in Japan, Scandinavia, Switzerland, the UK, and the USA⁸⁴. Australia can do the same, and better—we can take it a step further and be a leader. The good news is, we have a head start.

Since 2017, MissingSchool has run an Australian-first service through education and health systems to put sick kids back in their classrooms through telepresence robots (robots)^{85,86}. These robots enable sick kids to dial in to their class from hospital or home – where they can be seen and heard, and can take their lessons in real-time^{87,88}. The 'human' characteristics and interactivity of the robots cultivate greater social attachment through social experiences⁸⁹. The kids are excited to share the 'space' by moving their robot around the classroom from their remote location.

"The robot brought light into Jensen's life when he was at his saddest point in treatment and it assisted his motivation for recovery." - Heidi, Mum⁹⁰

Confirming MissingSchool's theory of change, parents and teachers report that solving the problem of absence by using the robots^{91,92} helps student friendships, eases anxiety, increases participation and learning, and reactivates school support. Further, funding in some schools has now been accessed, policy for robots in schools and hospitals has been applied⁹³, and collaboration with teachers and health professionals is taking place.

Three years on, an estimated 3,140 classmates have been reconnected through the deployment of over 100 robots, 310 teachers have been trained in their use, 1,040 teachers have been observers⁹⁴, and momentum continues to build through ongoing media and positive public feedback. One primary school student recently shared with Prime Minister Scott Morrison how using a telepresence robot has given him access to his school and his friends, despite a long illness⁹⁵.

"It's been good, I go on the robot...I can drive around!" – Joshua, Student⁹⁶

When schools see these students, count them, and take responsibility for their education, existing disability and assistive technology funding channels can be unlocked⁹⁷. The funding is there, sitting alongside the net social benefit. We don't need a change in legislation—the building blocks are already in place. With clear policy options in sight, we can start right away. Judging by ongoing media attention, policymakers will be backed by millions of people who value this innovation for sick kids.

For lasting change, systematic policy, data collection, utilisation of technology, and support must be folded into the fabric of schools, hospitals, and homes nationwide—equitably and consistently, as our Disability Standards for Education expect. Just like access ramps, robots can give our sick kids an unmistakable presence in their schools.

Policy recommendations

The zigzagging of sick kids between our education and health systems, and sometimes across state and territory borders for treatment, needs the Commonwealth to establish mutual obligations through education and health ministers. Here's how Australia can lead.

1. **Set a national policy initiative.** Consult to verify public need and parameters, consider evidence, policy alternatives and implementation choices, and conduct cost-benefit analysis
>**Start by making 'health condition' a priority equity cohort in National School Reforms⁹⁸**
2. **Collect and track data.** Ensure visibility of the number of students needing specialised support through NCCD, ABS, and state and territory school data, and identify funding models/schemes
>**Start by identifying students in need now and the range of existing funding channels**
3. **Establish education-health policy.** Manage school access by mandating and publishing school responsibility to support, technology for classroom telepresence and one-to-one lessons
>**Start by adding 'health condition' to 'other factors' and draft DSE absence guidelines**
4. **Set and monitor standards.** Enable equity by benchmarking explicit standards of professional practice and set compliance measures for school and hospital operations and support at home
>**Start by setting up education-health competency frameworks and mandatory training**
5. **Develop education-health guidelines.** Initiate inclusion and awareness by requiring a dedicated absence code and setting absence thresholds to trigger specialised school support
>**Start by setting a medical absence flag and a threshold to trigger absence adjustments**

Committing to a rigorous and transparent approach, such as Wiltshire's Public Policy Business Case, will set policy that translates into practice in states and territories.

Stakeholder consultation

It's time to move forward on an issue that exists in all schools, and cuts across all genders, school ages, socio-economic status, abilities and locations. To address the complexity of stakeholders, policymakers can build on current progress and public support by consulting with:

1. **Students and Parents:** students with serious illness and peers, siblings and carers; family, parent and citizens organisations; patient and consumer organisations; children's charities and illness groups; organisations representing children and young people; and intersectional representation.
2. **Practitioners:** allied health services; children's commissioners; disability sector groups; educators and health professionals; principal and paediatric associations; teacher and health worker unions; research and reference organisations; and tertiary training institutions.
3. **Policymakers:** child protection agencies; politicians and parliamentarians; education and health authorities; standards and regulatory bodies; statisticians; and data collection agencies.
4. **Public:** corporate organisations; logistics organisations; non-government organisations; philanthropic organisations; technologists; innovators; and citizens.

With the Commonwealth Department of Education leading, with input from the Commonwealth Attorney-General's Department and the Commonwealth Department of Health, we can start now.

Australia must achieve academic and social inclusion for personal, social and economic progress. We can be the best in the world at this. And so, we should. The wellbeing of our children, wherever they are, and the future of our nation depends on it.

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Megan Gilmour is an Australian Winston Churchill Trust Fellow, who studied school support for sick students in 2017 by visiting Finland, Sweden, Netherlands, Belgium, United Kingdom and Canada. She is cofounder and CEO of MissingSchool and Robots4Good, and creator of the national telepresence robot service in Australia for keeping sick kids connected to their classrooms – an initiative working across education and health systems.

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