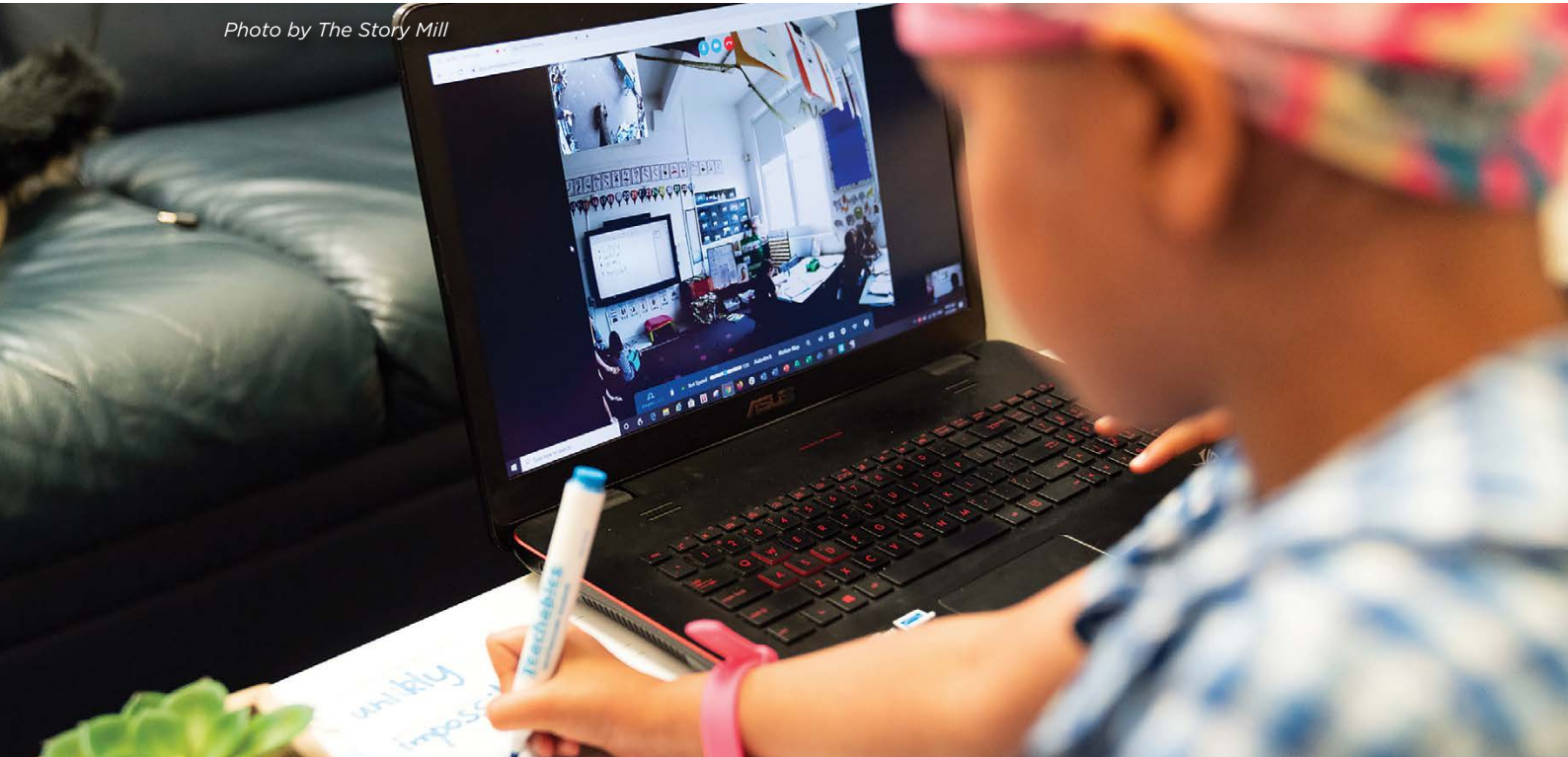*Photo by The Story Mill*

Don't Wait Until They're Well

School policy and technology to keep sick kids connected

By Megan Gilmour

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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 peers.[4] 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.

Good health and education are placed third and fourth in our global Sustainable Development Goals.[5] Yet in schools across Australia, up to 1,185,000 students may face a serious illness that affects their education and attendance.[6] Tens of thousands are missing months to years of school and are cut off from their classrooms and community.[7] They're not getting a complete education, but thanks to incomplete data, we don't know the full extent of the problem.[8]

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. With the estimated lifetime costs in lost productivity of incomplete education close to $1 million per student, the price tag of inaction could head into the billions.[17]

An increasing number of students is confronting this double disadvantage.[18,19] Advances in healthcare mean more survive serious illnesses (e.g. cancers), live longer with life-limiting illnesses (e.g. cystic fibrosis), and gain clearer diagnoses (e.g. anxiety).[20,21] As they brave medical trauma, these kids are spending less time in hospital and more time at home.[22,23]

Too often, the education of sick students is left to charity or chance, or they're segregated to distance education.[24,25]

In hospital, students may access hospital schooling. None of this provides what is vital for young people: continuous connection with their peers, teachers, curriculum, and community.[26] Unsurprisingly, it is parents who carry the burden of their child's learning and loneliness.[27,28,29]

The outpouring of anxiety over education in COVID-19 lockdowns makes the need for school connection extraordinarily clear.[30,31]

In 2012, after experiencing my own son's two-year medical isolation, I co-founded the advocacy group MissingSchool. It has engaged in several audits of Australian law, policy, standards, and guidelines for these students across all jurisdictions.[32,33,34] These found that there are critical gaps in governance, an absence of formal education and health agreements, and a lack of specialised support between school, medical settings and home. This means that sick kids across Australia are being educationally disadvantaged.[35,36] Some students have treatment across state and territory borders, facing additional risk of falling between the cracks.

Australia does not lack legislation.[37] The national *Disability Discrimination Act 1992* includes illness as a protected attribute.[38] Under the Act, the Disability Standards for Education 2005 require schools to give students with illness access to school facilities, accredited curriculum, and learning alongside their peers.[39] The Standards provide for learning adjustments, assistive devices, and school delivery of specialised support. Essentially, they prohibit restrictive and gatekeeping practices in education settings.

Incomplete governance explains why schools find supporting students beyond the school gates a significant challenge, and hospitals don't see education as their role.[40] The coding of "authorised absence"[41] for every health circumstance—from a common cold upwards—automatically suspends school support for students with serious illness during their absence, while enrolment continues. Without clear policy, standards and practice guidelines, coordinated systematic support for these students, wherever they are, is impossible.[42]

We can't afford to wait until these kids 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.[43,44,45,46] Critically, school connection offers hope by proving to sick kids that they are worth educating.

For these young people the value of urgent action is immeasurable. 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 returns[47] by giving these kids the opportunity to reach their potential.

Back to school from hospital.
Photo by parent.
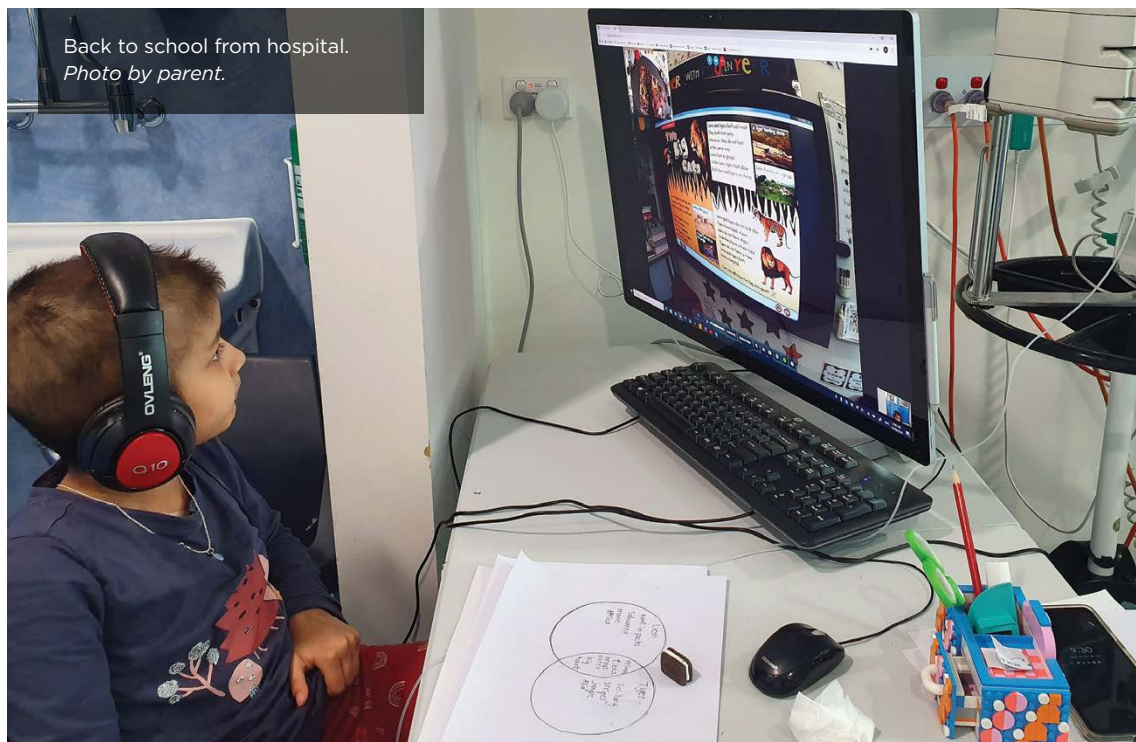
Issues for policymakers

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 isolation.[48]

In Australia, sick students who are absent slip into a policy wilderness, unable to attain equity and inclusion in their education on the same basis as others. This is despite equity and inclusion being enshrined by Australian law,[49] Disability Standards[50] and ministerial declarations.[51]

Non-compliance continues because of a blind spot in which schools fail to connect illness with the Disability Standards for Education in order to trigger action.[52] Still, the Standards 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 support.[53] In fact, the current pandemic confirms the role of schools and technology in continuing education for students homebound in a health crisis.[54]

Australia has the legislation—now it urgently needs 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,[55,56] and make effective, cost-neutral change. We simply need to apply support systems and technology to give these unseen students presence in their schools.

The first step is establishing standard operating procedures between education and health authorities and identifying resourcing options, so regular schools can manage continuity of education for sick students, wherever they are and throughout transitions between places of care.[57,58,59,60]

"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 Manager [61]

To ensure Australian schools and healthcare settings are fit for purpose, explicit standards for professional practice must be set for both school and hospital operations, and come with mandatory specialised training for educators and health professionals.[62,63] State and territory authorities should work with tertiary institutions and relevant professional associations to develop this 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, Principal [64]

An underpinning requirement is to establish data collection and monitoring at school, state and national levels. In Flanders, Belgium in 2017, real-time public school attendance data tracked students with chronic illness and observed absence at 1.7% of the student population.[65] This would equate to ~70,000 students in Australia.[66,67] 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".[68]

Surveys conducted through the Nationally Consistent Collection of Data (NCCD)[69] and Australian Bureau of Statistics (ABS)[70] must monitor 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, sometimes even explicitly excluded.[71] Without the right data, we can't understand or address their needs.[72]

National guidelines on absence due to serious illness should specify an explicit absence code (or flag) to track prolonged and cumulative absence.[73] Research verifies that there is "no safe threshold for absence",[74] and missing more than 10 school days per semester increases the likelihood of negative effects on education outcomes.[75,76] Therefore, we must formally define a chronic absence threshold. A breach of the threshold, along with a medical diagnosis, would oblige schools to intervene early and collaborate with medical settings to design and implement individualised plans for students.[77,78]

Ultimately, these actions will support national decision making, as explicit absence data and adjustments for these students flow up through the *National Standards for Student Attendance Data Reporting*[79] and NCCD.

" *The robot brought light into Jensen's life when he was at his saddest point in treatment and it assisted his motivation for recovery.*[93] "

— Heidi, Mum

Telepresence technology

To support school and social connection, schools should be required to offer telepresence for classroom attendance (**Fig 1**). Together with one-to-one videoconferencing with their teachers[80] to bridge learning gaps, this will ensure that students can connect with their schools from hospital and home.[81] Education authorities and schools must publish policies for serious illness, and specify technology and support options, so students and families know what to do.[82] Telepresence for classroom attendance must be supported through a coordinated service to ensure equity across students, schools and school systems.

"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." — Student [83]

The Netherlands has led the world in education technology for sick students, building on legislation from 1999.

In Belgium (Flanders), technology provided for sick students has driven education policy.[84] Since 2014, schools are required to offer two-way digital connection to every sick student who needs it, and government funding has followed.[85] Similar approaches are underway in Japan, Scandinavia, Switzerland, the UK, and the USA.[86] 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).[87,88,89] These robots enable sick kids to dial in to class from hospital or home. They can be seen and heard, and can take their lessons in real-time.[90,91] The 'human' characteristics and interactivity of the robots cultivate greater social attachment through social experiences.[92] The kids are excited to share the space and have agency in remotely moving their robot around the classroom.

Figure 1. Robots bringing sick kids into the classroom
....
Access via robot telepresence.
Photo by The Story Mill

Confirming MissingSchool's theory of change, parents and teachers report that solving the problem of absence by using the robots[94,95] helps student friendships, eases anxiety, increases participation and supports learning, and reactivates school support. Further, some schools have now accessed funding, policy for robots in schools and hospitals has been applied,[96] and there is collaboration with teachers and health professionals. Research is underway.

Three years in, an estimated 3,140 classmates have been reconnected as over a hundred students have used telepresence robots, 310 teachers have been trained in their use, 1,040 teachers have been observers,[97] and momentum continues to build through positive media and 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 illness.[98]

"It's been good, I go on the robot ... I can drive around!" — Joshua, Student[99]

When schools see these students, count them, and take responsibility for their education, they can unlock existing disability and assistive technology funding channels. Because we don't need a change in legislation—the building blocks are already in place—we can start right away. Ongoing media attention shows that millions of people would support this innovation for sick kids.

For lasting change, systematic policy, data collection, utilisation of technology, and coordination must be folded into the fabric of schools, hospitals, and homes nationwide.

This must happen equitably and consistently, as our Disability Standards for Education expect (**Fig 2**). 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 Reforms.*

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, and accessing 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 Disability Standards for Education absence guidelines.*

Figure 2. A cycle of policy progress for school inclusion
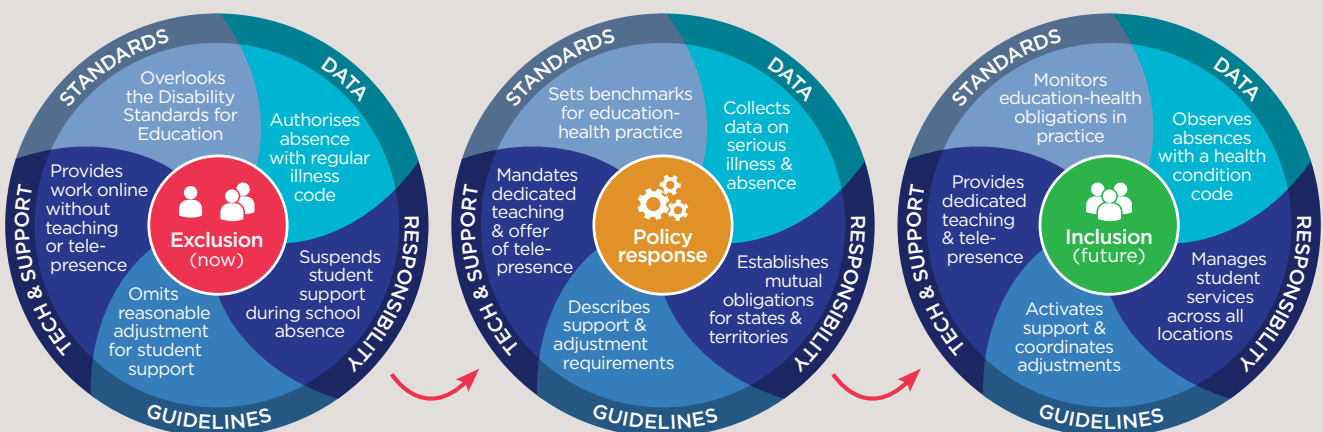
4. Set and monitor standards. Enable equity by benchmarking explicit standards of professional practice and set compliance measures for school and hospital operations and support at home. *Start by establishing education-health competency frameworks and mandatory training.*

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 'health condition' absence flag and a threshold to trigger adjustments.*

Committing to a rigorous and transparent approach will set policy that translates into sound, evidence-led practice across states and territories.[100]

Stakeholder consultation

It's time to address an issue that exists in all schools, and cuts across all genders, school ages, socio-economic status, abilities and locations. Policymakers can build on current progress and public support by consulting diverse stakeholders:

1. Students and families: students with serious illness and peers, siblings and parents/carers; family, parents and citizens associations; patient and consumer organisations; children's charities and illness groups; organisations representing children and young people; and intersectional representatives.

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; productivity commissions; and data collection agencies.

4. Public: corporate organisations; non-government organisations; philanthropic organisations; the media; technologists; innovators; and citizens.

With the Commonwealth Department of Education leading, and 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 sick kids 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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