

EDUCATING SICK KIDS

THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

A study on models to enable seriously sick kids to maintain their education connections, conducted in Finland, Sweden, Netherlands, Belgium, United Kingdom and Canada.

Megan Gilmour : 2016 Churchill Fellow

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**REPORT BY
MEGAN GILMOUR : 2016 CHURCHILL FELLOW**

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ABOUT THE AUTHOR

My career includes roles in government, the private sector and community organisations. I have worked on the personal staff of a government minister, built my own enterprises and those of international operations in which I've held senior positions.

I am Master's qualified in community and international development and have managed complex operations, and social and economic development programs across more than 24 countries. I have held a management committee role in an international non-government organisation, and am co-founder and Chair of Australian advocacy group, MissingSchool, for keeping seriously sick kids connected to their schools.

Most recently, I have authored published reports for the Aboriginal and Torres Strait Islander Healing Foundation, and co-authored an Australian-first report on Keeping Seriously Sick Kids Connected to their Schools. On release, that report received a statement of support from the Prime Minister. I am a Member of the ACT Disability Education Reference Group (DERG), and the H.E.L.P. (Health, Educators, Learner, Parents) national Committee.

My commitment to human development has converged with an interest in mobilising collective intelligence and leveraging accelerating technologies to disrupt barriers to addressing local and global challenges. I have a keen interest in creating change in complex systems, and am a social innovator and entrepreneur. My passion is in leading people in creating entities and global movements for social good.

To each there comes in their lifetime a special moment when they are figuratively tapped on the shoulder and offered the chance to do a very special thing, unique to them and fitted to their talents. What a tragedy if that moment finds them unprepared or unqualified for that which could have been their finest hour ~ Sir Winston Churchill

I am honored to be a 2016 Churchill Fellow to study overseas models for connecting seriously sick kids to their education. My project is passionately driven by my experience as a mother to a young son who survived a life-threatening illness. I am grateful to the Winston Churchill Memorial Trust of Australia for having faith in me to do this work and to my application referees, Professor Les White and Mr John Broome whose endorsement rallied me.

When life tapped me on the shoulder for this Fellowship, I felt both qualified and uniquely prepared. It's a work arising from absolute love, single-minded pursuit of solutions, determination for systemic change, and lasting belief that sick kids can thrive, not just survive. May this Churchill Fellowship galvanise Australia to advance to a finest hour.

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EXECUTIVE SUMMARY

Keywords: sick children, sick kids, special education, illness and education, inclusive education, disability education, education systems, education reform, education innovation, education technology, healthy schools, children's hospitals, hospital schools, paediatric medicine.

Around Australia an estimated 60,000 kids with serious illness or injury, remain at home or in hospital, watching from the sidelines and missing school. The number may be much higher, but no one knows because no one is counting them. Many of their siblings miss school, too. Some sick kids miss days and weeks, others miss months and even years. The evidence tells us there can be profoundly harmful consequences: Academic achievement hindered, relationships with peers and teachers disrupted, motivation and engagement diminished (ARACY, 2015).

And it's the failure to manage this absence for sick kids – and their transitions in and out of their schools – that leads to so much of the isolation these kids experience when they are back at school. These can create disadvantage now and forever.

The evidence tells us that maintaining school connection for students with serious illness mitigates risk and harm (ARACY, 2015). School connection offers a sense of normality. It keeps kids up-to-date academically and socially so they can move between school and treatment more easily.

We must intervene to maintain continuous school connection for seriously sick or injured kids.

Medical science is saving the lives of sick kids and extending the lives of kids with life-limiting illnesses. Technologies to connect us are growing exponentially. Our education and health systems need to keep pace.

Sick kids must have real-time inclusion in their classrooms, social connection with their peers and teachers, and the emotional support to feel and be “normal”. This should happen wherever they are and whenever they can. At school, in hospital and at home. And it should involve systemised education services for sick kids that also support their families and carers throughout with seamless arrangements between the education and health sectors (ARACY, 2015).

The aim is to ensure inclusion, equity, and access in learning and socialisation to galvanise their protection, development and lifelong wellbeing.

The Churchill Fellowship has enabled me to showcase approaches used in Finland, Sweden, Netherlands, Belgium, United Kingdom and two provinces of Canada to support education, social and emotional connection for sick kids.

My findings are an excellent resource for my advocacy work in the Australian context and will inform governments, educators, medical staff, and organisations involved in the care of sick kids. While the challenge of educating sick kids produced consistent themes across countries, including Australia, discoveries included critical solutions that Australia is missing. At the same time, there was wide variability within and between countries in applying these solutions.

We can now take our vision from a country that does this best. In this country exists:

- joint education-health legislation that is customised for sick students, they are counted and their right to an education on equal terms to their peers is upheld
- responsibility is owned by the regular school for education services informed by joint policy (including for digital connection) dedicated to sick students
- joint education-health benchmarks for education services for sick students where personnel have specific competencies and standards that are regulated
- jointly led processes and procedures to manage, administer, and fund a systemised service at school/hospital/home, matched with staff training
- joint tracking of absence and risk, with absences managed and kids and families engaged, supported and connected throughout the whole education journey.

Which country? This could be Australia by 2020.

Australia can innovate on continuous school connection for students with serious illness. We don't have to lag or iterate. We can advance on best practice from overseas, and we can leap.

In 2015, MissingSchool took this problem and drove it on to a national agenda for the first time. This got the Prime Minister's attention, and the attention of a nation through media all over the country. We led the Commonwealth to commissioning the first government report on this issue, and advised on its methodology. We are now intervening at school level with an Australian-first proof of concept for real-time digital connection for sick kids to their classrooms. The funding for this Australian pilot was received from St. George Foundation through whom I prepared and pitched the pilot concept while on my Churchill travels.

I will press my Fellowship findings through Australian schools, children's illness groups, conferences and fora, information to parents/carers, educators, and health practitioners, government submissions, the media, online platforms, professional associations, reference groups, research organisations, social media, members of parliament, and Australian education and health departments and ministries. The connections I made in overseas countries begins a global movement to meet this challenge.

The highlight of my discoveries was to find so many people deeply and passionately committed to keeping seriously sick kids educated and connected to their schools. People who said that this work is the most important they have done. People who asked me to connect them to each other. People who urged me to keep going and bring them along.

This is not an academic report, but a "working paper" and trip report based on both private and open discussions I had with practitioners in the countries I visited. It is like a grounded theory, based mostly on my observations and reflections, and offers the foundation for future formal research.

APPROACH

To guide my Fellowship investigations, I took the approach of using a theory of change developed in my work with MissingSchool.

This theory of change, shown in Figure 1 **Error! Reference source not found.**, is a compass for the challenge of keeping sick students connected to their schools when they are absent often, or for long periods. It is one of many possible ways to map the problem.

The scope and complexity of the issue is overwhelming to consider.

It's based on the governance framework for the problem statement: Students with serious illness in Australia experience exclusion from their regular schools.

The map shows why initiatives that don't consider the whole system can end up being situational and don't offer an ongoing solution for all kids who experience the problem. That's not to say those initiatives aren't good. Just that they're not mainstreamed, not consistent, and they reach few, rather than all. So, this theory of change considers the whole ecosystem and its limitations and opportunities.

Our mission, if we choose to accept it, is to raise the bar so that the change we create supports every sick kid to experience continuous connection to their schooling, everywhere in Australia, every day.

The map covers Who, What, When, Where, and Why. The Churchill Fellowship looks at How.

The Who is the child/family, educators, and medical staff - the people.

The What and When are about managing the issue in each moment.

The Where? Locations such as home, at school, or in hospital.

The Why is the awareness of the people involved in taking action.

And the How is about their competency in those actions.

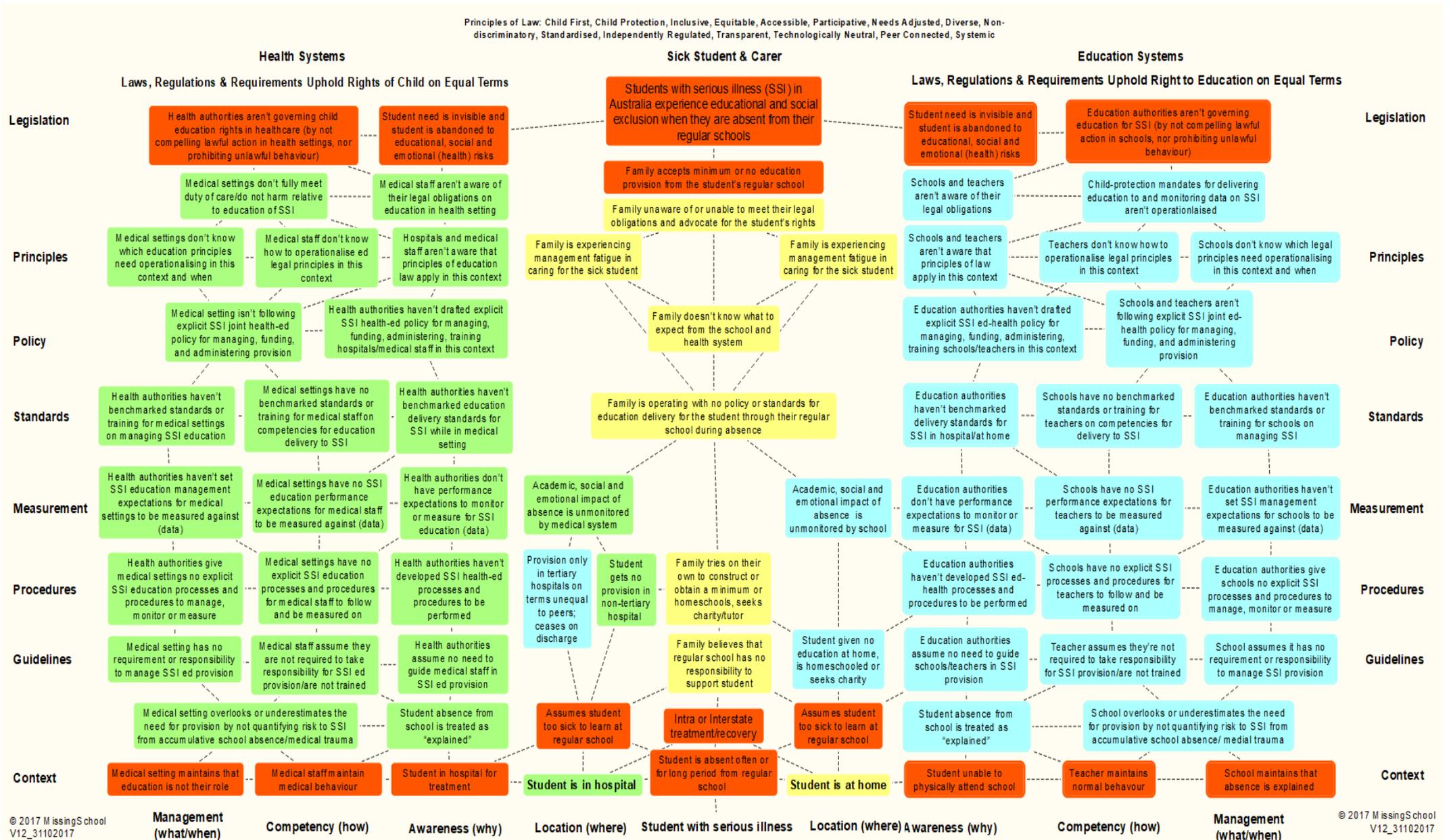
Looking at people and locations, my discoveries consider what happens in the countries I visited from an awareness, a competency and a management perspective in each location.

The theory of change takes us from the top of the problem down through a series of causes (this happens, because of that) right down to the root causes. And it takes us up through a series of effects (this happens, therefore that happens) – right up from the root cause of our problem.

It is important to consider how the system looks now – before moving to how it can be.

From top of systems to bottom – from directives to delivery – this paper will snapshot laws, principles and policies, standards and measurement (or data collection), and practice in Finland, Sweden, Netherlands, Belgium, United Kingdom and parts of Canada.

FIGURE 1: THEORY OF CHANGE PROBLEM MAP



THE PROBLEM

The theory of change suggests a weak system of governance in Australia for education services to students with serious illness. Student needs are invisible so students are abandoned to educational, social and emotional risks. The reasons are summarised as:

Laws on educating sick kids

- Education and health authorities aren't governing education service to sick kids
- Students' needs are invisible and students are at risk in and out of school
- Education and medical staff are unaware of their legal obligations

Principles of law and policy

- Education and health settings don't know which legal principles to apply in context
- Teachers and medical staff don't know how to operationalise principles of law
- No explicit joint policy to manage, fund, administer, train in education service

Standards, measurement and data

- Education and health authorities haven't benchmarked delivery standards
- Education and medical settings haven't benchmarked competencies for staff
- No performance or management expectations to be monitored against

Process, procedures and guidelines

- Education and health authorities haven't developed joint practice guidelines
- Education and health settings have no joint processes and procedures to follow
- Educators and medical staff assume they have no responsibility for delivery

Theory on base causes

- Schools and medical settings underestimate risk and need for service
- Educators and medical staff behave as they do for any explained absence
- All actors assume student at home/ hospital is too sick to learn at their school

Schools assume they have no requirement or responsibility to deliver education services to students with serious illness, so teachers assume they're not required to teach these kids. Hospital schools, where they exist, become the student's lifeline but it's only a short lifeline when kids are in hospital. At home, or in local hospitals, there is little or no support.

Ultimately, the regular school overlooks the need, because the accumulative school absence and medical trauma is not being measured. And why? Because the student's absence from school is assumed under the standard "explained absence". Medical staff maintain that education isn't part of their role. When the student returns to school, they are assumed to be "well enough" and essential adjustments to support them are not considered.

But what if these assumptions are abundantly flawed? Let's turn to our countries of study.

FINLAND

Helsinki and Tampere



System overview

FIGURE 2: FINLAND – SYSTEM OVERVIEW

DESCRIPTION OF SYSTEM	
<p>Finland advocates that all people must have equal access to high-quality education and training. The same opportunities for education aim to be available to all citizens. Education is free at all levels from pre-primary to higher education.</p>	
NUMBER OF SCHOOLS	2,384
NUMBER OF STUDENTS	556,700
NUMBER OF HOSPITAL SCHOOLS	25
YEARS OF SCHOOLING	
<p>Comprehensive, compulsory, basic education is given from ages 7 to 16. Pre-primary education is in place for 6-years-olds. Six years are spent in primary school, or alakoulu. After alakoulu students attend three years of middle school, yläkoulu. After 9th grade students may attend voluntary high schools, and vocational schools are attended from the ages of 16 to 19.</p>	
TYPES OF SCHOOLS	
<p>Government funded schools are termed municipal schools. The state council must approve private schools. After being founded private schools are given a state grant equivalent to a municipal school of the same size.</p>	
SPECIAL SCHOOLS	
<p>The Finnish basic education system has a long history of operating on the philosophy of inclusion. There is no streaming in basic education and students are supported individually to successfully achieve their basic education. This starts with general support; intensified support or special support for a student applies when assessment by multi-professional teams leads to developing individual learning plans.</p>	

<https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Finland:Overview>,

https://en.wikipedia.org/wiki/Education_in_Finland,

http://www.oph.fi/english/education_system/support_for_pupils_and_students/support_in_basic_education

Findings

The following is a synthesis of all meetings held in Finland and a summary of themes in Finland for keeping seriously sick kids connected to their education and schools.

LAWS ON EDUCATING SICK KIDS

- Kids have a right to get special help from their regular school. Nurses and doctors are aware of that as much as teachers in hospital schools.
- There is a national law (Law 18) specifically directed to the rights of sick students to education. The specificity of this law for sick students is seen as a critical precedent in any success (it is contra indicated for sick students to sit under a general disability or special education law because it is indeed a special and complex case).
- There are no formal combined health-education laws for educating sick students.
- Structural arrangements (where hospital school sits in terms of education line management is flexible) can be problematic in terms of mandating approaches.

PRINCIPLES OF LAW AND POLICY

- The municipality in which the hospital or school is located is responsible for arrangements and delivery of education services, and flows of funding.
- Regular school has clear responsibility under the legislation, however, the school's understanding of this responsibility and willingness to meet it varies greatly between schools. The school is often surprised by the responsibility and it involves a conversation between the regular teacher and the school principal. The hospital school plays an organising role and advocates for the student.
- There is no interpretation on the broader law and how to apply that in practice which leads to some variability across locations in Finland. However, there are three levels of special needs classification to guide the level of support to be applied in any situation.
- Parents must give written permission for the hospital school teachers to contact the regular school. Parents can deny permission; however, the hospital school and hospital maintain a duty of care and doctors and parents will meet to discuss.
- A conversation with a family demonstrated that cross jurisdictional issues arose when their child needed treatment in the UK. Interpretation was unclear as to whether Finnish responsibility for student stopped at the border or was based on citizenship. The hospital school advocated for the enduring rights of the student across locations.
- There is a different approach (location-based) on teaching students with somatic illness versus mental illness.

STANDARDS, MEASUREMENT AND DATA

- Schools are trusted to deliver a high quality of education and there is no formalised inspection. Benchmarks for delivery to sick students are taken from benchmarks in the full system.

- Educators in Finland are educated to master's level and the teaching profession is respected and valued, such that achieving a placement as a teacher is competitive.
- There is no specific training to teach students with chronic illness, nor for hospital school teachers. In most cases teachers found their own pathways (sometimes quite accidentally) to hospital school teaching. Most teachers in hospital schools have a special education teaching qualification.
- The hospital school is a physical bridge between the hospital and the school. It carries a vocabulary of understanding between medical condition and education. It creates an understanding of how the health condition and absence affect learning. Learning can take place anywhere, regardless of the medical condition. The hospital school is a translator between the medical setting and the learning setting.
- Hospital schools and schools maintain data on time in hospital and absences. The Department monitors the time in school and the time away. There is no national or local data that tracks students' accumulative absence. When the student is at home and not able to go to their own school they are marked as explained absence, raising no flags.

PROCESS, PROCEDURES AND GUIDELINES

- Very strong operational relationships between medical staff and hospital school staff, e.g. nursing staff are present for some of the teaching time in the hospital school, and doctors and teacher liaise quite closely. Outreach nurses also go to schools to advise on the illness and what to expect or do in the school setting.
- Teachers in the hospital school setting teach sick students the national curriculum but align the teaching to what is being taught in the regular school.
- The connection between the regular school and hospital school is forged by hospital school teachers and the liaison is ongoing, reflecting the fact that hospital schools are merely acting as agents for the regular school while the student is in their care.
- Hospital school teachers play a very strong advocacy role in ensuring that the student has clear arrangements between hospital, regular school and home. Their position is that this should not be left for the parent/carer to do.
- Charities do not have responsibility for providing education in this context.
- Personal plan is prepared for student and that operates as a contract between regular school and student, involving hospital school, regular school and home.
- Support for the student in hospital commences when the student has been in hospital for 3 weeks, or has an ongoing issue.
- Hospital school gives 45 minutes at the bedside, but student can spend most of the day in the hospital school itself if s/he is able. Prioritise parts of the curriculum to fast track the learning and more can be achieved in less teaching time because it's direct.
- Hospital school is involved in administering examinations in many cases. Regular school prepares the student's progress report, and usually liaises with the hospital school. Evaluation of the student is what teachers in hospital schools worry about a lot. Whose responsibility is it and how is it happening the regular school? What role does the hospital school teacher play in the evaluation?

- The family, regular school headmaster, teacher and hospital school teacher consult about home tuition. The regular school teacher comes to the home for 4-6 hours per week (varies based on community). However, it was noted that the actual provision varies from this, depending on school and student. The school can refuse to send their own teacher but must provide (and fund) an alternative.

Technology

- The education department has ICT solutions for distance learning of languages (there are three official languages in Finland).
- A Finnish teacher has been piloting a Skype (distance learning) solution for sick students. This has developed into a national pilot and is now partially funded by the education system, and working cooperatively with the education department ICT area. This solution is not used in hospital unless the student is in an isolation room because of the privacy of other kids in a shared ward. It is a solution applied where absence is long term (but there is no threshold of absence set for commencing). The biggest issue with using technology such as Skype is a teachers' uncertainty with using technology. Schools seem okay with using Skype, some students don't want to be seen. There is a technology policy stating that the student cannot take photos through the connection. There needs to be permissions signed. Better technology in new hospitals is cited as a positive development because existing hospitals have limited scalable wifi.
- Hospital ICT department in Helsinki is developing an app for sick students to use while in hospital and at home to manage appointments and illness, connect to class, etc. This has been developed without consultation with or awareness of hospital school highlighting silos of health and education that seem to persist across countries.

Networks and Advocacy

- Some hospital school staff are members of the HOPE (Hospital Organisation of Pedagogues in Europe) but others are not. National networks of hospital school staff are not as well developed.
- Collaboration on hospital school projects occurs between countries in Europe by way of grants, but these are localised to particular hospitals.
- Parent advocacy and support organisation, Silva, was praised for awareness raising and education to parents, teachers and medical professionals on educating sick students. Noted that parents need to be guided and reassured about continuing education and the role that it plays in supporting the student.
- NOBAD is an advocacy organisation that is staffed by nursing professionals. It guides on the rights of kids in healthcare and is actively involved and respected in guiding paediatric hospital practice (e.g. having clinics in the afternoon so that doesn't interfere with students' school days, a technology for school connection, play, and illness management).

THEORY ON BASE SOLUTIONS

- Awareness of rights and a language of rights at all levels and across departments.
- Regular school is the "owner" of the student and has a critical responsibility to uphold.

- Respect for professional status of the teachers and hospital school, that extends to an advocacy role to ensure regular school provides for the student when the student is at home.

Education is the healthy part of a child when they are sick, and it's normal for the healthy part of the child to resist education; that doesn't mean the education should stop ~ Riitta Launis, Principal, Tampere Hospital School

Lessons

The following captures notable challenges, opportunities, and observations from the Finnish education system for keeping seriously sick kids connected to their education and schools.

CHALLENGES

- Regular schools vary in their awareness, willingness, training and resources to meet their responsibility to keep the sick student connected. Hospital schools are limited to advocacy while the student is in their care.
- Education offices are not keeping macro level data across all locations, so resourcing decisions are based on a snapshot in one location, e.g. the hospital where the number of students and time spent is evidently reducing (this is a global trend in healthcare).
- Hospital school staff are typically not suited to internal political advocacy because of their operational role and the risks to tenure. This is a thematic problem since these are exactly the people best placed to inform non-operational decision makers on context and student need. Decisions are often being made by generalist civil servants who don't understand the whole context for sick students.

OPPORTUNITIES

- To expand the use of digital two-way connection from hospital school to classroom, and home to classroom. For the hospital and education offices to work together on this to avoid duplication of effort that arises through limited formal education-health arrangements (such as communication protocols).
- For hospital school teachers to become the “advocacy bridge” to interpret between medical and education/home setting on best approaches, adjustments and student support. Consider training the next generation of “hospital school teachers”. Consider a joined educators and medical practitioner advocacy arrangement that can guide on high level issues in hospital and at school and home. Stop calling hospital schools “hospital schools” and redefine their role as an extension of, not separate to, regular schools sharing in teaching students for a particular purpose.
- Forge formalised links between hospital, hospital school and home through protocols based on the Finnish example of mutual professional respect between medical staff and educators in the co-care of sick students.

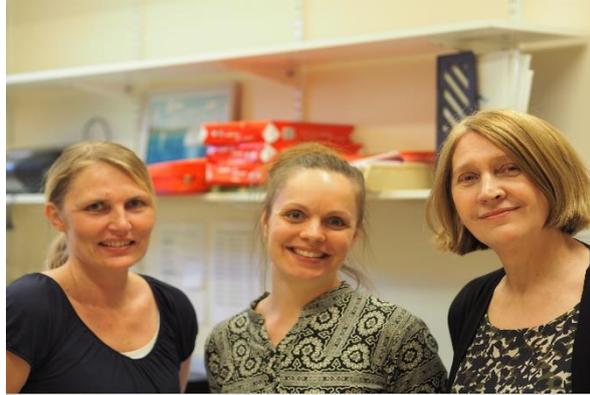
OBSERVATIONS

- Everyone speaks firstly in terms of the rights of students to receive education on equal terms, so there is a high level of awareness of the rights.
- Finland is embracing a transition point between the traditional hospital school approach and opportunities that technology can provide and this is being driven by need for economy. Communication between “silos” will avoid duplication.
- New hospital being built, shrinking hospital school staff numbers and political restructuring that could be perceived as undervaluing the role of the hospital school. This is an emerging theme across locations and conceivably reflects that students are spending less time in hospital.

When the teacher comes, I stop being a cancer patient and become a student (Paulina). We are hope for kids when the parent can't do the advocacy and we have to put aside the emotional aspects and focus on being the professional to the child ~ Ina Kivalo, Helsinki Hospital School

Humans

Here are some of the humans doing work in Finland to keep seriously sick kids connected to their education and schools.



SWEDEN

Stockholm, Huddinge, Linköping, Uppsala



System overview

FIGURE 3: SWEDEN – SYSTEM OVERVIEW

DESCRIPTION OF SYSTEM	
Swedish education is free of charge. The government has the overall responsibility, setting the framework for education at all levels. The Swedish system is goal and outcome focused.	
NUMBER OF SCHOOLS	4,832
NUMBER OF STUDENTS	1,368,000
NUMBER OF HOSPITAL SCHOOLS	7
YEARS OF SCHOOLING	
Preschool, or forskola, is heavily subsidised and available from age 1. Grundskola is compulsory schooling, attended from ages 7 until 16. Upper secondary school is attended from ages 16 to 19.	
TYPES OF SCHOOLS	
Most Swedish schools are public schools. There are a small number of private schools, friskolor, primarily funded by local contributors.	
SPECIAL SCHOOLS	
Sweden offers students adjustment and support in their education when needed. This adjustment and support is offered above the standard education program. If the adjustment is not sufficient, the head-master has responsibility to ensure that the pupil's needs are urgently investigated and met. There are 290 municipalities that have responsibility for administering education under a national system.	

<http://www.expatarrivals.com/sweden/education-and-schools-in-sweden>
<https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Sweden:Overview>

Findings

The following is a synthesis of all meetings held in Sweden and a summary of themes in Sweden for keeping seriously sick kids connected to their education and schools.

LAWS ON EDUCATING SICK KIDS

- Educating sick students is recognised as a legal right in Sweden and openly discussed as such. Private schools are included in the law since 2011, as are private hospitals.
- Education Department issued a common advice in September 2015. As well as directing that all students in tertiary hospitals have access to teaching, it allows siblings to also receive teaching if they are spending time in the hospital (and it can be officially recorded). It is noted that the hospital school is not a single system, but embedded in both the education system and the hospital system, bringing operational complexities.
- There are no formal combined health-education laws for educating sick students. But having strong education advocates within the hospital setting drives forward the agenda around students' rights and child centred approaches.
- Education law means that regular school has responsibility for the student and for providing face-to-face teaching when sick students are at home.

PRINCIPLES OF LAW AND POLICY

- Education services are planned, and funding is given, at the community level so approaches vary across communes. Some hospital schools are part of the community school health program, not the education system. Hospital schools do not operate in all hospitals in Sweden, they do operate in "university" or tertiary hospitals.
- All regular schools have a team of people to support special needs: headmaster, school nurse, psychologist, social worker, and special education teacher. This team works to plan for the student with special needs, and this makes it easier for the hospital school teachers and nurses to advocate on behalf of sick students; the infrastructure is already in place. Hospital teachers are part of a multidisciplinary team.
- Regular school has responsibility under the legislation, however, the school's understanding of this responsibility and willingness to meet it varies greatly between schools. The school is often surprised by the responsibility. The hospital school plays an organising role and advocates for the student, but this varies based on hospital school and local protocol. Some take the position that it is not their job to police the role of regular schools and avoid enforcing links with the regular school.
- Hospital school teachers came together to have the law changed in Sweden so that all students in hospitals (where there are schools) can have access to teaching and education support. There was no definition on what the original threshold of "long stay" meant. Noted here that students are staying in hospital for shorter periods which is what prompted hospital school teachers to work for change.
- Hospital schools play a role in educating regular schools and providing guidelines on what is expected of them under the law.

- Parents must give permission for the hospital school teachers to contact the regular school (this can be verbal).
- Hospital school staff in some hospitals are not permitted access to medical records or databases due to privacy laws.
- An extension of time is offered to students who are absent from school to complete the compulsory schooling.

STANDARDS, MEASUREMENT AND DATA

- There is an inspection body which inspects all schools for compliance and competency. Inspection of hospital schools occurred for the first time in 2016. After that visit, authorities set guidelines for hospital schools to be measured against.
- There is now a national effort to identify students who are “sitting at home”, though this is not applied to the “explained absence” situation of a sick student.
- Inspection body wants hospital schools to identify students who aren't attending hospital school (who may be over the age of 18 but under 21 and still in school).
- There is no formal teacher training for teaching students with serious illness. Teachers cited that they have special education training, but learned to teach sick students “on the job”. They say it’s a problem when there is no formal training nor guidelines. There is no career pathway and most hospital school teachers found their way to hospital schools “coincidentally”. Since 2015 hospital teachers must be qualified teachers.
- Teachers noted that in their experience no operational documentation existed in the hospital school when they started, they had to create it.
- Hospital school teachers have a self-organised national professional association of hospital school teachers. This body is working to get curriculum standards for teachers in hospital schools and has been responsible for systemic change through advocacy.
- The hospital school teachers get education from nurses on the disease to guide the consequences of medical conditions for learning. The hospital school is a physical bridge between the hospital and the school. It carries a vocabulary of understanding between medical conditions and education. It creates an understanding of how the health condition and absence affect learning. Learning can take place anywhere, regardless of the medical condition. The hospital school is a translator between the medical setting and the learning setting.
- Hospital schools and schools maintain data on time in hospital and absences. The commune monitors the time in school and the time away. There is no national or local data that tracks students’ accumulative absence from regular school. Some communes have absence teams (new law) but when a student is at home because of illness the absence is marked as explained, raising no flags.

PROCESS, PROCEDURES AND GUIDELINES

- Strong relationships between hospital school teachers and medical staff was cited as critical to success in the hospital environment.
- There is evidence of multiple funding streams for different education programs in hospitals based on illness type, e.g. cancer and eating disorders. Clowns, play and music therapy are examples of educational and play programs that are funded outside

of the education system (and sometimes health system). There are examples of charities funding some provision, e.g. sibling support.

- Because play therapists are employed by the hospital, they get access to medical records and, in some hospitals, provide the hospital school with the list of students on any given day. In other hospitals, the list comes from the nursing staff.
- There is no set amount of time from the hospital school to a student per day – they provide anything from 10 minutes up to an hour per day. There is no set amount of provision at home (the school decides). Previously it was five hours per week where a teacher (or a teaching assistant) from the regular school goes out to the home. The school is responsible for releasing teachers but it's hard to get this contact. Schools often ask if the hospital school maintains responsibility when the student is at home.
- In one location, “middle care” is the role of hospital school teacher who attends the home to help with transitions when the student is not back at school. They work to outcomes and assist in preparing a family plan through a consultative process. All parties sign that plan. This was in a mental illness context.
- Hospital schools cannot grade or evaluate students, even those who have spent much of their time connected to the hospital school. This is noted as problematic, except in cases where the regular school and hospital school collaborate most effectively.

I've been teaching for 40 years, but when I arrived I couldn't see what I needed to do because I was comparing this to my regular leadership role in the regular education system. But this work is different. There is no formal teacher training for this role. Hospital School Teacher, Sweden

Technology

- There is a small robot technology, AV1, being trialed in some parts of Sweden. It is a technology from a Norwegian company called “No Isolation”. It is obtained on license or rental, and is in trial through funding by a cancer charity.
- There are also connective technology developments in local settings through hospitals working with innovation offices in the education system, though these are developing through the hospital rather than the education department with no information sharing.

Networks and Advocacy

- Hospital school teachers belong to a national professional association of hospital school teachers. Many are also part of the European body, HOPE.
- There is a formal arrangement for collegial collaboration between health and education that is organised by a kids' cancer charity.
- There are examples of raising the profile of educating sick students via local media.

THEORY ON BASE SOLUTIONS

- Awareness of rights and a language of rights, particularly via hospital school teachers.
- Regular school has a critical responsibility to uphold education for the student.
- Respect for the professional basis of hospital school teaching that extends to an advocacy role for students with the regular school, and at a national networked level.

Lessons

The following captures notable challenges, opportunities, and observations from the Swedish education system for keeping seriously sick kids connected to their education and schools.

CHALLENGES

- Political underrepresentation of student education in the hospital environment, e.g. hospital and education do not co-plan especially in infrastructure development and education becomes an afterthought in the hospital setting, while the hospital school is a satellite from the main education system.
- Inconsistency across locations in interpreting the law resulting in variability and uneven provision, nationally, and the way in which hospital schools are line managed and funded, and how regular schools see and take responsibility for their sick students.
- Unclear line management arrangements for hospital teachers in hospitals can render them marginalised in their critical role of delivering education services and running advocacy for students and families.

OPPORTUNITIES

- To expand the use of digital two-way connection from hospital school to classroom, and home to classroom. For hospital and education offices to work together on this to avoid duplication of effort due to limited formal education-health arrangements.
- Formalised qualifications and competencies for play therapists and “one roof” education-health arrangements for combined programming of play therapy and learning. This is especially important for pre-school students who typically miss out on formalised education in this context.
- Hospital school teachers carry authority with the student’s regular school, help prepare the school and arrangements for the student once they leave hospital. They are confident in talking rights and explaining responsibilities, and in helping their colleagues in regular schools to make adjustments and teach in this special education context. They focus on critical curriculum to fast-track learning so sick students can keep pace with fewer “schooling” hours.

OBSERVATIONS

- Politics in the hospital environment can promote or detract from the value of education in the medical setting. Strong internal advocates and formal arrangements employed

by health departments (law, policy and guidelines) are needed to bridge the gap between health settings and education for the wellbeing of sick students.

- A national association of hospital school teachers increases capacity to raise awareness on issues, influence decision makers, and change existing approaches.
- Learning in hospital provides the student with a safe space in an environment that can be threatening. This should not be underestimated as a way to mitigate trauma and provide a sense of normality. It is most effective when combined with in- and out-patient support, and “middle care” teams that visit the home through transitions.

Humans

Here are some of the humans doing work in Sweden to keep seriously sick kids connected to their education and schools.



NETHERLANDS

Amsterdam, Utrecht, Leiden, Eindhoven



System overview

FIGURE 4: NETHERLANDS - SYSTEM OVERVIEW

DESCRIPTION OF SYSTEM	
<p>In the Netherlands education is primarily government led. Individuals are free to provide education, without prejudice to the authorities' right of supervision.</p>	
NUMBER OF SCHOOLS	7,631
NUMBER OF STUDENTS	2,506,400
NUMBER OF HOSPITAL SCHOOLS	7
YEARS OF SCHOOLING	
<p>The compulsory education act states that students aged 5-18 must attend school. Primary education is available for 4 to 12-year-olds. Secondary education is available from ages 12 until 18. There are three types of secondary schools, each have a different duration. Prevocational secondary education is a four-year program, senior general secondary education is for five years and pre-university secondary schools is for six years. There are special schools for kids with learning and physical disabilities.</p>	
TYPES OF SCHOOLS	
<p>There is mainstream primary education, and secondary education encompassing pre-vocational secondary education, senior general secondary education and pre-university education. There are special schools catering for both cohorts. There are government schools (along with a smaller number of schools of various religious or educational philosophies) across all these categories. Individuals have the right to privately establish schools based on their religious, ideological or educational beliefs.</p>	
SPECIAL SCHOOLS	
<p>In 1999 a policy was established to integrate more kids with special needs into mainstream primary schools. The policy broadened and strengthened special needs facilities at schools. Students with special needs can remain in mainstream education and receive the support they need. In 2014 the new policy "Passend Onderwijs" ("Fitting Education") was introduced. The policy comes with pupil-related financing (backpack) for students who need extra support, such as students with a serious illness.</p>	

<https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Netherlands:Overview>

Findings

The following is a synthesis of all meetings held in the Netherlands and a summary of themes in the Netherlands for keeping seriously sick kids connected to their education and schools.

LAWS ON EDUCATING SICK KIDS

- In 1999, the Dutch government changed the law for special education (education for sick students) to produce a national network and provide education services for sick students. Prior to that there were 13 hospital schools (services). Government stopped those in smaller hospitals and they now only operate in seven tertiary hospitals. The government recognised that kids were spending shorter stays in hospitals.
- Government gives responsibility for the education of sick students to the regular schools of those students.
- Government funded a national network of organisations to deliver education services to students with illness. Hospital school teachers were redeployed to those organisations and became Consultants Education Sick Pupils (Consultant ESP).

PRINCIPLES OF LAW AND POLICY

- Cautions that disability cannot be the overarching legislation for this context. For education services to work for sick students, there must be education legislation specific to serious illness.
- Netherlands Education law separates illness into two parts: somatic illness and mental illness. Education professionals working in these fields have different backgrounds and services are based in different locations. In 1999, mental illness was more clearly delineated from somatic illness for education services. Special schools are in place for psychiatric and behavioural issues, and dedicated support addresses the issues particular to each group. The grey area between the two is eating disorders and is typically grouped with somatic illness in terms of approach to education services.
- In 1999, Government established a funding formula for financing educational support to students with somatic illness. The formula counts all students in the education system (or catchment area), primary and secondary schools, and multiplies it by €1.61 per student. It then quarantines that money from the district/school budget (as a kind of insurance) and pools it in a national budget of €1,200,000 to finance education to sick students. Eighty-five percent of that budget is for salaries paid at the level of special needs teacher to Consultants ESP.
- Consultants ESP are contracted and paid by education organisations (which are mostly private sector, but can be not for profit entities). Tutoring in the home is provided by hospital teachers and volunteers who are arranged by the national network of education consultants. Students' regular schools also offer lessons at the home, when the student leaves hospital and has not returned to school. This is a system grown organically without intervention by national government (funder).

- Alongside this formula-based budget, there is a fixed budget for education services in the seven University Medical Centres (tertiary hospitals). Consultants ESP are contracted and paid by the tertiary hospital in which they work. Beside their work as Consultants, they are also allowed to teach in hospital (at the bedside or in classes).
- The services mentioned, including technology, are only provided to students in government education, not to students in private schools (those students are allowed to apply for another technology – Webchair or Quby – through a different channel, i.e. not KlasseConnect).

STANDARDS, MEASUREMENT AND DATA

- Research (Prof. Dr. Hugo Heymans) suggests that chronic illness in kids is rising (may be because kids with critical and life-limiting illnesses are living longer). The figure for Dutch children was 10% (in 1999) and is now around 15% (for 3-18yo). Ten percent of those are serious illnesses that cause school absence often or for long periods (amounting to around 1.5% of the student population).
- The national network uses a documented professional profile with mapped competencies, for Consultants ESP, and maintains a website with information on student education and illness.
- All Consultants ESP (120 fulltime; 78 part-time) get basic six-day communication training on top of their special education qualifications. It is estimated that a teacher becomes a Consultant ESP after 30-40 days of in-service teacher training (including communications, digital connection, on the job learning, mentoring and modelling).
- National government periodically runs expenditure evaluations of education organisations spread throughout the country. Government has not set specific service standards or benchmarks for educating sick students nor is there national monitoring of service delivery.

PROCESS, PROCEDURES AND GUIDELINES

- Reference to hospital pedagogues which is the term for a child-life specialist. Play therapists hold this qualification in the Netherlands.
- The Ziezon professional network is a cooperation between the Consultants ESP in tertiary hospitals and the Consultants at education advisory bureaus. They work together to deliver education consultancy services and advice to schools. In some tertiary hospitals, and in some special children's hospitals, Consultants also teach students in hospital. The Consultants ESP support students outside hospital by liaising with their regular schools and arranging education connection while they are at home.
- Support starts for students at three-and-a-half years (as school starts at age 4). Parents give verbal permission for hospital teachers to liaise with school, and enjoy the advocacy role that these teachers play in engaging the regular school in the process of taking responsibility. Hospital teachers also support school to get financial support from the government to meet their educational care of sick students. This is called "back pack" money, but the system has had some problems with overpayments in recent years and is being overhauled. The back pack funding is through "Passend

Onderwijs” policy (“Fitting Education”), where schools receive a higher fixed budget, coupled with additional responsibilities for special needs students.

- In tertiary hospitals, students get at least one hour per day (sometimes two hours), four times a week. It’s effective one-on-one teaching and learning that cuts out “soft” parts of the curriculum to focus on core learning. It includes invigilating exams.
- Sometimes documented student care plans are arranged between hospital education service, regular school and home. The regular school has the ultimate responsibility for continuity in education, with some evidence that regular schools vary in their commitment to providing this.
- School support starts at three and a half years of age because kids in the Netherland start school at age 4. Hospital education services start if a student is hospitalised for two weeks, or two weeks accumulatively.
- The need for better protocols for school, social work, play therapy advised. In some hospitals, play therapy does the preschool teaching.

Technology

- Klasgenoot is a two-way digital connection technology provided by private telecom company KPN (previously government). It is in arrangement with the organisation of national consultants to service students while at home or in hospital. KPN has been providing and servicing the KlasseContact program since 2007. The student receives a laptop on which to work at home. This laptop cannot store data, it cannot record and if the student uses a recording device they will lose the opportunity (this has not happened since 2007). A contract with clear conditions is signed by student/parent prior to use. KPN provides logistics for delivery and staff for set up and runs a help desk which students, teachers or parents can contact. There are around 480 units currently in circulation and the technology has connected over 1000 students. It takes one day to set up at school and two weeks from order to placement (previously it took 3-4 months). There are fewer technical problems and now better logistics. KPN developed this latest device for KlasseContact. KPN’s regular technicians also work to place the devices for KlasseContact at the student’s school and home.
- KPN (technology providers) run television advertisements to create awareness of education rights and support for sick students.
- AV1 from No Isolation is being tested in at least one location in the Netherlands.
- Netherlands has been iteratively developing its digital connection platforms for sick students since 2003. It’s a world leader.

Networks and Advocacy

- The national network system for sick students in the Netherlands has produced a handbook for each illness and resources for ongoing teacher professional development. It employs a national coordinator to organise professional development.
- Parent-formed illness advisory groups are an expected and accepted part of the cooperative Netherlands health system. For example, a cancer paediatric parent’s group (VOKK) has been operating in the Netherlands for 30 years (it now has 4,000 members). VOKK is also member of the International Confederation of Childhood Cancer Parents Organisation (ICCCPO). Their primary objective is to support families

and kids with illness information support, meet each other and improve things in health care, influence the way things are organised in hospitals, schools and governments, advocate for a single centre for kids' cancer treatment in the country to streamline protocols and care. Also to achieve other outcomes, such as better health care insurance. VOKK have 12 paid staff (7-8FTE) and they have 200 volunteers.

THEORY ON BASE SOLUTIONS

- A government funded, and successful self-organising system of educational care for sick students that includes teachers, consultants, private sector technology provision, and volunteers for integrated hospital, home and regular school education services.
- Competencies are established and there is ongoing networked professional development for teaching in this context along with a national network of teachers and consultants who work together to ensure education delivery and standards are met.
- Collaboration and consultation is strong between all actors, including a primary role for parents and carers in advocating for and guiding education support for sick kids.

I saw a young student with chronic illness connecting with his class from home, and heard from his sister who used the technology to connect to her classes for the nine years before successfully graduating. Their home teacher was there to fill the gaps. This works! ~ Megan Gilmour

Lessons

The following captures notable challenges, opportunities, and observations from the Dutch education system for keeping seriously sick kids connected to their education and schools.

CHALLENGES

- A robust financing formula with a static multiplier which means that the budget for servicing sick students has not increased.
- Uneven provision in areas where volunteer teaching staff are not available.
- A distributed arrangement of private sector providers not governed by education system and relying on a network of personnel to successfully systemise.

OPPORTUNITIES

- A scalable and massively successful self-organising system of educational care for sick students that includes teachers, consultants, private sector technology provision, and volunteers for integrated hospital, home and regular school education services.
- Competencies set and ongoing networked professional development for teaching students with serious illness and a national network of teachers and consultants who work together to ensure education delivery and standards are met for sick students.

- Collaboration and consultation between all actors, including a primary role for parents and carers in advocating for and guiding education support for sick kids.

OBSERVATIONS

- Hospitals fund Consultants ESP (hospital teachers), so there are interesting line reporting arrangements.
- Physical location of the hospital school was noted as an important consideration. Hospital schools that are thoughtfully and strategically located in the hospital offer more effective access to kids and are more visible as a service.
- The self-organising nature of education services in the Netherlands may be the reason for its success (despite what appears to be a loose governance structure). The nature of the system and commitment of the people within it have kept standards high and enabled adaptive responses and solutions to develop without intervention from government administrators that have limited understanding of the complexities and the context.

Humans

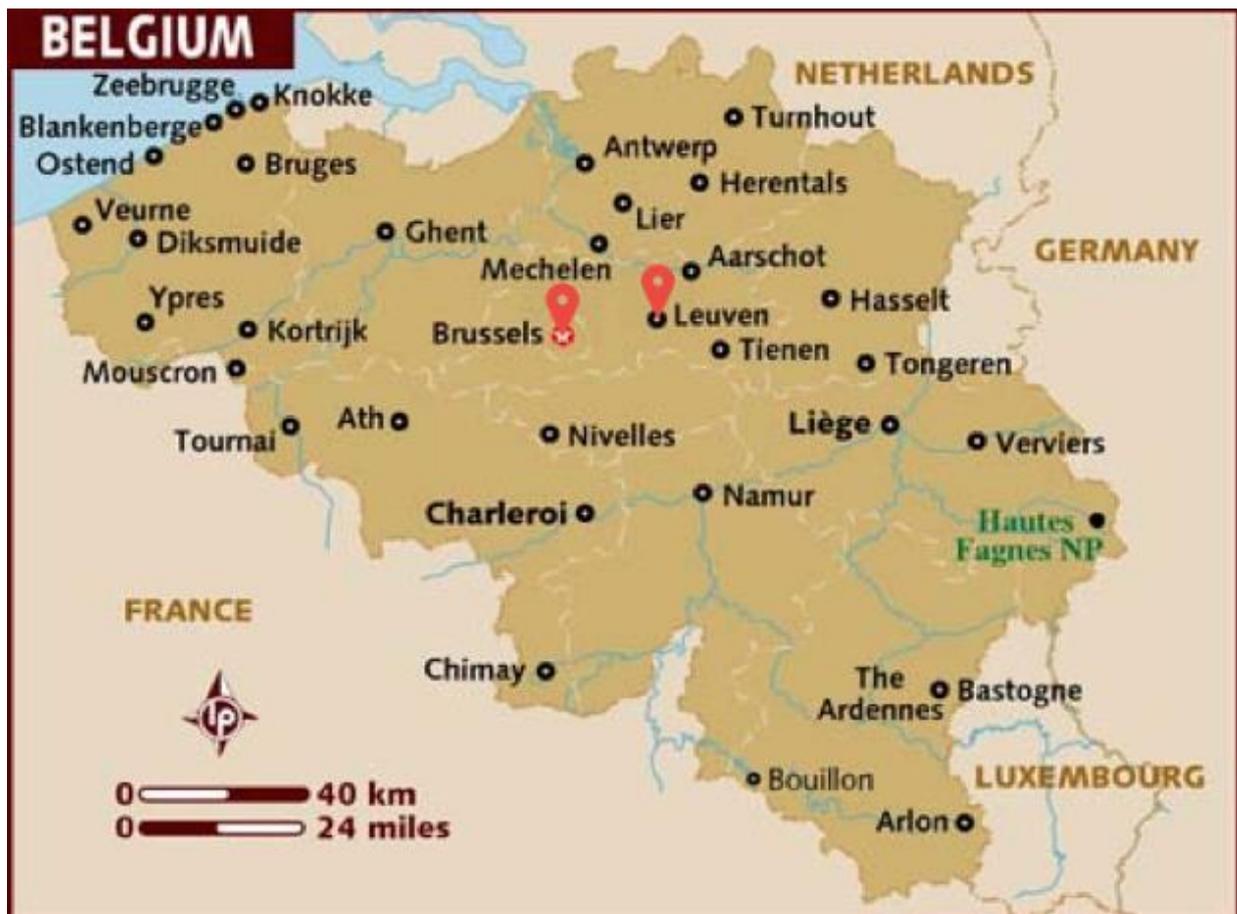
Here are some of the humans doing work in the Netherlands to keep seriously sick kids connected to their education and schools.





BELGIUM (FLANDERS)

Leuven, Brussels



System overview

FIGURE 5: BELGIUM (*FLANDERS) - SYSTEM OVERVIEW

DESCRIPTION OF SYSTEM	
Education in Belgium is compulsory. Parents are able to choose home schooling for their child and it is regulated and monitored through the government.	
NUMBER OF SCHOOLS*	3,651
NUMBER OF STUDENTS*	1,156,800 (19,000 SICK STUDENTS)
NUMBER OF HOSPITAL SCHOOLS*	7
YEARS OF SCHOOLING	
Education is compulsory from ages 6 until 18. Elementary education includes pre-school education and primary education. Pre-school is voluntary and accessible for kids from ages 2.5 until 5. Children attend six primary school grades from ages 6 to 11. Secondary education is organised for students from ages 12 to 18. Fulltime secondary education contains three stages, each stage consists of two grades. Students must attend fulltime compulsory education until the age of 15. From 15 onwards students may choose part-time schooling that combines part-time vocational education in an educational institution with part-time employment. The vast majority of students stay in fulltime education.	
TYPES OF SCHOOLS	
Official education (GO!) is organised by the government. There are three education systems: Dutch-speaking, French-speaking and German-speaking. While these governments have a duty to provide secular education, individuals may also establish private, denominational schools. Government-aided private education is free and organised by a private person. Some private schools are not government funded.	
SPECIAL SCHOOLS	
Special needs education is provided for kids needing temporary or permanent support. There are primary and secondary education special needs schools providing this support. In 2014 the Flemish Parliament approved an inclusive education act for kids with special needs. The act contains measures allowing students (including sick students) to participate fully, effectively and equally in regular schools and classrooms.	

<https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Belgium-Flemish-Community:Overview>

Findings

The following is a synthesis of all meetings held in Belgium (Flanders) and a summary of themes in Belgium (Flanders) for keeping seriously sick kids connected to their education and schools.

LAWS ON EDUCATING SICK KIDS

- The Flanders government has a long commitment to supporting sick students. Hospital schools have been in place for decades, home tuition was implemented in 1997, education in child psychiatric services was funded from 2003. Flanders instituted specific legislation in 2014 to decree rights to equality and continuity in education for students with illness as supported by two-way telepresence to connect students to their classrooms when they are absent because of illness.
- Government provision of education for sick students is increasing. In 2015, Flanders extended legislation to decree rights to real-time digital connection for sick students to their classrooms (currently provided by Bednet – see technology in this section). All schools are now obligated by law to advise parents that this is available.
- These laws only extend to schools that are funded by the Flemish government (so not to French-system schools and not to private schools).
- The Ministry of Education finances the hospital school as Category 5 Special Education.

PRINCIPLES OF LAW AND POLICY

- Rights and responsibilities-based language across all domains. Point of view of government is to reduce educational lag, prepare students for return to school, keep in touch with teachers and peers.
- Progressive thinking on rights of students in medical settings, including flexibility at school, hospital school services, temporary education at home and digital connection.
- Government requires the regular school to be responsible and funds that support.

STANDARDS, MEASUREMENT AND DATA

- The support system in Flanders for sick students includes regular school, home tuition (4 hours per week), real-time digital connection to the classroom, hospital schooling and privately funded volunteers (not endorsed by the government).
- There is no professional pre-service teacher training for hospital school teachers, only postgraduate studies in special needs. It's learning on the job.
- Play therapists require university level qualifications.
- The government is putting a bigger focus now on healthcare in schools, but schools aren't equipped to properly deal with it yet. Teachers are not equipped. It's highly variable as to what they can provide even though it's the student's right and the government requires the regular school to be responsible.

- Flanders has been using electronic rolls (for the last 5-7 years) so the education department gets real-time data. This appears to be the only country in the study that can confirm the number of its students who meet the Flanders' Government's definition of significant absence - 36 half days (4 weeks accumulatively per year) of school missed because of a medical or mental illness. The number of students is 19,000, or 1.7% of the student population.
- Flanders is working on identifying students at risk of unexplained absences, or absences of any duration that are not being attended to.
- There is no evidence in Flanders to say that siblings experience a lower quality of education – the small geographic area of Belgium may contribute to siblings staying connected to their schools more than in countries where better medical care comes at distance.
- Parents have a learning duty, that is to make sure their child is learning at a registered institution (which could be the home, if registered).
- Inspections occur and government intervenes if learning duty (through school or parents) is not being met. There are categories of allowable absence: illness is one.

PROCESS, PROCEDURES AND GUIDELINES

- Students in hospital school get at least one to two hours of teaching at the bedside per day, depending on their program and health. Some students can attend hospital school almost full time. Students qualify for hospital schooling if they have been in hospital for one week (unless they have accumulated absence of more than a week). Medical staff provide the student list.
- Educational support for sick students commences (according to the government) at 36 half days (one week is nine half days) – or around four weeks of medically verified absence from school. In the case of chronic illness, it starts at nine half days' absence.
- The hospital school teaches the program of the student's regular school to keep the student aligned with the class. There is hospital schooling for pre-school and early childhood.
- Hospital school provides support to students to arrange temporary support from their regular school when the student is at home.
- Schools vary in their delivery of education services to students at home. Most do well but some will say they are not able to provide. Government requires school to provide for students up to 10 km from school, but will pay school to deliver to students residing/staying (could be a local hospital) up to 20km from school. There are three categories that can apply to meet basic conditions: long term absence (15 school days), frequent/repeated absence (9 half days absent); and maternity leave.
- Hospital school teachers talk with/visit regular schools to explain and act as a bridge between the hospital and the school. Teachers in the regular school often ask for help. The hospital school plays the role of advocate.
- There are rules about privacy on medical issues, so the hospital school must get verbal permission from parents to connect with the regular school.

- Hospital school mentioned that Bednet is important for continuous school connection because the hospital school cannot provide all the subjects a student needs, isolation is a big problem, and students are spending more time out of hospital, at home.
- Students can have Bednet “up until the last day”, in the case of terminal illness. More than one hospital school teacher across Fellowship interviews said that they had students who wished to be connected to their classroom in their final days. This demonstrates the critical place that school holds for many kids.
- The hospital school can skip parts of the curriculum and find quicker ways for the student to achieve core curriculum.

Technology

- Belgium Flanders has Bednet, a two-way digital technology developed by a social enterprise and available to sick students aged from 5-20 years who miss school, as well as (lately) to teenage mothers. One in five schools have used Bednet since the beginning, along with 2000 students. Bednet was founded in 2004, and ran its first pilots for children in 2007. Across the years of operation, Bednet has received incremental government support, but is now substantially funded by the Flanders education department. Bednet is now a top of mind solution and can be applied for by schools and parents. Students are assessed for suitability based on criteria developed in collaboration with the education department. I watched it in operation in the classroom and it was effective and assimilated for teaching and learning. Bednet provides a system of personnel to support students, parents, and teachers in the placement and ongoing operation of the technology in schools.
- Bednet has arranged with Proximus (internet service provider) to give internet access to sick students at home, if they don't have connectivity.
- Wallonia (French government) in Belgium also offers a smaller-scale Skype-based programs to students in its schools. This was not investigated.

I care about school work but most of all I want to be with my friends because they give me so much support through my illness. I miss them.

Do they miss me? – Mattias, 16yo student fighting leukemia

Networks and Advocacy

- The recent resurrection of a health and education forum was mentioned. There has not been much collaboration on this front, however, the latest forum provides hope that a stronger alliance can be built.
- Noted on literature (a book) for schooling produced for parents, doctors, psychologists and, of course, the students themselves.
- Belgium has professional networking events and exchanges for hospital school teachers.

THEORY ON BASE SOLUTIONS

- Active promotion of rights by government decree including an obligation to inform on student rights and school responsibilities to parents.
- Regular school has responsibility for the student and has a critical responsibility to uphold rights, including by delivery of two-way digital connection (which they see as essential “digital adaptation” for teachers) and at home face to face teaching, when not at school and not in a hospital with hospital school services.
- A robust funding model which includes government funded digital connection for sick kids to their classrooms.

Lessons

The following captures notable challenges, opportunities, and observations from the Belgian (Flanders) education system for keeping seriously sick kids connected to their education and schools.

CHALLENGES

- Privacy issues in the health and education setting can be challenging at the best of times, but no more so than at the intersection of health and education. There are challenges in transmitting medical information to teachers, there are challenges with proximity to other students and staff in medical settings, there are challenges with digital connection and who is being observed and there are challenges around how privacy is treated in relation to home settings.
- Provision across different jurisdictions, and education sectors to produce universal equity in a national system (e.g. only for government schools in certain jurisdictions).
- Ensuring there is equity in take up of education support, including digital connectivity, across all socio-economic groups. Belgian experience is that middle classes tend to advocate better for student’s rights, so it’s critical that rights are automatically conferred, otherwise kids from lower socio-economic backgrounds won’t get support.

OPPORTUNITIES

- To expand the use of digital two-way connection from hospital school to classroom, and home to classroom. For hospital and education offices to work together on this to avoid duplication of effort due to limited formal education-health arrangements.
- Play therapists must be university qualified as child development specialists. There is a cultural commitment to using scientific principles and evidence in the teaching of sick kids, or even in play therapy. Since hospitals fund these placements, this is one area where health and education can work together in marrying efforts in early childhood where there is a large gap for sick kids in Australia.
- A robust government funding model to support home based education services, digital connection to classroom and a network of personnel who can set up and support both.

OBSERVATIONS

- Teacher engaged in digital delivery of teaching to sick student commented that privacy is not an issue for her, she doesn't mind who observes her teaching, anyone is welcome in her classroom. This is instructive, especially in a digital age of teaching.
- A progressive model that has strengths from law right through to principles, policy, standards and data collection, and practice. It has a clear and robust funding model and arrangements, and legislates digital connectivity as well as home-based tuition.
- A network of dedicated personnel is needed for set up and support of digital connection, sustainable government funding for technology for digital connection, and schools have clear mandates around disclosure of services to families and the government support (both clear guidelines and funding) to deliver services.

Humans

Here are some of the humans doing work in Belgium (Flanders) to keep seriously sick kids connected to their education and schools.



UNITED KINGDOM

London



System overview

FIGURE 6: UNITED KINGDOM - SYSTEM OVERVIEW

DESCRIPTION OF SYSTEM	
<p>Overall responsibility for the education service lies with the UK Government. The parent of every child of compulsory school age shall facilitate the attendance of the full-time education suitable to age, ability and aptitude. Parents who wish to educate their child at home can do so after informing their local authority of their decision.</p>	
NUMBER OF SCHOOLS	24,372
NUMBER OF STUDENTS	8,560,000
NUMBER OF HOSPITAL SCHOOLS	26
YEARS OF SCHOOLING	
<p>Full-time education is compulsory from the term following a child's fifth birthday until age 16. The Education Act outlines that from ages 16 to 18 young people must be in full- or part-time education or training. ISCED 0 is free part-time provision available for all kids from age three. From age 4 to 5, most kids attend a primary school reception class full time. ISCED 1 is primary education consisting of Key Stage 1 for ages 5 to 7 and Key Stage 2 for ages 7 to 11. ISCED 2 is Key Stage 3 for ages 11 to 14. It is provided in secondary schools, catering for students from 11 to 16 or 18/19. In ISCED 3 Students normally continue at the same school for Key Stage 4, which is the final phase of compulsory full-time education for ages 14 to 16.</p>	
TYPES OF SCHOOLS	
<p>There are a variety of types of schools. Community schools are controlled by the local council and are secular. There are Independent or "public schools". Foundation schools are independently run, and therefore many of them have a religious or ideological background. Academies are independent of the local council and are run by their own governing body. A council, trust or founding body runs grammar schools (selective, comprehensive, or free schools).</p>	
SPECIAL SCHOOLS	
<p>The 2010 Equality Act provides a single legal framework seeking to protect the rights of individuals and advance equality of opportunity for all. Responsibilities under the Act are subscribed to government departments, government agencies, local government, and education providers at all levels of education.</p>	

<https://www.gov.uk/types-of-school/overview>

<https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/United-Kingdom-England:Overview>

Findings

The following is a synthesis of all meetings held in the United Kingdom and a summary of themes in the United Kingdom for keeping seriously sick kids connected to their education and schools.

LAWS ON EDUCATING SICK KIDS

- The Education Act 1996 says: 'Local authorities have a statutory duty to arrange suitable education for children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them', Education Act, HMSO, 1996. This duty is restated in Section 100 of the Children, Schools and Families Act 2014 (new duty on schools to support students with medical conditions).
- There is a legal framework for minimum provision. Schools are expected to support kids with medical conditions in school. This is now matched with statutory guidance. Head teachers are "held to account" for full education and subject to Office for Standards in Education, Children Services and Skills (OFSTED) inspections under the same inspection framework as all schools.

PRINCIPLES OF LAW AND POLICY

- In 2014, the UK Department for Education set statutory guidance for local authorities for "Ensuring a good education for children who cannot attend school because of health needs".
- Mandates and "duty" language used rather than rights language.
- Alternative provision (suitable to age and ability) is given for any child who cannot be at mainstream or special school. Local authority has to work with schools and parents. This alternative provision sits alongside hospital education. There are "pupil referral units" involved in this process.
- Hospital schools are established legally as schools under Department for Education. All students who are supported by a hospital school are dual registered (regular school and hospital school). The regular school retains final responsibility for their progress and records.
- There are informal arrangements between health and education for hospitals to provide space for hospital schools and some guidance on this within Department of Health (but these arrangements haven't been updated for many years). This means there are challenges when hospital wants to rearrange space.

STANDARDS, MEASUREMENT AND DATA

- Since 2014, every academy, state and free schools (not independent schools) are required to have medical policies and openly publicise those policies. This primarily deals with "in school". Schools did not receive additional funding to do this.
- The exact number of kids with healthcare issues in school is not known by government, but Diabetes UK estimates that two-million kids are affected.

- OFSTED “found that, in too many cases, children and young people did not have access to full-time provision or as near to full time as their medical needs allowed.” Diabetes UK, who did a randomised evaluation, found that only 15% of schools are responding by the letter, the remainder are variable in their compliance.
- The effectiveness of Local Authorities in administering services to sick students is said to be variable.
- Not for profit sector has worked directly to ensure that OFSTED monitor schools for compliance to responsibilities for educating sick kids. Monitoring of local authorities in their role for “at home” support is less clear.
- If a student misses school for 15 days it becomes a legal issue, but in cases of illness the absence is explained and ceases to be flagged. The 15 days absence (in a year) is used as a trigger point for alternative provision (in addition to hospital education).
- There are arguably no tangible formal arrangements between health and education in the UK.
- Hospital schools have databases to track student numbers and in some cases student progress, interaction and for evaluative reporting.

PROCESS, PROCEDURES AND GUIDELINES

- Local Authorities (150 in total) administer schooling in the UK. Local authorities are responsible for education services to sick students when they are at home.
- If a student is expected to spend more than 10 days at home, they should be provided with at least 5 hours of home education. At other times, the provision has been stipulated as 25 hours per week but it was never funded. All local authorities do it differently and “do what they can”. School of enrolment has responsibility.
- Until 2013/14 the UK used a system of “Recoupment” which meant hospital schools invoiced the Local Authorities of students in the hospital school. From 2013/2014 the Department for Education “top-sliced” funding to Local Authorities by £8.50 per pupil to fund hospital education places (£70 million). Place funding is extremely variable across the UK and has resulted in inequality based on historic funding arrangements, locally. Currently, place value can vary from as much as £20,000 per place per year to as low as £8,500. Governments are concerned about the cost of supporting the education of students with serious illness (this was indicated in every country).
- Hospital teaching starts for admissions of 10 days or recurrent admissions. In most long-stay inpatient settings, teaching is prioritised for patients with an admission of five days or longer (although teaching can start on day one). In most settings, students get one hour per day at the bedside. Once again it was noted that the intensity of teaching (one-to-one) means that the student can achieve more progress than in the same amount of time in a one-to-many teaching and learning setting.
- Hospital education is tasked to provide the full curriculum to students in hospital.
- QNIC provides a framework and accreditation for inpatient psychiatric settings only (reviewing specialist teaching and, in some locations, standards developed for nursing, medical staff and teachers).
- Hospital school sometimes feels like an “unwelcome guest” in the hospital. There are always struggles with funding and who has responsibility.

- The education system (because of changes in government funding arrangements) is remolding itself with academies (blocks of multiple schools) emerging. Finding a suitable “block” or arrangement into which hospital schools fit is ongoing.
- School nurses are employed by local authorities to provide medical support in schools.
- Careers counselling and transitions programs for young adults with medical conditions is a part of the work of hospital schools.

In illness, education plays the role of positive expectation for a student, and the teacher creates that role. Mostly students rise to the expectation ~
Headteacher, London

Technology

- No particular focus on connective technology solutions were discovered. There was some evidence of Skype being used to connect students in hospital ward to ward.
- Since Fellowship visit, there are reports of some robot technology emerging as connective options.

Networks and Advocacy

- Changes to the UK law for the education of sick students was the result of collective action from a range of kids’ illness groups, led by Diabetes UK. The action included petitions and stories from families, taken to UK Parliamentarians and presentation of draft laws. This action represents two million kids in the UK. Further action was needed once change was achieved because randomised reviews found wide variability in school adherence. An important discovery was that schools found it difficult to interpret the laws. Statutory guidance was developed to give local authorities and schools a clearer understanding of their obligations.
- CLIC Sergeant priority group was mentioned.
- Since Fellowship visit, word that a new national organisation is being formed for supporting the education of children with medical needs. It is being developed through an active steering group, will have a website, and is expected to launch at a conference in October 2018. HOPE UN Charter was mentioned as needing to be enshrined in the UK.

THEORY ON BASE SOLUTIONS

- Explicit legislation is needed for education services to sick students, backed by simplified funding arrangements, and government communication to schools about responsibilities and awareness raising.
- Law is not enough. Those mandated to provide education services to sick students must have the law interpreted for practice, e.g. statutory guidance that includes requirements for transparency on schools’ education services for sick students.
- Collective lobbying involving families and organisations with a perspective on specific illnesses is a powerful catalyst for change.

Lessons

The following captures notable challenges, opportunities, and observations from the British education system for keeping seriously sick kids connected to their education and schools.

CHALLENGES

- Hospital school funding and funding for sick students is complex and fraught.
- Monitoring compliance, particularly delivery of education by schools in the home.
- Lobby for changes in provision for sick students in school has been strong but there remains a gap in lobbying for changes and compliance to standards for students who are absent at home because of medical conditions.

OPPORTUNITIES

- Clear laws, cross referenced in more than one legislative framework sets the tone.
- Statutory guidance has taken the ambiguity out of interpreting the law and this has provided a strong basis for monitoring compliance.
- Strong political push for medical policies in schools from not for profit illness lobby and maintaining pressure for compliance has resulted in significant changes in the landscape.

OBSERVATIONS

- Complexity of school system and multiple policy and funding streams for provision for sick kids in school, in hospital and at home makes it hard to say that provision is even.
- Monitoring by the government standards body (by lobbying from not for profit groups) is raising the profile of education support in schools for kids with illness and maintaining positive pressure for compliance. More work needed on missing school.
- Attention to careers advice and support and transitions for young people are a positive element of the UK system not found elsewhere.

Humans

Here are some of the humans doing work in the United Kingdom to keep seriously sick kids connected to their education and schools.



Image from Chelsea Community Hospital School Website



Image from Google images

CANADA

Toronto, London, Vancouver



System overview

FIGURE 7: CANADA (ONTARIO & BRITISH COLUMBIA) - SYSTEM OVERVIEW

DESCRIPTION OF SYSTEM	
<p>Canada has no national department of education. Each of 13 provinces and territories can outline the legislation that dictates education standards. While most of the provinces and territories have similar systems, there are differences in the curriculum and accountabilities of schools. Provinces and territories are divided into school districts or divisions, which are responsible for implementing education services at a local level. Ages for compulsory education vary between provinces and territories. Education for indigenous students who live on First Nations reserves is federally funded and coordinated by First Nations councils or school boards. The remainder of this table focusses on British Columbia and Ontario.</p>	
NUMBER OF SCHOOLS	1,919 (BC) AND 4,891 (ON)
NUMBER OF STUDENTS	641,000 (BC) AND 1,993,400+ (ON)
NUMBER OF HOSPITAL SCHOOLS	1 (BC) AND 5 (ON)
BRITISH COLUMBIA	ONTARIO
YEARS OF SCHOOLING	
<p>Full-time education is compulsory from ages 6 to 16-18 (depending on which province). Elementary schools provide education from age 4-5 to 13. Four to 5-year olds participate in kindergarten one full day per week (starting age four, for two years, in Ontario and starting age five, for one year, in British Columbia). After kindergarten kids go through grades 1-8. Secondary schools provide education from grades 9-12. Students begin at 14 and graduate at 16 or 18 years of age (depending on the province).</p>	
TYPES OF SCHOOLS	
<p>Public education is free and accessible to young Canadians. It is completely funded by the government. In British Columbia, the Ministry of Education regulates private schools. These schools are termed separate schools when they have religious foundations. They are either partially or completely funded by a source other than the government.</p>	
SPECIAL SCHOOLS	
<p>School boards are responsible for informing on special education services and are required by law to meet the needs of students who are deemed to have exceptional needs. Students with special education needs can have accommodations and special placements formalised through individual education plans. Their cases are assessed by the Identification, Placement and Review Committee who modify the curriculum to needs. Students with serious illness can be supported through this process though their needs may not be deemed “exceptional” based on current formulation of the criteria.</p>	

<http://settlement.org/ontario/education/elementary-and-secondary-school/general-information/at-what-age-do-children-attend-school/> <http://www.cmec.ca/299/education-in-canada-an-overview/>

<http://www.ourkids.net/ontario-private-schools.php> <http://cdnsba.org/wp-content/uploads/2010/07/cross-country-overview-public-education-copy.pdf> https://www.bced.gov.bc.ca/specialed/special_ed_policy_manual.pdf#page=31 <http://www.edu.gov.on.ca/eng/general/elemsec/speced/ontario.html>

Findings

The following is a synthesis of all meetings held in Canada (Ontario and British Columbia) and a summary of themes in Ontario and British Columbia for keeping seriously sick kids connected to their education and schools.

LAWS ON EDUCATING SICK KIDS

- Canada operates a province-based education system, there is no national department of education or ministry. Multiple District School Boards (School Boards) report up to provincial ministry level.
- All provinces have both French and English language school districts or divisions and provide education in both of Canada's two official languages. Seven of the 13 provinces and territories also provide public funding for Catholic schools (one of these only until Grade 9).
- In one province there are schools that provide services to kids who cannot attend their community schools because they are in care and/or treatment, or custody. These schools include hospital schools and operate under a different funding model than other schools.
- In one province, missing 15 days of school is a trigger point for action, but this is not specific to students who miss school because of serious illness. A student cannot be kept on school rolls after that time period unless documentation is provided explaining the absence. School funding for community schools is determined by the head count of students, which is conducted by School Boards twice per year. Technically, a student can only be registered at one school. This creates significant administrative work (for teachers, who could be teaching) whenever a student moves back and forth between community and hospital schools.
- One hospital school quoted that home tuition provision applies after one month of absence although it is unclear if there is uniformity on this across the province, based on experience in another provincial location.
- Boards may provide instruction in the home or in the hospital for children who are unable to attend school due to medical reasons. The implementation of this is left to local school districts and policies vary among school districts on how much instruction is provided each week, and the length of the expected absence required to qualify. Generally, at least three hours a week is provided.
- Noted that "figuring out the process" of home tuition is not always easy – as requirement is open to varied interpretation. Some challenges noted are: trouble finding teachers (especially in less populated areas or in high school subjects where teachers are in demand), delays in getting approval and providing a teacher, limited flexibility in how hours are allocated (e.g. hours unused due to illness or treatment can't be carried over for use when the student is able/available), teachers only being available after school hours (when the student may be less available to learn, or there may be other children at home etc.).
- Home-hospital tuition is not required by private schools.

- A child can access their home-hospital tuition in a hospital that does not have a hospital school (and also instead of attending the hospital school in a hospital that has one). However, this is not realistic for students who live outside school district.
- In one province the law is supported with guidelines. A doctor must formally advise a “chronic health designation” with “serious impact on learning”. Hospital school teachers often support the form of wording suitable to meet the guidelines for support. In the other province there is not a formal designation that would capture students whose problems are primarily health-related (but do have to provide documentation to justify home hospital instruction). Doctors and other health professionals can be asked for documentation to assist in developing a child’s education plan (e.g. audiologist, psychologists, physiotherapists, etc.).

PRINCIPLES OF LAW AND POLICY

- In the cases reviewed, there appears to be weak governance links between education and health. Stronger, informal links can be seen between practitioners at local levels rather than led by government policy, guidelines or mandates. In one case there are school health support services that provide hands-on care for students with serious health needs while they are in school (e.g. tube feeding at school, occupational therapy assessment etc.). These are coordinated by the local health networks.
- A hospital school in one province was able to produce a “Protocol Agreement” from 2013 which outlined formal arrangements and procedures between Education and Health, however, was not being referred to by any current staff from the hospital or the hospital school. It was not clear whether this agreement had expired or been forgotten over time as staff changes occurred. This raises the point that permanence of protocols is unreliable in big systems where staffing fluctuates, or when there are political (leadership) changes, because education-health arrangements are not formally woven in governance through all levels of the system.
- A student missing 15 days of schooling is a trigger point for action, but this is not specific to students who miss school because of serious illness.
- Funding for education services, including those in hospitals is a provincial responsibility. Special needs funding goes to Districts in a package to be distributed based on need.
- Treatment of privacy of health information seems to differ from province to province and hospital to hospital. In some locations, hospital school teachers are better integrated into the health care team and granted access to patient records. This influences the extent to which teachers are aware of student admissions, needs and limitations. In other cases, they are provided lists determined by medical staff.

STANDARDS, MEASUREMENT AND DATA

- Ministry performs audits on a regular basis, as part of accountability in schools, these focus on a range of issues from staffing, special education implementation, whether a wage freeze was implemented, or to ensure school board has documentation to justify maintaining students on roll after 15 days of absence. Audits on standards to meet

needs of students who are absent because of serious illness don't occur because there is no specific government policy outlining a standard.

- Noted that changes in staff and administration can lead to changes in the way legal provisions for students are interpreted and administered (provisions are open to interpretation).
- The difficulties facing parents in this context was noted. Parents can't keep complaining to schools because it creates an adversarial situation between school and parents (which is seriously counterproductive since parents are working to maintain the relationship so their child gets greater support in and out of school). Teaching parents to be advocates is a priority but the system should not rely on this.
- Parents who are already coping with a seriously ill child may not always have the time, energy, or emotional resources that are necessary for advocacy. Parents are not in a position to be fighting for the rights of their child through the Human Rights Commission, though this might result in preventing inequity.
- There is no teaching specialisation for hospital school teachers or home-hospital teachers (not considered vocational). Hospital school teachers may have special education qualifications. Typically, home-hospital will be provided by substitute teachers, however, there is no provision if the home-hospital teacher is away. In some jurisdictions there is ongoing professional development for hospital teaching staff.
- There is variability in terms of attention by medical teams to education considerations for sick students.
- Home-hospital usually only given to students from grade 1-12. Kindergarten students don't get home-hospital tuition unless there is a real push for it. This indicates the discretionary nature of this offer. Numbers of home-hospital teachers is reducing in one province (from 14 staff to 2) where the need for the service is potentially increasing.
- Individual schools collect data on absences but it wasn't understood if illness absence data is rolled up to be monitored at provincial level.
- Evidence that the hospital school size and number of hospital school staff is being reduced (even in a major children's hospital) because the only data being considered is reduced length of hospital stays. This has implications for resourcing the advocacy role that hospital school teachers play in arrangements for home tuition and transitions back to the regular school, a role that has already been noted as extraordinarily difficult for parents to fulfill.

PROCESS, PROCEDURES AND GUIDELINES

- There is evidence of hospital psychologists being involved from diagnosis through into long term follow up and educating regular school staff in barriers and issues to educating sick students (this was seen in, and may be limited to, oncology setting).
- Noted that kids are in hospital for shorter and shorter lengths of time (noted as a global trend). Students who are absent due to illness, and not in hospital - while entitled to one-on-one home-hospital instructional support (if they are medically unable to attend school they get a teacher to their home) – may not be routinely offered it.

- Noted that 40-60 minutes of tuition is given at bedside in hospitals where there is a hospital school but this will vary between hospitals and provinces, and is dependent on staffing. It may not be given every day during hospitalisation. If not scheduled, bedside tuition can be sidelined by competing medical treatment and investigations. Some hospitals institute a blanket rule that students cannot be in the hospital school classroom concurrently (due to risk of cross infection) meaning that resource is used for one-on-one tuition on a scheduled basis. The extent to which this decision is supported by individual context, evidence, consultation, or discussion with education authorities is not understood. It does indicate the need for clearer education and health arrangements that are not simply based on localised, unidimensional decision making (and where an appreciation of the evidence for education and socialisation may be absent in decisions).
- There is evidence that students with long-term illness are prioritised for education support in hospital schools as teaching resources are spread thin. In one hospital there was previously classrooms on the oncology ward given the length of hospital stays for many of those students, however, the hospital stopped it on grounds of cross-infection. If students are isolated, even on their wards, connective technology becomes critical.
- Hospital schools can provide opportunities for students to become educated on their own illness and how to manage it in their regular schools, increasing the student's self-agency and advocacy. There are hospital-based programs that do this for students, e.g. in the epilepsy setting.
- In one province, many school board's home instruction policies are set up to address the needs of students who have a time-limited illness and miss school for a single, extended period. It is assumed a child will be attending school regularly or receiving home instruction. Home-hospital instruction policies typically do not address the needs of students who attend school sporadically (e.g., a child who had a number of shorter absences that add up to the equivalent of several months over the course of the school year.) Some school boards are flexible and allow a student to switch seamlessly between attendance and home instruction, while others may say the child has to choose one or the other. The lack of clear policy and direction from the province on home instruction results in a lack of consistent service across the province.
- Provision of home-hospital instruction is the responsibility of the School Board and the principal of the student's regular school. Provision is variable (and at the discretion of Boards and schools) but is usually between 3-6 hours per week at home; five hours per week is common in one province.
- Noted that while schools have responsibility, they cannot do it on their own. There is a need for cross-disciplinary skills where education and health intersect and the implications of health conditions on education, and vice-versa, can be translated.
- Current processes, documentation for adjustments, and meeting special needs (formal identification of needs processes) was seen to be inadequate or ill-suited to the context of serious illness and education.
- Many high schools offer online study with credit, however, there are tight timelines and no adjustments, flexibility, or support for alternative arrangements. Credit accumulation (getting credit for what they've done) for secondary students in this context is noted as the number-one challenge. A new development that is helping address this is "blended

learning”. The student uses online materials but can work at their own pace with some support of a face-to-face teacher.

- Child Life Specialists (with post-graduate qualifications) deal with medical play, diversion and distraction and are linked to hospital school but employed by hospital.
- It varies by hospital on who provides the list of students. In some cases, nurses give it to hospital school teachers, in other hospitals teachers can directly access the list (see earlier comments relating to privacy of health information).
- In some locations, parents sign an agreement to allow the hospital school and regular school to communicate about the student, in other locations verbal permission suffices. There is no formal agreement for the home-hospital care.
- Regular school teacher is responsible for student reports but may not have the student in their class for long periods of time. This was the case in other countries.
- There is no provision for early education (preschool kids). Most Boards say no to kindergarten students getting home-hospital tuition unless there is pressure for it. This is ironic considering promotion and provision (in some provinces) of full-day funding for school for 4- and 5-year-olds.
- There is interagency collaboration (multiple services for kids) at the District level, e.g. Ministry for Health and Ministry for Child and Youth Services. Multidisciplinary clinical meetings are held in hospitals on certain wards. Because of health privacy laws, in some hospitals, hospital school teachers are not allowed into medical or “case” meetings. This indicates the disconnection between treatment and holistic care. Parents give teachers unsolicited updates on medical situation as it has implications for school, teaching and learning.
- One teacher commented that regular schools are more sympathetic to physical illness and that support from the regular school in cases of mental illness remains a challenge. Hospital school teachers noted their advocacy between the medical and regular school setting. In one province there needs to be five days of hospitalisation (accumulatively) before the students is seen by a teacher. In another province the hospital school staff advocated for provision as soon as a student is admitted.

Technology

- Technology was not a big focus in hospital school settings. This was interesting since Canada had one of the first telepresence robot programs in this context. This now seems to be defunct as there was no evidence that the manufacturing company still exists, nor did people talk about it or know about it.
- Use of Google classroom was noted as assisting secondary school students who are away from school because of illness.
- Noted that some regular schools allow students who are absent due to illness to Skype in, other schools refuse. This appears to be at the discretion of schools and teachers, meaning that digital connection is not a part of the support landscape in legislation, policy and practice.
- Comments that hospital wifi was often inadequate for digital connection to classrooms, and opposition to use of cameras for privacy of staff while at bedside.

Networks and Advocacy

- Childhood cancer has strong advocacy groups, however, funding for adult oncology through charities is much higher.
- It was a parent in Ontario who lobbied at District and Ministry level to have roles created in hospitals to focus on the psychosocial impact on kids with cancer.
- Medical diagnosis is shown to interrupt a child's development, socially, emotionally, and educationally. Because of what they miss, frontloading care and overlooking long-term effects puts kids at risk of learning deficits (psychosocial development psychologist).
- Paediatric Oncology Group Ontario (POGO) is a large organisation and advocates for a government funding model to direct money to childhood cancer care. This has been especially effective for introducing multidisciplinary teams in hospitals. They want a bigger focus on long term follow up and issues, including consultation with schools.
- C17 Children's Cancer and Blood Disorders – an arrangement of people from 17 oncology treatment centres - produced a working paper on guidelines and standards for School Reintegration for Children with Cancer (at external content review in June, 2017). It outlines psychosocial guidelines and school related needs and practices. Noted that the efficacy of evidence is patchy.
- In London, Ontario, parents of kids with cancer worked through a parent-run not-for-profit to fund an outreach program from hospital to schools (because their kids were at risk for education deficits). This service was eventually funded by the hospital.
- In Ontario, because of funding through the Pediatric Oncology Group of Ontario, there are school consultation services available for all children receiving treatment for cancer. There is also a successful academic and vocational transition initiative to work with students aged 16-25. This is about aftercare program and connecting to the "next piece" of vocational capability which includes a vocational rehabilitation counsellor.
- Mention of the Lance Armstrong Foundation in one jurisdiction providing a resource on students returning to school.

Kids wake up from procedures and ask for the teacher because some days, maybe even some years, school might be the only good thing in the day. Somehow it becomes more important to them when it's not there. ~ Hospital School Teacher

THEORY ON BASE SOLUTIONS

- A robust legislative basis for provision and funding for students who are absent from school because of illness, with clear responsibility and accountability of School Board and principal.

- The legislation and policies specifically direct home-hospital for one-to-one tuition for student by a teacher from their school, which can be applied in hospitals where there is no hospital school, involvement of medical practitioners in process.
- Professional groups working on evidence for school integration guidelines (for some illnesses) and thereby raising the priority of this issue to achieve better standards of education in the illness context.

Lessons

The following captures notable challenges, opportunities, and observations from the Ontario and British Columbia education systems for keeping seriously sick kids connected to their education and schools.

CHALLENGES

- Treating education services for students with serious illness in the same section of legislation (rules) as those in care and custody is a problematic mismatch.
- Policies on home-hospital instruction including the number of hours provided for home-hospital instruction is not mandated but at the discretion of the School Board and the principal of the regular school making provision variable across and between Districts, Boards and schools.
- Funding arrangements for schools and policy for enrolment in only one school at a time is procedurally incompatible for students who move in and out of their regular school (e.g. kids with serious illness) and demonstrates low contextual awareness.

OPPORTUNITIES

- Indicates the need for a national drive for greater consistency in supporting seriously ill students (e.g. use of connective technology), since Canada was a forerunner in telepresence technology in the context and that has disappeared. Hospital mandates around separation of kids to minimise cross-infection makes connective technology a vital solution for education and socialisation.
- Multiple jurisdictions with education (and health) service responsibility create silos of better and worse approaches, wider variability in protocols, practice and compliance. Formal arrangements are needed to cultivate cross-jurisdictional parity.
- Nationally legislated arrangements between education and health in this context that are reflected in law, and policy-led practice in and between jurisdictions.

OBSERVATIONS

- Legislative provision without specific policy and qualitative and quantitative benchmarks for service delivery means interpretation is varied, practice is discretionary

and potentially inequitable between students, schools, districts and jurisdictions and leads to ambiguity in measuring compliance.

- Health privacy issues are noted as a major issue for hospital school teaching (though the protocols for these differ from hospital to hospital, province to province).
- Hospital schools can provide positive opportunities (programs) for students to become educated on their own illness and how to manage it in their regular schools, increasing the student's self-agency and advocacy for integration.

Humans

Here are some of the humans doing work in Canada to keep seriously sick kids connected to their education and schools.



RECOMMENDATIONS

Using the theory of change problem map, solutions that are working in comparative education systems internationally, and my own observations, experience and reflections, the following 15 areas of change in Australia are recommended.

The recommendations should apply to all medical contexts for students – for physical and mental illness, for serious injury, and for undiagnosed chronic illness that separates a student from their regular school. They should work in school and out of school (at home, in hospital, and recovery at locations other than home and hospital), across jurisdictions, across all years of schooling (including preschool, formalised early childhood), all geographic areas, and across all school systems (government, private, independent, and faith-based). In other words, for all students who experience non-negligible absence from school because of a health or medical condition, wherever they are. Every child has a right to education on equal terms to their peers, to enabled learning, to protection and holistic care. While this is governments' responsibility, we must all play our role in seeing the responsibility is upheld.

Laws on educating sick kids

CUSTOMISED AND COMPLEMENTARY

Education and health have customised and complementary legislation governing sick kids' education. This legislation should:

- address education of sick students as a specific group, with specific definitions (and what constitutes non-negligible absence), and not sweep into provisions for disability more generally, special needs more generally, or inclusion more generally.
- define exactly who is responsible and how for education services to the student with illness, including definitively outlining the role of the regular school in its census "responsibility" for the student.
- complement and cross-reference specific health and care of children legislation for the care of sick students.

NATIONAL DATA COLLECTION AND PROCTOCOLS

Sick kids are counted nationally and their needs and risks are protocolled. This includes:

- data collection at national level to define the scope of the problem and inform conventions and protocols for all other systemic elements to lift the veil of invisibility.
- developing risk profile for students with serious illness and siblings that crosses both medical and educational experiences and informs all other system elements.
- mobilising a national cross-sectoral advisory conversation (COAG) to guide the national approach, and create coherent cross-jurisdictional arrangements.

AWARENESS OF RIGHTS AND RESPONSIBILITIES

Everybody first thinks and talks in terms of rights and responsibilities. This means:

- awareness is raised on the law for educators and on their responsibility to uphold sick student rights to education.
- awareness is raised on the law for medical staff and on their responsibility to uphold sick student rights to education.
- national alliance of kids' illness groups developed to inform the relationship between illnesses and education and guide parents, educators and medical staff.

Principles of law and policy

RECOGNITION OF THE ROLE OF THE REGULAR SCHOOLS

Education and health settings recognise that the regular school has responsibility. This includes:

- data collection at school level that enables absences of students with serious illness (and siblings) to be tracked and their locations monitored to ensure continuity of education services.
- funding model for regular schools to deliver education services to appropriate standards at school and when the student is at home.
- establishing arrangements by which schools can accommodate appropriate and inclusive two-way digital connection, including funding arrangements and support.

JOINT AND EXPLICIT POLICY

Education and health authorities have customised joint policy (including for digital) for sick students. This should offer:

- customised education-health joint mechanisms for administering education services to sick students, managing those services, a comprehensive approach to funding, and training. Such policy should address matters facing siblings in this context.
- requirements for those services in schools, in hospitals and when students are at home, including the way transitions are managed between the three locations and direct schools to actively and transparently provide information to parents/carers.
- policy for two-way digital connection to students to their classrooms during absences where digital connection to classrooms is enabled, or a matched alternative.

INTERPRETING POLICY TO PRACTICE

Policy for students with serious illness comes with national interpretation for all actors. This means:

- developing statutory guidance/definitions to consistently interpret the law and policy so that schools and educators avoid ambiguity in operationally applying these policies.
- developing statutory guidance to consistently interpret the law and policy so that hospital and medical staff avoid ambiguity in operationally applying these policies.
- developing and displaying information (e.g. websites) and guidelines so that students, parents and carers know what steps to take, and what to expect from whom.

Standards, measures and data

SERVICE BENCHMARKS

Education and health authorities have set detailed benchmarks for education service. This means:

- monitored service standards and benchmarks for education services for sick kids at school, that also cover transitions between school, home, and hospital.
- monitored service standards and benchmarks for education services for sick kids at home, including cross-referenced monitoring for non-negligible absence.
- monitored service standards and benchmarks for education services for sick kids in hospital, including cross-referenced monitoring for non-negligible absence.

PERFORMANCE COMPETENCIES

Educators and medical staff are trained in competencies to be performed in service. This could mean:

- pre-service teacher training courses specific to educating students with serious illness mapped and offered, branched for teaching in schools and in hospitals.
- new and dedicated skills for teaching at the intersection of health and education for an emerging area of concern for health and education systems.
- mobilise a national professional body for raising teacher competencies and advocacy for hospital teaching and teaching students with illness in regular schools.

DATA COLLECTION AND MONITORING

Schools and hospitals keep real-time student data and are independently monitored. This means:

- data is collected by school on absences and with reference to accumulative absence and student location.
- data is cross-referenced between health and education to flag absences that occur at home so that education services at home are commenced.
- data collection is carried out in a way that enables data to be rolled up to macro level.

Process, procedures and guidelines

ADMINISTRATION, MANAGEMENT AND FUNDING

Education and health authorities have processes to manage, administer, fund, and train staff. This means:

- operational tools, documentation and steps to administer and manage education services for sick kids.
- operational tools, documentation and steps to fund education services for sick kids.
- operational tools, documentation and steps for training educators and medical staff in delivering education services to sick kids.

TRAINING & PROFESSIONAL DEVELOPMENT

Educators and medical staff are capable of delivering all sick kids a full and systemised service. This includes:

- development of compulsory university-level pre-service teacher training for teaching kids with serious medical conditions
- development of compulsory university-level modules for paediatric and generalist medical staff on education connection for sick kids
- continuous professional development and vocational training on education connection for sick kids for educators and medical staff.

PROTOCOLS FOR SERVICE DELIVERY ACROSS LOCATIONS

School and hospital respond with full service to protocols at school, in hospital and at home. This includes:

- management, administrative, funding and training protocols for education service delivery at school for sick kids.
- management, administrative, funding and training protocols for education service delivery at home for sick kids.
- management, administrative, funding and training protocols for education service delivery in hospitals for sick kids.

The basis of any solutions

TRACK AND TRIAGE RISK

Schools and medical settings track and triage accumulative absence, and quantify risk. This means:

- Schools record absences and evaluate accumulative absences and know where the sick student is when the student is away (home, or hospital) so that support kicks in.
- Schools monitor the student for education, social and emotional risks based on absences and severity of illness and impact on learning. Students are triaged for different levels of support and interventions based on risk assessment.
- Hospitals and medical settings include explicit risk monitoring on school absence and there are protocols to guide how that information is shared and what actions are taken.

MANAGING ABSENCE & TRANSITIONS WITH FAMILY

Educators and medical staff manage absence and support student and family throughout. This includes:

- mandated and transparent provision of information, advice, guidance, documentation and ongoing support for arrangements.
- dedicated network of personnel who liaise between students and families, schools, hospitals and home, through transitions, to support sick student with continuous education. This includes vocational transitions into adult settings for young people.
- clear communication protocols, and contract/plan around provision between all parties that assigns who is responsible for what and when.

FULL ENGAGEMENT AND CONTINUOUS CONNECTION

Parents engaged in the process, student is digitally connected with class, and taught in their home. This means:

- student and parent/carer voices captured in any planning and management. This should include consideration to all aspects of education beyond base subjects and include connection with regular school teachers and peers.
- student and parent/carer engaged by regular schools in all locations.
- digital connection to their classes is available to students, when they are absent (home or hospital), supported by a reliable service model of interaction with their peers, and face to face teaching from the regular school.

IN APPRECIATION

Thank you to the Churchill Foundation for giving me the opportunity to discover more ways in which Australia may advance to a finest hour and become a country that supports all kids and young people with serious illness to reach their potential through comprehensive and consistent support in their education and connection to their education communities.

They fight hard.

We must rally with them to make their fight worthwhile.

TABLE OF MEETINGS

I am grateful for the generosity of the people whom I met in Finland, Sweden, Netherlands, Belgium, United Kingdom, and Canada. They so willingly shared their challenges, hopes, knowledge, ideas, information, and data. Without them I could not have accomplished this work. I look forward to strengthening ties with many of these people as we grow the global movement to support school connection for seriously sick kids.

Finland

1. Tampere: Riitta Launis, Rehtori, Koivikkopuiston Koulu, and Aki Halme, Laura Tuusa, Tuula Hannula, Sanna Raisanen, Annukka Raevuori.
2. Tampere: Harri Mantila (Skype solution tuuve.fi) and Harri Jurvela (Education ICT)
3. Tampere: Kati Ollila, Mother of Ilpo
4. Helsinki: Ina Kivalo, Sophie Mannerheimin koulu, Helsinki and Anna, Maija and Paavo (hospital school teachers)
5. Helsinki: Tuula Kortekangas, Suomen NOBAB Advocacy Group

Sweden

6. Stockholm: Jane Oxalaryd, Karolinska Universitetssjukhuset,
7. Stockholm: Anika and Elizabeth Haematology and Oncology Outreach Nurses
8. Stockholm: Charlotte Elf, Karolinska Universitetssjukhuset
9. Huddinge: Erica Sundqvist, Teacher, Karolinski Hospital School, Huddinge
10. Uppsala: Anders Westerlund and colleagues, Teacher, Hospital School, Akademiska barnsjukhusetanders
11. Linköping: Klas Brunnander, Sjukhuslärare, Leg. Speciallärare, Sjukhuskolan, Nina Lindberg, Andreas Svensson, Ingela Kaliff

Netherlands

12. Amsterdam: Anja de Jong Coördinator of Foundation OZL (Educational support sick children) and Vice-President of HOPE (Hospital Organisation of Pedagogues in Europe)
13. Utrecht: Jan Haverkate, Team Leader of Foundation OZL and President of HOPE, Prinses Maxima Centre (Children's National Cancer Centre), Michel Kleuters Ambassador of HOPE, and Maya Carbin, Hospital School Principal, Educatieve Voorziening of the University Medical Centre of the Children's Hospital
14. Utrecht: Annechien Kuis, Consultant, Hospital School Network and Marian Potters, Children's Cancer Parent Advocacy Group, Prinses Maxima Centre (Children's National Cancer Centre)
15. Leiden: Sylvia Klunder, Researcher/Hospital School Teacher, Leids University Medical Centre and her manager Monique and other hospital school teachers
16. Leiden: Ed Bontrop, KPN, Manager of KlasseMaatje
17. Amsterdam: Carla Heindrik, Director of Hospital School, AMC Academic Medical Centre/ Hospital School

18. Eindhoven: Teacherspool for home-education Foundation OZL
19. Eindhoven: Family where KlasseMaatje is used by two children, their mother, regular school teacher, home tutor

Belgium

20. Leuvan: Sophie Reyntens and Tinneke Rayen, Bednet
21. Leuvan: Matthias and Teacher, Boys' Technical College for Secondary Students
22. Leuvan: Ingrid Donceel, Coördinerend directeur - Ziekenhuisschool
23. Brussels: Luc Van Beeumen, Policy Officer, Departement Onderwijs en Vorming (Ministry of Education)

United Kingdom

24. London: Jayne Franklin, Principal, The Children's Hospital School, Great Ormond Street Hospital
25. London: Alex Yates, Head Teacher, Royal Free Hospital Children's School
26. London: Nick Cedal, Team Leader Children's Health in Schools, Jessica Paddock, Policy Advisor, Alternative Provisions, UK Department for Education.
27. London: Janette Steel, Principal, Chelsea & Westminster Hospital, School Office, Chelsea Community Hospital School
28. London: Thalie Martini and Tara Finn, Make The Grade Delivery Manager, Diabetes UK

Canada

29. London, Ontario: Anne Klinck, School Liaison, Children's Hospital, London Health Sciences Centre
30. Toronto: Joy Reiter, Principal, District School Board and Kathy Anderson, Teacher, SickKids Toronto
31. Vancouver: Dr Elaine Peddie, Dr. Joanna Chung, Ilana Katz, Emily Jewels, Kristina Jackson, and Kristin Marr, British Columbia Children's Hospital
32. Vancouver: Lorri Taylor, Teacher, British Columbia Children's Hospital

REFERENCES

A critical comment on the data and information obtained in preparing this visit report. The discovery included wide variability in education protocols and support for sick students, within a given country. Some practitioners were not aware of the interpretation and application of the law in locations other than their own. This and the deficiency in most countries of detailed and publicly available information on the subject – a reflection of its invisibility - means that much of the data is anecdotal and obtained from secondary sources. Fact checking and verification have been challenging. The report will be updated if errors in information are identified.

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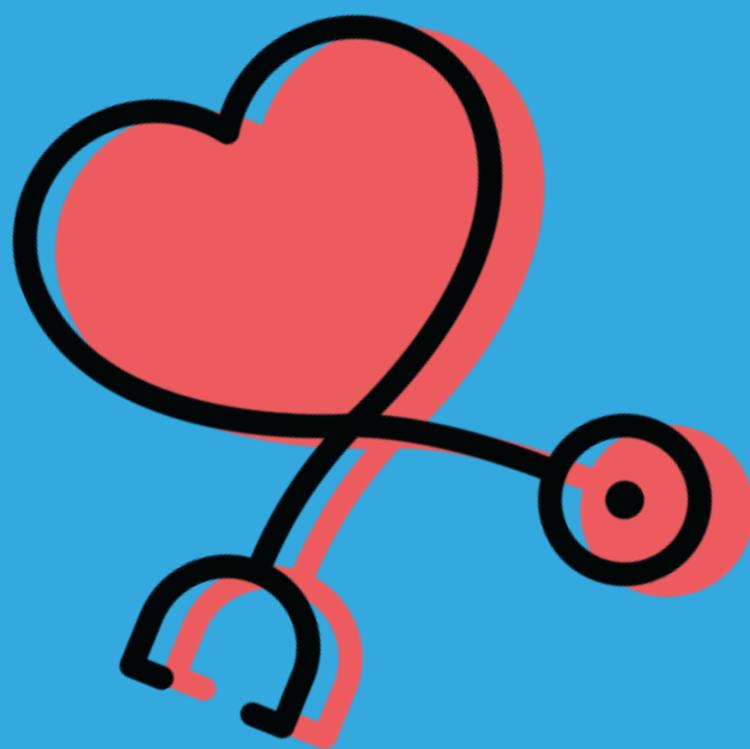
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