Premier's Xstrata Coal Rural and Remote Education Scholarships

Investigation of strategies used in the USA to support the learning of students with serious and chronic medical conditions.

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Introduction

In the last two decades advances in medical research have vastly improved the medical outcomes and quality of life for many children and adolescents experiencing serious and chronic illnesses. There has been a consequent shift for them, from simply surviving, to obtaining quality of life. Nevertheless, the seriousness of their illness and their medications result in ongoing life challenges. A growing body of research has determined that there are significant educational impacts resulting from many illnesses and their treatments. Because Education Systems are under constant pressure to cater for a vast range of student needs, the task of accommodating those with serious medical conditions adds another critical requirement. While many educators have made efforts to cater, the issue remains a work in progress. Central to the problem is the “invisible” nature of many medical conditions and the perception that medication is all that is required. There is a clear need to raise teacher awareness of the many educational and psychosocial issues inherent in living with serious medical conditions.

Serious and Chronic Illness, in the context of this project, is defined as *“mostly characterised by complex causes, multiple risk factors, long latency periods, a prolonged course of illness and functional impairment or disability”* (Australian Institute of Health and Welfare, 2011)

Some of the most common conditions which fall into this category are asthma, brain injury, burns, cancers, Crohn’s disease, cystic fibrosis, diabetes, epilepsy and heart conditions. As identified in the Ronald McDonald House Charities’ Submission to the NSW Parliament for theInquiry into transition support for students with additional and/or complex other needs (2011), difficulties often experienced by students with serious illness include:

* + Delays in developmental skills due to missed experiences
  + School absenteeism
  + Academic under-achievement
  + Behavioural problems
  + Increased anxiety
  + Attention and concentration problems
  + Reintegration difficulties
  + Specific learning needs
  + Low self esteem

This list is in addition to the illness-specific physical challenges faced such as fatigue, headaches, susceptibility to infection and side effects of medication**.** (RMHC Submission to NSW Parliament 2011)

The Australian Institute of Health and Welfare (2011) estimates that the incidence of serious or chronic illness across the population of children, adolescents and young adults in Australia ranges from 15 -20%. This translates to approximately 1 to 2 children in each classroom. Because of the negative impacts of learning disability, the effects of this have the potential to create additional social, financial and emotional distress for the student throughout their lives with an attendant cost to the state.

Rural and Remote Context (NSW)

The experience of students from rural and remote areas diagnosed with a significant medical condition is complicated by additional factors, including: geographic and social isolation, cultural issues, unavailability of specialist educators and allied health professionals, high turnover of staff, difficulties of providing staff training, lack of technological infrastructure. Distance from medical treatment centres involves absence from school (in some cases, for many months). Absence of local psychosocial supports needed to manage the emotional challenges attached to living with a medical condition may result in untreated anxiety and depression which may profoundly impact learning.

Currently, the only NSW Teachers’ Institute accredited professional development program in this field is implemented on an outreach basis free of charge by Ronald McDonald House Charities. The program, called EDMed, takes1-2 hours and provides classroom teachers with information and education strategies that can be useful for students with a diverse range of illnesses. The facilitator travels to a cluster of schools upon request and, although it is an excellent resource, its implementation is compromised by cost, distance (especially in rural areas), and the burden of competing with increasing demands on staff development for schools’ registration and compliance.

Most universities provide a mandatory module on Disabilities Education in Education Faculties. The focus is generally on students with intellectual disability, behavioural disorders or the classically recognised visual, hearing and mobility impairments. Whilst these are all critical needs, this narrow focus overlooks many common yet serious medical conditions with profound impacts.

Equity Issues

The Australian Disabilities Discrimination Act (1992) defines disability as:

# Total or partial loss of the person’s bodily or mental functions; or

# Total or partial loss of a part of the body; or

# The presence in the body of organisms causing disease or illness; or

# The presence in the body of organisms capable of causing disease or illness; or

# The malfunction, malformation or disfigurement of a part of the person’s body; or

# A disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or

# A disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

The first goal of the Australian Government Melbourne Declaration on Educational Goals for Young Australians (2008) states that:

Australian governments, in collaboration with all school sectors, commit to promoting equity and excellence in Australian schooling. This means that all Australian governments and all school sectors must: provide all students with access to high-quality schooling that is free from discrimination based on gender, language, sexual orientation, pregnancy, culture, ethnicity, religion, health or disability, socioeconomic background or geographic location.

Despite the above legislation, the reality for many students with serious illness is that the educational impact of the illness is simply overlooked by education professionals and systems.

Although the range of potential impacts from the spectrum of medical conditions may seem limitless, a strategic approach to management is a critical step towards providing for this currently under-catered sector of the student population.

While at one end of the spectrum the interventions required to support a medically compromised student may be very significant, at the other end, simple strategies and increased staff awareness may suffice. Nevertheless, the absence of such provisions may have profound effects, thereby limiting the student’s opportunities.

Why tour the USA?

The USA has explicit legislation pertaining to the education of children with medical disability. There are two primary laws that cover a child’s right to education:

* + Individuals with Disability Education Improvement Act (IDEA)
  + Section 504 of the Rehabilitation Act of 1973

Section 504 and IDEA complement each other to ensure the right to a Free and Appropriate Education (FAPE) to allow for maximum educational success.

The *Individuals with Disabilities Education Act* (IDEA), is a statute which funds special education programs and which underpins the regulatory interventions for students with serious and chronic medical conditions. (This supports the 504 PLAN interventions at school level). Theoretically, the problem is acknowledged and legislation exists to support meaningful intervention and advocacy on behalf of these students.

While Alaska is a profoundly different place to anywhere in Australia, because of its geographic isolation, extreme climate and transport challenges and high indigenous population, it shares similarities with remote areas of NSW.

I investigated practice and procedures in rural and remote areas at three tiers: Government Administrators, Education Providers/Schools and finally, Parents and their Advocates. The purpose of the three-tier investigation was to inform the development of policy and practice within NSW education. Pitfalls to avoid and positive strategies to implement are noted below.

SIGNIFICANT LEARNING

**STRATEGIES THAT WORK: - Advocates and Disabilities Attorney**

* Ensure students ARE placed on 504 Plans, this refers to Section 504 of the Rehabilitation Act and the [Americans with Disabilities Act,](http://specialchildren.about.com/od/disabilityrights/qt/ada.htm) which specifies that no one with a disability can be excluded from participating in federally funded programs or activities, including elementary, secondary or postsecondary schooling and/or an individualised education program (IEP).
* Use of 1:1 careful supervision for paraprofessionals within the school.
* Case management that keeps all stakeholders informed.
* In cases of grievance, first seek negotiation with the school (or system) on the issue prior to pursuing a formal legal case.
* Appoint a specific case manager or liaison to ensure all efficiency by and for all stakeholders.
* Regular follow up on progress of student by case manager and parents.
* Communication with relevant teaching staff should be regular.
* Collaboration between health and education providers is required for all stakeholders to understand student’s needs.
* Overcome ‘confidentiality’ barrier by obtaining clear parental permission in writing for information disclosure.
* Availability of a Dispute Resolution Service.
* In small communities ACTIONS BY THE SCHOOL are particularly important as communities are close and geographically isolated.
* Parents should be open and honest with the school re the child’s medical circumstances and any known cognitive or emotional implications or risks.
* To overcome the legal ‘confidentiality’ perceptions have a standard form available for parents to sign granting permission for information to be passed on to classroom and specialist teachers.
* Teachers should keep their own records on student progress and pass them on to the following year/course teachers.
* Seek schools that are flexible in approach.
* Small schools in the USA have demonstrated greater success.
* A liaison teacher between parents, health workers and the school is critical.

Disabilities attorney -advice to parents on written communication procedures

* Give all notifications in writing. Follow up any conversations with a written version of the information.
* Written information needs to be detailed and outline precise needs.
* Clearly outline functional impairments and needs to determine provision.
* Use email that is single- issue focused in school communications.
* Effective communication is best in bites of small amounts of information.
* Parents need to be vigilant. Keep everything from administrators in a binder.

Challenges - Advocates and Disability Attorney

* School/systems sometimes fail to treat the parents as co-equals.
* Once parents reach legal dispute stage with the school it is difficult to negotiate a satisfactory outcome.
* The US System states the school district (state funded) remains responsible for provision of Special Education services even in private schools. In reality they do not actively identify such students unless forced to. Thus, medically compromised students in private schools are often overlooked.
* Some parents fear the stigma of a ‘label’ on their child and fail to communicate needs of the child.
* A perceived need for ‘confidentiality’ within schools becomes an excuse for not acting or communicating information to classroom teachers.
* School administration funding structures compromise school principals’ power to commit to funding. District Special Education Directors must be involved and committed to ensure provision.
* A lack of specialist resources in rural/remote districts limits Administrators’ resolve in acknowledging and providing for needs of medically fragile.

Strategies That Work – Health Providers

* Use of paid paraprofessionals working 1:1 with students in class (non-teachers given 6 hour training session).
* Government funded parent advocacy groups (such as Stone Soup Group, Disabilities Law Centre, Alaska's family agency supporting families caring for children with special needs) operate in liaison role between parent, schools, health providers and government agencies.
* Regular school visits by allied health professionals; physiotherapists, speech therapists, occupational therapists.
* Psychosocial impacts of medical condition recognized and conveyed to school.
* Health and education providers’ collaboration.

Strategies That Work – Hospital School Teachers

* Hospital teachers implement strategic/liaison roles- visiting schools, educating staff on student needs, maintaining contact on behalf of the student.
* Stagger student re-entry to school with core classes re-scheduled to suit needs.
* Allow flexibility of student attendance determined by level of health.
* Extra tuition beyond class time.
* Tutor/teachers from school district paid to assist students in their home. (Home and Hospital Services). Supporting documentation by medical providers must be provided within 10 days of child’s absence.
* Modification of teacher workload (by school administration) helps free one teacher to additionally support student.
* Rural community volunteers to work with students.
* Local community employers provide time off work to allow employees to mentor children.
* Run workshops to teach school leavers advocacy skills at university level.
* Peer mentoring within universities.
* Prior to enrolment at school or university, investigate their attitudes to medical issues.
* Select a school with previous experience/support of the same medical issue.
* Liaison staff from health providers visit schools to prepare them prior to student entry.
* Seek teachers/schools with flexible approaches.
* Organise baseline psychological/educational assessments at school re-entry point.
* Use Health and Student Information Cards to include information on educational impacts.
* Enable staff access to student information database (as appropriate via parental permission).
* Trauma Sensitive Schools Training Program creates awareness (North Carolina model).
* Each school should appoint a person responsible for liaison of homebound work.
* Find the right person in the school to implement action.
* Obtain a release by parents to allow communication of medical information within the school.

Challenges – Hospital School Teachers And Health Providers

* Not all teachers/stakeholders attend IEP Meetings.
* Community is unaware of wide impacts of medical conditions.
* Parent advocacy is compromised by fear of alienating the school and perceived potential backlash against children.

Strategies That Work –School Administrators And Teachers

* Undertake annual reviews to determine levels of success with programs.
* Implement a Child Study Team to consider specific needs and interventions (provide release time).
* Hold meetings for all stakeholders to discuss approaches and issues. Formally record outcomes of the meeting.
* Assign a case manager to each student. Ensure workable caseload.
* Ensure inclusion of allied health people in planning.
* Provide flexibility in educational transition points.
* Use specialist technicians and curriculum support technology in catering for individual needs and dissemination of information to staff.
* Use technology to allow flexible catch-up on content and assessment tasks.
* Recognition of the importance of parental advocacy at school and district administration levels.
* Promote collaboration and communication between the healthcare provider and school.
* Use volunteer mentors from the local rural community.
* Implement staff awareness training on educational issues for medically fragile students.
* Inform staff and parents of relevant websites.
* Create an additional file on student database including learning impacts of illness.
* Ensure Medical Letters are precise in their requests of school provisions. E.g.
  + 1. Extended time for tests
    2. Minimal distraction environment for test administration
    3. Home instruction if absent for 2 consecutive days
    4. Extended time for handing in homework and projects
    5. Early dismissal or shortened days, as needed

Successful Communication Systems Within Schools

* Existence of Individual Student Data Collection Sheet (summary for staff to log on all information per day/week). This is kept in possession of class teacher but accessed by others.
* A journal sent between school and home, documenting general progress and significant events of student’s day.
* Negotiate an appropriate level of student determination of their own need to withdraw to deal with medical episodes.
* IEPs should determine specific educational goals and likely limitations.
* Schools should provide a teacher who liaises between school, homebound tutor and health provider.
* Smaller schools are reported as more successful communicating and catering for needs.

Challenges- Teachers

* The system is slow to react to student needs. Everything depends on successful parent advocacy or committed individual teachers.
* Inefficient communication of precise student needs at teacher changeover each new-year.
* High school electives subjects overlooked in implementing educational provisions.
* Insufficient flexibility in assessment and grading systems.

Technology Systems For Support – (Home And Hospital School, Baltimore County)

* This is a government funded alternative education facility.
* It organises 1:1 tutoring and distance education via sophisticated technology to isolated students, especially those medically compromised.
* 1 hour tutoring support is given for every day of school missed.
* A full time program is available for those absent for longer periods.
* Access facilitated by doctor completing appropriate forms stating medical condition, educational impacts, learning interventions needed.
* Student support teams within schools facilitate the process when a pattern of non-attendance is noted.
* Each school must have a liaison person to coordinate with Home and Hospital facility re student work.
* Instructional materials forms are filled out by the student’s school, detailing the work and resources required.
* Parents are required to liaise with both the school and home and hospital centre.
* The Distance Education Delivery Program is called Blackboard Collaborate (formerly known as E-lluminate)
* This program allows for real time, coordinated voice, visuals, on-screen interactive notes and reference to links.

Successful Strategies –Parent Perspectives

* Establish and maintain contact with the most significant individual teacher each year.
* Arrange early advocacy by hospital advocate/healthcare representative to the school raises staff awareness.
* Contact the school on a yearly basis to ensure interventions are organised.
* Establish an efficient tracking system/database maintained by the school, with one contact person responsible for the entire situation.
* Include a liaison person/case worker in all school meetings.
* Identify a ‘classification’ (504) for the student so that staff become more accommodating in attitude.
* Provide explicit acknowledgement of the medical condition relieves student anxiety.
* Implement 1:1 tuition provided by the school district.

Challenges - Parents

* Parents should not assume the school will cater for their child. Advocacy may need to occur to enable it to happen. (This is also reflected in the perspective of former directors of special. education in Alaska and most school executives.)
* Parents’ frustration that information on their child’s need may not have been conveyed each year to the subsequent teachers.
* Once students leave high school for tertiary education advocacy must be re-visited.
* Parental concern that smaller, rural schools do not attract quality staff to deal with the precise needs of medically compromised students. This highlights the need for professional development.

CONCLUSION

The USA has had the foresight to implement legislation explicitly supporting medically compromised students educationally. Because of this, in some areas where the will and the right people have been present, outstanding strategies exist. Although the legislation is sometimes rendered inadequate this appears to be more a result of bureaucratic dysfunctionality inherent within the US education and economic situation rather than the result of the legislation itself. The existence of the U.S. Federal Government’s *Individuals With Disabilities Education Act* is critical as it underpins the right to advocacy and provision within education. It enshrines the concept of equity for all students with significant medical conditions, not only those whose disability is visible. In the US context, there remains much work to be done for effective implementation and it is important that in NSW we take heed to avoid the same pitfalls. These have been noted under the Challenges headings above.

The issue of staff awareness was consistently raised during my research. There was a reported lack of understanding by teaching staff and administrators that students suffering serious medical conditions had educational impacts/needs. In some cases, where administrators stated they had effective systems to provide information and support to classroom teachers on medical/educational implications, the teachers themselves (and sometimes the parents) contradicted this perception. Occasionally, there was clearly little connection between rhetoric and reality, as to what was theoretically happening and what was actually happening for the student. The existence of government funded advocacy groups to support parents and students on this issue was a positive strategy that would be of benefit in rural NSW.

Future possibilities for rural and remote areas exist in the technological infrastructure model in the USA. This allows for the delivery of interactive distance- based ‘catch up’ education for medically compromised students and is administered by purpose- specific education facilities. A Telemedicine Satellite program in Alaska offers a model for educational and developmental assessments for remote areas.

The need for comprehensive, funded staff professional development on educational impacts of illness was a strong finding, as was the use of local volunteers in addition to funded, paid tutors in rural communities. All interviewees recognized that the most successful outcomes were largely dependent on individual teachers and administrators taking an interest. In light of this, a useful, immediate strategy for implementation in NSW would be an illness-specific, single page Teacher Alert Notice to be given to parents by health providers at the point of re-entry to school after diagnosis. The notice would list the educational impacts of the illness along with suggested interventions.

Currently, in NSW, serious medical conditions are not broadly recognized as a source of educational disability. Funding is difficult to access despite credible research documenting the cognitive and emotional impacts. Professional Development in this is a simple but essential accommodation. Clearly, a government-funded strategy on staff training is a key to the first step in a raft of necessary provisions as outlined above. It is a potentially straightforward strategy with the power to make a profound difference to the lives of students who not only suffer physically, but educationally.

In NSW, concerned parents and educators will benefit from a clear mandate to access educational provision for medically compromised students. A precise educational application of the Australian Disabilities Discrimination Act (similar to U.S Section 504) will provide parents and educators with the power to implement meaningful change.

*The greater the invisibility of the illness the greater the gap in the provision.*

(Parent, Salem N.Y. State)

“*Parents of a child with a (medical) disability aren’t asking for more, they’re just asking for the same chance as everybody else*. “

(Alaskan Disabilities Law Attorney)

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