Submission No 36

INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR FAMILIES

Organisation: Ronald McDonald House Charities

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Inquiry into transition support for students with additional and/or complex needs and their families.

Ronald McDonald House Charities

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Introduction

There have been enormous advances over the past two decades in the medical treatment of children and adolescents who are either born with, or acquire a chronic medical condition. These advances in medical treatments mean that many more children are surviving and living with complex medical conditions. These complex illnesses/conditions/treatments directly impact upon a child's development: cognitive, physical, social and emotional development. **These children are entering or returning to our schools every day.** Ronald McDonald House Charities (RMHC) is dedicated to helping these seriously ill children and their families.

The Ronald McDonald Learning Program is a core program of Ronald McDonald House Charities. The Learning Program is the leading educational catch-up program in Australia, helping children recovering from serious illness catch up with missed education. In New South Wales alone there is provision for 300 students to receive Learning Program assistance, with 20 more on the waiting list. This submission examines the additional and complex transition support needs for students like those that we work with, who are managing serious illness.

Chronic Illness in children and adolescents

Many illnesses and health conditions can be classified under the broad heading of chronic illness or disease. Chronic illness is mostly characterised by complex causes, multiple risk factors, long latency periods, a prolonged course of illness and functional impairment or disability (AIHW, 2011). These many factors associated with chronic illness lead to additional and complex management and support needs for many children and adolescents.

Ten of the most common medical conditions in children and adolescents are: asthma, brain injury, burns, cancer, Crohn's disease, cystic fibrosis, diabetes, epilepsy and heart disease. (Ronald McDonald House Charities, 2009).

Some of these medical conditions are congenital; that is the child is born with the condition e.g.: cystic fibrosis or heart disease. Other conditions that require intensive medical management may develop without any or with limited warning. Examples of this include; traumatic brain injury, diabetes or cancer.

Estimates from the Australian Institute of Health and Welfare identify that the **incidence of serious or chronic illness ranges from 15 -20%** across the population of children, adolescents and young adults in Australia. Some students may be managing more than one medical condition at a given time. Table 1 shows the incidence of students in Australia, in both the younger and older age groups, who have one or more chronic health conditions.

Table 1 - Proportion (%) of chronic conditions reported, by age group, 2004-05

Number of chronic conditions	**0-14 years**	**15-24 years**
None	86.9	80.8
One	12.3	17.0
Two	0.8	1.9
Three	-	0.3
Four	-	-

Source: AIHW analysis of the 2004-05 National Health Survey.

Chronic Illness and education

The physical, social, emotional and cognitive domains of the child are central to their personal and educational development and all of these domains can be affected through serious illness. Many children and adolescents are able to manage complex medical conditions very well, especially when they have a supportive family and can readily access necessary community resources. However, it is recognised that about one-third of the children with chronic illness will 'experience consequences severe enough to interfere with school functioning and performance'

(Kaffenberger, 2006). This equates to **1 or 2 children in every classroom** who may be attempting to manage a serious medical condition at any given time.

Some of the more common difficulties experienced by children and adolescents 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
- (Ronald McDonald House Charities, 2009; Kaffenburger, 2006 & Theiss 1999)

The difficulties as outlined above, are often in addition to ongoing illness specific difficulties such as fatigue, headaches, susceptibility to infection and medication side effects. Any of these difficulties experienced by a child or adolescent are **amplified at key transition points** in a student's education. These transition points, as recognised within this valuable inquiry, include commencing preschool, commencing primary school, entering high school and leaving high school.

One of the other key transition points that is well recognised within those who work with students with chronic illness is the transition back to school after long periods of hospitalisation and/or treatment. This can be a particularly difficult period for the both the student and their family. Health needs have to be explained, peers have lots of question, the student is often still not fully healthy, teachers are often not prepared and academic skills require catching up.

Additionally when a child has either been born with or develops a serious medical condition, they can be vulnerable to missing important developmental or learning opportunities through extended periods of hospitalisation or confinement to their home. They can miss out on the opportunity to play with others, engage in sport, apply fine motor skills and negotiate age appropriate milestones. This can make it increasingly difficult to reintegrate to a preschool or school environment and even more difficult when they have to transition to a new learning environment.

Aside from the complexity of the above issues, many of the chronic illness have their own specific effects on a child and hence their education. Cancer in children is a clear and well researched illness which leads to educational challenges for many children. It is estimated that up to two thirds of children and adolescents diagnosed with cancer will also experience at least one long-term consequence or late effect of their cancer and the associated treatment.

Some of the well-recognised late effects of cancer treatment include:

- Neurocognitive dysfunction – IQ changes over time, memory, executive function, problem solving, information processing, organisational skills
- Hearing loss or mobility issues
- Ongoing fatigue
- Visual, perceptual and motor function difficulties
- Attention and concentration difficulties
- Psychological dysfunction and manifestations including anxiety, depression, post-traumatic stress, social isolation, adjustment difficulties, risky behaviours and school absenteeism
- (Nathan et.al, 2007; Butler & Mulhearn, 2005, Keene, 2003)

The challenges faced by students with cancer have led to the development of the **collaborative Educational Pathways Project**. This project, now in its fourth year of operation is a component of the Ronald McDonald Learning Program. It is jointly funded by Ronald McDonald House Charities and the three major paediatric oncology treatment hospitals in NSW; Sydney Children's Hospital, The Children's Hospital at Westmead and the John Hunter Children's Hospital. The project conducts research and develops resources and support models to assist with the complex and often long term schooling and psychological issues associated with a cancer diagnosis and treatment in childhood, adolescence and young adulthood.

A submission to the 2010 NSW Parliamentary Inquiry – *The Provision of Education to Students with a Disability or Special Needs*, was made by the Committee of Management of the Educational Pathways Project, in order to highlight the complex educational and disability of students with cancer. The work of this project currently operates independently of any structured government funding.

Barriers to successful transition support for students with chronic illness

Within the context of educating a student with chronic illness, there are many barriers faced by the student as well as his/her parents and siblings. One of the biggest issues that is observed within the Ronald McDonald Learning Program is the fact that **serious illness is not recognised by many educational professionals as a disability.** As such, parents often have an extraordinarily long battle trying to convince others of the needs of their child. This is in spite of disability legislation that clearly recognises illness as a disability.

Australia holds legal regulations pertaining to the education of all children including those with a disability. The first goal of the Australian Government *Melbourne Declaration on Educational Goals for Young Australians* (2008 –ref: Ministerial Council on Education, Employment, Training and Youth Affairs) 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.

Furthermore the *Australian Disability Discrimination Act 1992* defines *disability* in relation to a person as:

> (a) total or partial loss of the person’s bodily or mental functions; or
> (b) total or partial loss of a part of the body; or
> (c) **the presence in the body of organisms causing disease or illness;** or
> (d) **the presence in the body of organisms capable of causing disease or illness;** or
> (e) the malfunction, malformation or disfigurement of a part of the person’s body; or
> (f) **a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction;** or
> (g) a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

Despite this legislation, a child with a chronic illness will rarely be able to access additional support or funding for educational or transitional needs within education systems. As recognised within the background information for this inquiry, the DET currently holds very narrow definitions of what constitutes disability. Many of the frustrations experienced by parents of a child with chronic illness relate to the inability to receive any sort of support for their child because they do not fit the current 'disability categories' or 'boxes' for funding support and yet their children often have complex and ongoing needs.

Following are just a few of the many words documented through our work with parents that illustrate their frustrations:

- 'Unfortunately I feel that my son has slipped through the cracks as he is not labelled with any disability, but really he now has a 'hidden disability'.'
- 'I hope the government takes this issue seriously and supports the needs of all these children.'
- 'We need continued updated information on what services are available to help in the classroom and to make information about these services easier to access.'
- 'When it's their brain that's sick (intracranial hypertension) it's so hard; it would be different if they lost a leg.'

The acquisition of appropriate school based services and support for a child who has a chronic illness can be challenging for many reasons.

- School staff are often unaware of the immediate and long term educational consequences of serious illness.
- Communication structures between schools, hospital schools, parents, students and the many multidisciplinary professionals who are involved in the management of serious illnesses can be inconsistent, or at worst inadequate.
- Parents may be reluctant to constantly label their child as sick or different.
- The effects of serious illness may be dismissed as issues related to the child and their medical circumstances such as laziness or disinterest rather than being recognised as very real medical challenges which require structured and ongoing support from educational professionals.

Parent and siblings of students with chronic illness

There is an increasing body of research both nationally and internationally which recognises the complex effects that chronic illness may have on the parents and siblings of a child who is chronically ill (Williams, 2009; Kaffenbergur, 2006; Shui, 2004 & Theiss, 1999). Parents can face intense periods of stress, communication battles, medical terminology confusion, ignorance and disjointed family conditions. As Williams' (2009) research with the families of children diagnosed with cystic fibrosis and cancer found; the family burden of chronic illness, produces strain being placed on physical, financial and emotional resources. The difficult situation experienced by family members is perhaps best summed up in the following case study from a family who entered the Learning Program:

A student living in a rural area hundreds of kilometres away from city hospitals was diagnosed with leukaemia one Friday. The following Friday she was diagnosed with diabetes brought on by her medication. Months of treatment at a large city based hospital was required. There were two small siblings in the family, both under 3 years of age. The mother stayed with the sick daughter during the week because the father had to work to sustain the family. The siblings pined for mum; so every Friday evening, the parents would travel long distances to exchange roles and then return on the Sunday evening. To add to the emotional and logistical upheaval of this situation, the family could only access financial support for one airfare; being for the parent who actually supported the sick child!

Ronald McDonald House Charities and students with chronic illness

As outlined in the introduction, Ronald McDonald House Charities is dedicated to helping seriously ill children and their families. Given a family situation as outlined above, accommodation at a Ronald McDonald House could be provided, a holiday at a Family Retreat offered and time out in a Family Room accessed. In the context of the student's education, an educational catch up program could be commenced for the student and professional development for the teachers of the student could be delivered. The challenge is that in the absence of structured government funding for assisting children and their families with chronic illness, **charity dollars are currently providing the majority of the educational support** for these student and their families.

The Ronald McDonald Learning Program was specifically developed to prevent primary and secondary school children from falling behind in their education, dropping out of school and never reaching their full potential. Children receive a comprehensive tailored assessment and weekly sessions with highly-qualified teachers, psychologists, speech and occupational therapists. This year over 700 children will be supported by the Learning Program. Since 1998 almost 3500 children have received a much needed boost to their confidence and self-esteem through the Learning Program.

In aiming to meet the needs of students with chronic illness, the Learning Program has also begun offering accredited professional development session for teachers via a program called EDMed. EDMed provides classroom teachers with information and educational strategies that can be useful for students with a diverse range of illnesses.

As previously outlined, The Learning Program also works in collaboration with other services such as within the Educational Pathways Project.

Recommendations for transition support for students with chronic illness and/or additional and complex needs.

Recommendations for improved service delivery and transitional support for students with chronic illness primarily relies on the recognition of the many challenges faced by these students and their families. The need for improved recognition is similar to the challenges faced over the past ten years across the fields of mental health and autism. The developments in these fields of health and disability commenced with understanding and recognition. Improvements to service delivery, funding and community understanding can be made for students with chronic illness; but communication and understanding is required. As such the following recommendations for supporting the transitional needs of students with chronic illness are outlined below:

Key actions for improved support include:

- Funding for the assessment of students at key transition points
- Early intervention for students with a chronic illness
- Structured assistance to be provided to families to help them communicate the complex needs of their child especially when transitioning between educational institutions.
- Structured assistance that reaches all students and families regardless of geographic location.
- Individual education plans developed for each child and renewed at least annually for the duration of the school years
- School or medical based coordinator of services for students with chronic illness
- Improved education system adherence to disability legislation
- Mandatory teacher training on chronic illness as a disability

- The development of programs about chronic illness to support classmates
- Classroom accommodations – e.g.: seating, rest breaks or modified curriculum
- Ongoing assessment task modifications and support – particularly at the senior level.
- Examination support – special provisions
- Regular School Counsellor support

Conclusion

Over the past twenty years there have been enormous advances in the medical care of children and adolescents who are either born with, or acquire a chronic medical condition. Many, many more children are surviving complex medical difficulties and they are entering or returning to our schools every day. It is to be hoped that our government and education professionals can now recognise and meet the survival needs of these students within the school environment so that they can live a full and active role within our schools and the community.

Ronald McDonald House Charities would welcome the opportunity to further discuss the transitional challenges for students with chronic illness as outlined in this submission. We value the recognition made by this NSW Parliamentary Inquiry that starting, changing and leaving school presents complex difficulties for many students which require additional understanding and support.

Prepared by:

Barb Donnan	Mrs Tracey Webster
Educational & Developmental Psychologist	National Learning Program Manager
Ronald McDonald House Charities	Ronald McDonald House Charities

On behalf of:

Mr Malcolm Coutts
CEO Ronald McDonald House Charities

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