Submission
No 43

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

Organisation: Royal Australasian College of Physicians

Date received: 30/08/2011

The Royal Australasian
College of Physicians

From the President

30 August 2011

The Hon Niall Blair MLC
Chair
Social Issues Committee
Legislative Council
Parliament House
Macquarie Street
SYDNEY NSW 2000

Via email: socialissues@parliament.nsw.gov.au

Dear Mr Blair

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

The Royal Australasian College of Physicians (the College) welcomes the opportunity to contribute to this inquiry. Please accept my thanks on behalf of the College for accepting this late submission.

Please find the College's submission attached. Based on advice from paediatricians who support and manage children and adolescents with complex needs, the submission's key recommendations include:

1. that there is greater consistency in defining what constitutes a transition within the education system across agencies

2. that definitions of disability are clarified and enhanced with an emphasis on functional impairment

3. that children with complex conditions are better supported at the time of transition

4. that there is an enhancement of other services in recognition that disability is often a lifelong condition

5. that additional training and professional development be provided for teachers.

The College would be pleased to be kept informed of future developments in this matter. Should you wish to discuss any aspect of the matters raised in the submission please contact Alex Lynch, Regional Policy Officer (New South Wales) on [redacted]

Yours sincerely

[redacted]

John Kolbe

Enclosure: College submission

The Royal Australasian
College of Physicians

Submission

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

August 2011

The Royal Australasian College of Physicians (the College) welcomes the opportunity to provide a submission to the *Legislative Council's Standing Committee on Social Issues Inquiry into transition support for students with additional or complex needs and their families.*

Executive Summary

Complex care extends to a range of needs including the use of specialised equipment, health care procedures and additional cognitive and learning requirements.

The definition of "complex needs" in the education setting is a fundamental issue that requires further clarification. Currently in New South Wales, there appear to be varying definitions of "complex needs" from school to school. Often there is no clear evidence of how decisions are made about school placement either at the point of entry into the system or at the transition from primary to secondary schooling.

For example, children with cerebral palsy with an intrathecal baclofen pump who require an emergency procedure plan can be managed in different school settings as long as their emergency plan and staff involved in their care are familiar with the plan and actions needed. If the child has significant co-morbidities, such as epilepsy and respiratory difficulties, a higher level of vigilance by education staff may be needed.

The identified educational implications of transition for children with complex needs vary from school to school. The College supports an approach that builds a consensus view including collaboration with the school, the numerous agencies involved in a child's care, especially health agencies and most importantly the families themselves. The College also supports a consistent application of best practice models across different educational settings.

Consistency in agreed transition points across agencies

Transition points occur at a number of different life stages and include entry into early childhood education, into primary education, into secondary education and leaving school. Significant transitions may occur on other occasions, and include movement between levels of supported education class, (eg. special school to special school), return to school after significant absences due to ill health or for other reasons and commencement of a new school year. Clarification of these transition points by NSW Health would assist in establishing appropriate transition support.

Clarification of definitions of disability with emphasis on functional impairment

Definitions of disability should be based on degrees of functional impairment and be consistent with those described in the World Report on Disability conducted by the World Health Organisation (WHO) in 2011. Here, disability refers to difficulties encountered in areas of functioning, such as body functions, activities and participation. "Health conditions" are diseases, injuries, and disorders, while "impairments" are specific decrements in body functions and structures, often identified as symptoms or signs of health conditions.

Disability is termed as arising from the interaction of health conditions with contextual factors. Understanding the degree of functional impairment and needs of the child requires consideration of these factors. Descriptors of functional impairment that are relevant to key agencies (eg. education or health) should be developed to improve the shared understanding of the child's needs and eligibility for services.

Improved support for children with complex conditions at the time of transition

It is widely acknowledged that children with complex conditions and disabilities, their carers, and professionals supporting them should receive additional support during periods of transition. This is particularly important for these children when transitioning through the education sector.

Checklists are important as a tool to ensure appropriate transitional support is provided. Concerns regarding parental understanding of their child's disability, the changing nature of the disability, and the level of existing support require documenting.

Effective interagency models of care that coordinate services are key foundations to the checklists. Effective interagency models of care can also contribute to improved referral pathways, with an emphasis on improving pathways involving paediatricians and other paediatric health services (including mental health). It could also contribute to better transfer of information within and between schools, recognising that each year is a new transition.

Other measures to improve access and support include:

1. inclusion of provision of support for children, carers and staff at key points of transition in school counsellor role descriptions

2. ensuring carers of children with complex needs are aware of relevant staff within their school, specialist support staff at the Department of Education, and local specialist services

Enhancement of other services in recognition that disability is often a lifelong condition

As disabilities often continue beyond the primary and secondary education years of a students, older children and adolescents should have access to diagnostic and assessment teams, with direct linkages to specialist disability services in other agencies. Long-term disability management would be well-served by increasing case management availability to older children, especially at periods of transition, as well as increased visibility of and access to transition care coordinators (a health-based professional, often a nurse with specialist disability skills).

These measures are particularly important in rural and regional areas.

Additional Training and professional development

Any changes that result from this inquiry should be regularly communicated to relevant, non-education sectors, including information on new models of care and initiatives. Ensuring all agencies are well-resourced with this information is key to ensuring active involvement in any measures taken to improve transitional support for students with complex and additional needs.

Regional conferences bringing together multiple agencies, and multidisciplinary skill training for all professionals in the model of care, are two tools that could be effective in improving transitionary support.

Issue of complex needs

Students who meet the Department of Education and Training (DET) disability criteria have Individualised Education Programs formulated. Individualised funding is allocated to the child or the child receives a place in a specialised class or unit addressing specific disability issues (eg. language disorder, severe physical disability or intellectual impairment). These children appear to have a clearer transition pathway as their needs have been regularly reviewed and documented.

Many children with an acquired brain injury have cognitive problems such as poor memory, reduced planning and organisational skills, cognitive fatigue and reduced attention which do not meet the DET criteria for funding for a Learning Support Officer (LSO) (previously called Teacher Aide). The LSO would, if available, assist the child or support the classroom teacher in individualising the child's learning program and maximise learning. Therefore this group of children has to share the resources offered by the Support Teacher Learning Difficulties (STLD) in the school. Unfortunately, they may become 'lost' when considering which students require additional support for transition from primary school to high school.

Targeted guidance from a facilitator or case manager familiar with the child's needs for the family of a child is essential. Ideally, this case manager would work in conjunction with an advocate for the child and their needs.

The Paediatric Brain Injury Service NSW provides case management services for some children with acquired brain injuries. Case management has been set up to enhance the provision of services by the Brain Injury Teams. The main aim of case management intervention is to ensure that the short and long term rehabilitation needs of the child with a brain injury and their families are efficiently and comprehensively identified and met. Importantly, in the context of this Inquiry, the Case Manager acts as the central, identified 'managing body', gathering and disseminating information to and from the Brain Injury Rehabilitation Team and community rehabilitation service providers, family, school, insurers, solicitors and community. The Case Manager acts as a liaison between the child and family and the educational setting and individualised support and advocacy at all four stages of transition identified by the Inquiry. The success of the case management approach provides the basis for better resourcing brain injury teams.

Key transition periods and relevant issues:

Key transition periods include:

- the transition into the pre-school or schooling system
- the transition into high school
- the transition back to school after an acquired disability
- the transition leaving school.

The first transition into pre-school or the regular schooling system is often the smoothest transition phase. Early intervention services are well established and efficient at identifying children with developmental needs, such as those with autism. The consistency of this process across NSW public, Catholic and Independent schools is important and can be improved.

Transitioning into high school can be psychologically challenging for students and their families. Difficulties sometimes arise when families take the opportunity to express optimism their child will no longer require additional support of any kind once they have reached secondary school, particularly where this is not a realistic expectation.

Often a period of inpatient rehabilitation is required prior to a student’s return to school. There are instances where students fail to meet Department of Education and Training criteria but nonetheless have severe impediments in executive function, meaning they require additional support. An established and effective means of communication between Paediatricians and other health professionals and teachers is important to a student’s transition. Anecdotal reports have indicated that email is an effective means of circumventing differences in schedule across these professions.

Later, difficulties in transitioning out of school can be compounded when a student is also leaving their primary health care services. This often occurs when a student turns 18 and moves to the adult system.

Other initiatives to improve care for children with complex conditions, with a focus on evidence based initiatives

Other initiatives to improve transition support for students with additional and complex needs could include:

- ongoing participation by disability and education agencies in the Agency for Clinical Innovation’s Intellectual Disability Network
- ongoing focus during the early school years on adaptation to the diagnosis and implications for the future and learning potential of a child with a disability, especially an intellectual disability
- establishment of a closer connection between Special Schools and schools with special classes to share expertise, resources and increase the likelihood of a successful transition to less restrictive environments

- clarification of the types of therapies available within schools and ensure that these have an evidence base

- increased involvement from the Children's Commissioner in these issues as they reflect the needs, both met and unmet, of a vulnerable group in our community

- increased support for research that has a focus on interagency models of care

- recognition of the critical importance of the family, including siblings and grandparents, in meeting the lifelong needs of children with a disability and other complex conditions. This includes a recognition that adaptation to the diagnosis may present challenges later in life and that provision of care may be associated with significant stress.

Acknowledgement

The College acknowledges the contribution of Dr Jacqueline Small FRACP, Team Leader at the Disability Speciality Unit at Westmead Children's Hospital.

The College also acknowledges the contribution of the Kids Rehab Department of the Sydney Children's Hospital Network to this submission.