Submission No 20

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

Organisation: Association of Doctors in Developmental Disability (ADIDD)

Date received: 12/08/2011

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The Hon Niall Blair MLC
Committee Chair
Standing Committee on Social Issues
Parliament House
Macquarie St
Sydney NSW 2000

12th August 2011

Dear Mr Blair,

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

Thank you for the opportunity to comment on the above Inquiry.

The NSW Association of Doctors in Developmental Disability (ADIDD) is a group of medical specialists from various disciplines with extensive experience in developmental disability and health promotion in schools. As dedicated clinicians, we want to see improvements in transition support for students with developmental disabilities and their families.

In the attached submission, ADIDD writes specifically concerning the **transition of youth with developmental disabilities** and associated complex health and mental health needs in the transition from school to adult orientated services.

ADIDD emphasises that every student should have the gold standard of a multidisciplinary health assessment and comprehensive transition plan that underpins their educational post-school option program and transition from paediatric to adult health services.

ADIDD acknowledges the input of the Agency for Clinical Innovation (ACI) Transition and Intellectual Disability Networks in collating the document. The ACI is the peak body for development of innovative models of health care throughout NSW and supports the principles outlined in the submission.

Please do not hesitate to contact our association should you require any further information.

Yours sincerely,

Dr Robert Leitner
Chairperson, ADIDD

Dr Hunter Watt
CEO, Agency for Clinical Innovation

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

EXECUTIVE SUMMARY

The Association of Doctors in Developmental Disability (ADIDD) writes specifically concerning the transition of **young people with developmental disabilities** and associated complex health and mental health needs in their transition from paediatric to adult services.

Students with developmental disabilities are likely to have a variety of educational, social and health and mental health needs which continue or exacerbate as a young adult. Students and their families /carers must often deal with a confusing array of professionals, interventions and agencies to meet their needs during their transition from the world of school to the world of adulthood.

The submission outlines gaps in the interface between paediatric and adult services, gaps in physical and mental health services, key transition principles and examples of best practice, including the Transition Network of the Agency for Clinical Innovation (ACI).

Every student with a developmental disability should be offered the gold standard of a multidisciplinary health assessment and comprehensive transition plan that underpins their educational post-school option program and ensures an integrated continuum of care in their transition from paediatric to adult health services. Additional funding should be provided to develop and enhance best practice models across the state.

1. THE ADEQUACY AND ACCESSIBILITY OF APPROPRIATE SUPPORT FOR CHILDREN AND THEIR FAMILIES – *transition of students with developmental disabilities from school to adult services*

1.1 Needs of Students with Developmental Disability:

- The developmental disability population is a heterogeneous group with a wide range of clinical needs. The needs of a student with a borderline to mild intellectual disability are significantly different to a student with a severe to profound disability. Students with multiple disabilities have a range of complex physical and mental health needs. Students with Autism Spectrum Disorders have unique needs in communication, social skills and other areas.
- Youth with developmental disabilities are a disadvantaged group with complex health, educational and socio-economic needs that require services from a number of professionals and agencies. They are particularly vulnerable to the stresses of the transition period from paediatric to adult services including access to health services.
- Youth with developmental disabilities and mental health problems present significant difficulties during transition between stages of education.
- Families often describe the transition from school to adult life as a period of high stress.

Result:

- There are many gaps in the adequacy and accessibility of support services for students and their families, particularly in the transition from paediatric to adult services.

1.2 Gaps between Paediatric and Adult Health Services:

Paediatric Health Services	Adult Health Services
Paediatricians tend to focus on younger children rather than adolescents	Adult physicians have generally not been involved in the care of adolescents in schools
Paediatric services are more child and family focused and holistic than adult services	Families are often not included and their expertise ignored as the focus is on the patient who is expected to be autonomous
Paediatric services are more multidisciplinary than adult services	There are minimal dedicated resources for allied health in adult public health services
Paediatric services tend to be better resourced with more time allocated for appointments than adult services	Adult services tend to be not as well resourced with less time allocated for appointments and less holistic approach
There are limited paediatric transition services for adolescents with developmental disabilities	There are limited adult specialists in medical, nursing and allied health services with expertise in young people with developmental disabilities

Results:

- There are limited transition services across the state and limited services which can provide adequate ongoing assessment and review.
- The student with developmental disability and their families/ carers are often not well prepared for the changes in health care and the significantly reduced access to support.
- Children from Out-Of-Home-Care, Aboriginal, Refugee and Culturally and Linguistically Diverse (CALD) populations are particularly disadvantaged and at risk groups.
- Students and families living in regional, rural and remote areas have significantly less access to specialist services than children with living in metropolitan areas.

Clinical Scenario:

- Youth with physical disabilities who are not transitioned to an adult team may be lost to follow-up and only represent when they are in a crisis – e.g. smouldering gastro-oesophageal reflux, painful arthritis, unrecognised diabetes, urinary tract infections and obesity-related problems.

1.3 Gaps in Mental Health Services:

- The mental wellbeing of students is essential for sustained familial relationships, good quality of life and access to the school curriculum.
- The youth to adulthood transition period represents the period of highest vulnerability for mental health problems.
- There are many gaps in services and pathways to care as well as inequity to access for students with developmental disabilities and mental health problems.
- A total of 40% of students with an intellectual disability have associated mental health problems. The challenging and disruptive behaviours that accompany many of these students continue or exacerbate as a young adult and may result in a forensic pathway without appropriate assessment and management.
- There are particularly vulnerable groups that include:
  - Students with mild intellectual disability and comorbid mental health issues who fall in the gap between Ageing, Disability and Home Care (ADHC) and Mental Health services.
  - Students with an intellectual disability and severe challenging behaviours without a formal psychiatric diagnosis.
  - Students with Autism Spectrum Disorder and particularly Asperger's syndrome.
  - Students transitioning from paediatric to adult services.
- The diagnosis and management of mental illness in the context of intellectual disability is a difficult and challenging field. Schools alone cannot provide the professional help and support required for students with the highest mental health needs.

  Result:

  - Students with developmental disabilities and mental health problems/ disruptive and challenging behaviours experience major problems accessing appropriate mental health care.

1.4 Gaps in Therapy Services:

- There is limited therapy intervention for students. Many parents report that the level of intervention services declines dramatically once their child reaches school age and even more so when the adolescent leaves school. Waiting lists in place are extensive for adults living in the community which results in crisis driven intervention.
- In the current system, various government agencies including Ageing, Disability and Home Care (ADHC), NSW Health and Non-Government Organisations are funded to provide therapy services for students with specials needs.
- Once therapy intervention has been established, this is generally of limited scope - i.e. often less than 3-5 visits before the case is closed by ADHC. There are constant changes in service delivery and limited consistency and the parents and schools may not be informed.
- There is poor capacity for therapists to support clients with mild-moderate support needs - e.g. for speech pathology services there is a focus on clients with feeding and swallowing difficulties. There is often no plan for review or re-assessment. The parents need to re-refer to ADHC for a service. The parents may be unaware of the system or too busy caring for child to follow this process.

  Result:

  - There is confusion in responsibilities, significant variations and frequent changes in service criteria and therapy models, increased complexity for families and teachers navigating the system, inequity of access and gaps in services.

2. BEST PRACTICE APPROACHES TO ENSURE SEAMLESS AND STREAMLINED ASSISTANCE DURING TRANSITIONS – *transition of students with developmental disabilities from school to adult services*

2.1 Key Principles:

- The best practice models ensure a seamless transition service which begins in adolescence and continues into adulthood. The key principles in the transition from leaving school to adulthood for students with developmental disabilities include:
  - ***Affordable*** – encourages access to care for students with a chronic illness
  - ***Choice*** – maximised involvement of the student in planning for their future
  - ***Collaboration*** – effective interagency partnerships to meet the variety of educational, social and health needs of students and their families/ carers
  - ***Collocation*** – conjoint paediatric and adult services encourage cross fertilisation of knowledge between specialties
  - ***Comprehensive scope*** – continuing education, employment, health, living arrangements, leisure and recreation
  - ***Communication*** – between the various services providers and the client family
  - ***Consent*** – careful consideration of confidentially and informed consent
  - ***Consumer held records*** – improve communication between families and service providers, especially when they are geographically dispersed
  - ***Continuum of care*** – continuity of high-quality and coordinated health care that is person-centred, developmentally appropriate, flexible and comprehensive in the transition from paediatric to adult services
  - ***Coordination*** – an identified professional to coordinate the transition process and to ensure engagement with the adult services after the student leaves school
  - ***Flexibility*** – services that can manage a broad range of concerns and not cut-off at specific ages
  - ***Preparation period*** – begin early to allow adequate time for the student, the family/ carers and professionals to plan for the transition to adult-oriented services
  - ***Prevention*** – services that are preventative with a focus on wellness rather than reactive and crisis driven
  - ***Primary care involvement*** – shared care between the regular GP as the key primary clinician and adult specialist services
  - ***Responsiveness*** – services that respond to the holistic needs of students and families/ carers
  - ***School-based*** – health promotion, prevention and clinical services based in school promote involvement of the school community and integrated services
  - ***Service agreements*** – between Departments of Education, ADHC, Health and key stakeholders
  - ***Transition plans*** – individualised plans that are reflective of the student and family's needs, goals and aspirations
  - ***Welcoming adult service*** – active participation from interested adult services

2.2 Examples of Best Practice Models:

ACI Transition Care Model

- The Agency for Clinical Innovation (ACI) Transition Care Network provides a state-wide approach to improving systems and process for young people with chronic illnesses arising in childhood including those with intellectual disability when they transition from paediatric to adult health services.
- The ACI Transition Network Coordinators have established links with transition support teachers. This collaboration has proven to be effective in helping to ensure that young people with chronic health problems and disabilities have transition health plans developed before they leave school.
- The ACI Transition Care Network Coordinator for the Southern Eastern Sydney Local Health District regularly attends transition clinics in special schools with the Team from Kogarah Developmental Assessment Service to facilitate discussion and planning for health transition.
- The expanded ACI Transition model aims to develop this collaboration across all schools in NSW, not only special schools. ACI Transition Care Coordinators would provide information and support about transition to adult health services to all students enrolled in the post school options program.

NSW Health Service Framework Metro-Regional Model

- The ACI Transition / School Clinic model will be expanded in the NSW Health Service Framework pilot to improve the health care of young people in services in regional, rural and remote areas.
- The development of this metropolitan-regional network will make use of modern technologies – videoconferences and the National Broadband Network to increase access to specialised services and build capacity of local services.
- Commonwealth funded Specialist Training Positions (STP) in Paediatrics, Psychiatry, General and Rehabilitation Medicine will offer specialist support to rural areas via outreach clinics and video-conferencing and expose trainees to practising in regional settings.

School Physical Disability Team Model

- These multidisciplinary teams typically employ Occupational Therapists, Physiotherapists and Speech Pathologists who work with the student's key school contacts such as the class and support teachers, school counsellors and learning support teams to determine functional difficulties and physical or communication barriers to accessing the curriculum.
- The teams facilitate the transition of adolescents with physical disabilities from school to adult orientated services by meeting with school transition staff members, participating in ADHC post-school funding assessments as required, planning and coordinating equipment and care provision in preparation for tertiary education and independent accommodation/ living arrangements.

School-Link Model

- This collaborative initiative between Mental Health, NSW Health and Department of Education and Communities facilities early identification, management and support of students with mental health problems in schools.
- The model ensures that school counsellors are trained in the early identification, assessment and management of mental health problems and provide support strong links with Mental Heath services.

3. ANY OTHER RELATED MATTERS – *transition of students with developmental disabilities from school to adult services*

Recommendations

- That every student with a developmental disability should be offered the gold standard of a multidisciplinary health assessment and comprehensive transition plan, which underpins their educational post-school option program and ensures an integrated continuum of care in their transition from paediatric to adult health services.
- That additional funding should be provided to develop and enhance the current best practice models across the state.

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