

Submission
No 1

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

Organisation: Queensland Centre for Intellectual and Developmental
Disabilities

Date received: 26/07/2011

School of Medicine
Queensland Centre for Intellectual and
Developmental Disability (QCIDD)
Director
Professor Nicholas Lennox FRACGP PhD
CRICOS PROVIDER NUMBER 00025B

**NSW Legislative Council, Standing Committee on Social Issues:
QCIDD SUBMISSION to the Inquiry into transition support for students
with additional or complex needs and their families**

Adequacy and accessibility of appropriate support for children and their families

Australian youth with intellectual disability are not always making the transition from adolescence to adulthood in such a way as to maximise their life outcomes.¹ Qualitative research with families suggests that high levels of unmet need for service support in the early adult years are contributing to poor outcomes particularly for these young people. Families frequently comment on the significant 'drop off' in services that occurs once their son or daughter leaves the school system.² It is repeatedly highlighted that negotiating 'the maze' of services available to a young adult with intellectual disability remains, for most, a highly stressful and frustrating experience.³ The onus that falls on families wishing to receive formal supports and services to their young adults transitioning from school creates a sense of bargaining as opposed to one of entitlement.⁴

In 2009, 55,250 young people with intellectual disability left the secure and structured environment of school and entered adult life. This is a period of enormous adjustment and high stress for both the individual and their family. Family impacts can include significant loss of income as they may have to cease employment to care for their young adult who has limited employment or day placement options.

Our randomised controlled trial which utilised both health diaries and health assessments as interventions with a cohort of adolescents⁵ clearly raises major parental concerns about their adolescents' futures as being dependency, general health, challenging behaviour, and increasing support needs.⁶ These concerns include poor access to high quality and knowledgeable healthcare providers, ongoing levels of dependency and challenging behavior and unmet support needs.

Best practice approaches to ensure seamless and streamlined assistance during transitions

We are not aware that any best practice approaches exist for transition for adolescents with intellectual disability to adult services.

However, we are currently conducting an Australian Research Council funded project about transition. This is a descriptive project which seeks to explore the experiences of young people

School of Medicine
Queensland Centre for Intellectual and
Developmental Disability (QCIDD)
Director
Professor Nicholas Lennox FRACGP PhD
CRICOS PROVIDER NUMBER 00025B

with intellectual disability and their families as they move from secondary school into adult life. The study is investigating the factors at an individual, educational, family and societal level which positively and adversely affect outcomes for young people with an intellectual disability and their family. The project aims to identify the structural and policy changes that can be made locally and centrally in keeping with parent expectations to improve outcomes for young adults with intellectual disability and their families. QCIDD has joined the project as part of a national study based at the Telethon Institute for Child Health Research at the University of Western Australia under Dr Helen Leonard, and the NSW Victorian ACAD arm under Professor Einfeld. This project will identify the potential factors which lead to either better or poorer outcomes in the individual and the family. In this way important opportunities for change in policy and service development across a number of sectors and service providers will be identified. Gaining the knowledge to minimise the disruption to family life which often occurs at this time of transition will lead to strengthening Australia's social and economic fabric.

In Australia, legislation has not been formally developed to support children and families as the adolescents transition to adult services. In recent years New South Wales has developed initiatives around transition for individuals with intellectual disability, with commitment from both government and educational sectors. A small sample of students involved in these initiatives was followed to determine transition best practice principles.⁷

Other issues - Health issues and service delivery gaps

Intellectual disability is the 'label' given to disturbance in mental cognition and functions that results from a diverse range of underlying and pathological processes. The prevalence of intellectual disability is 14.3/1000 live births, with 10.6% of children having a mild or moderate intellectual disability and 1.4% severe level of intellectual disability.⁸ Prevalence is 1.6 times greater in males and 2.3 times greater in children of Aboriginal mothers⁸ and there is a considerable increased risk for children of socioeconomically disadvantaged mothers.⁹ Common health issues that may be present in adolescents and young adults with intellectual disability are epilepsy, gastrointestinal problems, thyroid disease, obesity, musculoskeletal and hearing and visual problems.¹⁰ Individuals with intellectual disability have also been estimated to be up to seven times as likely as persons without a disability to have a diagnosable psychiatric condition.¹¹

However, we have conducted several randomised controlled trials and observational studies using health interventions for adults and adolescents with intellectual disability which show clear effect on health outcomes.

School of Medicine
Queensland Centre for Intellectual and
Developmental Disability (QCIDD)
Director
Professor Nicholas Lennox FRACGP PhD
CRICOS PROVIDER NUMBER 00025B

The Comprehensive Health Assessment Program or CHAP health review is designed to encourage communication about health needs between the person with intellectual disability, their care provider and their GP. It is a two-part health review of 21 pages, with part one designed to be completed by the care provider, and part two by the GP. Part one records the person's current symptoms and past health history. Part two contains a brief check-list of common unmet health needs to alert the GP to possible deficits in healthcare and then prompts the GP to perform a guided health assessment with physical examination. Immunization status, health screening activities, newly and previously detected diseases, measurement of weight and height, and current signs and symptoms of disease are recorded. Finally, the GP and care provider are encouraged to jointly develop a health action plan.

The CHAP has been successfully trialled among people with intellectual disability in a number of settings, and has consistently shown significant short-term health improvements¹²⁻¹⁶. In particular, there was a seven-fold increase in detection of vision impairment, a nine-fold increase in immunizations, and a 30-fold increase in hearing testing. Women's health promotion saw similar effects, with a 15-fold increase in Pap smears, a two-fold increase in breast examinations, and a four-fold increase in mammography. This remains the largest published RCT of the health assessment process in world literature and, largely based on this work, Medicare Australia established new Medicare Items in July 2007 to reimburse GPs for performing health assessments in people with intellectual disability. NSW currently uses this approach in the government and NGO sectors which provide support to people with intellectual disability.

In our current randomised controlled trial with adolescents, across South-East Queensland, 368 teachers, 731 adolescents with intellectual disability and their parents in 101 schools, 29 Special Education Schools and 56 Special Education Units enrolled in our study, as well as 540 nominated GPs. Analysis of date is currently underway including medical records from the 286 practices involved in the study. At this early stage in the analysis, it is clear that their poor health status is persistently alarming, similar to the adult population, and that parental concerns are high about their adolescent's movement from paediatric to adult health services. Preliminary data from this study about the usefulness of a whole-of-life health diary, in this case, the *Ask diary*,¹⁷ indicates that a simple tool such as this may facilitate better primary healthcare interactions and has potential for improvement of health outcomes during this vulnerable time of life.

Overview

As the Director of the Queensland Centre of Intellectual and Developmental Disability and President of the Australian Association of Developmental Disability Medicine (AADDM), I have

School of Medicine
Queensland Centre for Intellectual and
Developmental Disability (QCIDD)
Director
Professor Nicholas Lennox FRACGP PhD
CRICOS PROVIDER NUMBER 00025B

been working at QCIDD for 14 years in Queensland with the single goal of improving the health of adults with intellectual disability. An overview of our randomised controlled trials indicates significant gaps in health service delivery to adolescents with intellectual disability as they transition to adult primary and specialist healthcare.

Australian adolescents and young adults with intellectual disability face disadvantage and discrimination beyond the choices they make during transition. They are more socially isolated, unemployed, less educated, poorer, living on the outskirts and have poor health including mental health than their peers.¹⁸ However, this is not an inevitability. Targeted responses to this vulnerable group can obviate many of the life problems they experience during transitions.

Sincerely

Professor Nicholas Lennox
18th July 2011

References

1. Hughes C. Transition to adulthood: Supporting young adults to access social, employment, and civic pursuits. *Mental Retardation and Developmental Disabilities Research Reviews* 2001;7(2):84-90.
2. Knox M, Parmenter TR, Atkinson N, Yazbeck M. Family Control: The Views of Families Who have a Child with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 2000;13(1):17-28.
3. Timmons JC, Whitney-Thomas J, McIntyre JP, Butterworth J, Allen D. Managing Service Delivery Systems and the Role of Parents During their Children's Transitions. *Journal of Rehabilitation* 2004;70(2):19.
4. Schneider J, Wedgewood N, Llewellyn G, McConnell D. Families challenged by and accommodating to the adolescent years. *Journal of Intellectual Disability Research* 2006;50(Pt 12):926-36.
5. Carrington S, Lennox N. Advancing the curriculum for young people who have an intellectual disability: Advocacy in health and wellbeing. *Australasian Journal of Special Education* 2008;32(2):177-86.
6. Tucker M, Taylor Gomez M, Rey-Conde T, Lennox N. Parental concerns about the health and well-being of adolescents with intellectual disability - A brief report. *International Journal of Family Medicine* 2011;doi:10.1155/2011/164080.
7. Riches V. A review of transition from school to community for students with disabilities in NSW, Australia. *Journal of Intellectual and Developmental Disability* 1996;21(1):71-88.

School of Medicine
Queensland Centre for Intellectual and
Developmental Disability (QCIDD)
Director
Professor Nicholas Lennox FRACGP PhD
CRICOS PROVIDER NUMBER 00025B

8. Leonard H, Petterson B, Bower C, Sanders R. Prevalence of intellectual disability in Western Australia. *Paediatric and Perinatal Epidemiology* 2003;17:58-67.
9. Leonard H, Petterson B, De Klerk N, Zubrick S, Glasson E, Sanders R, et al. Association of sociodemographic characteristics of children with intellectual disability in Western Australia. *Social Science & Medicine* 2005;60:1499-513.
10. Lennox N, Beange H, Davis R, Durvasula S, Edwards N, Graves P, et al. *Management Guidelines: Developmental Disability*. Second ed. Melbourne, Victoria, 2005.
11. Emerson E. Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *J Intellect Disabil Res* 2003;47(1):51-58.
12. Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology* 2007;36(1):139-46.
13. Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings *Journal of Applied Research in Intellectual Disabilities* 2010;23(4):303-11.
14. Lennox N, Rey-Conde T, Cooling N. Comprehensive health assessments during de-institutionalization: an observational study. *Journal of Intellectual Disability Research* 2006;50(10):719-24.
15. Lennox NG, Green M, Diggins J, Ugoni A. Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research* 2001;45(Pt 3):226-32.
16. Lennox NG, Ware RS, Bain C, Taylor Gomez M, Cooper SA. Effects of health screening for adults with intellectual disability: A pooled analysis. *British Journal of General Practice* 2011;61(584):193-96.
17. Lennox N, Taylor M, Rey-Conde T, Bain C, Boyle FM, Purdie DM. *ask for it*: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. *Health Promot Int* 2004;19(2):167-75.
18. Emerson E, Honey A, Madden R, Llewellyn G. The well-being of Australian adolescents and young adults with self-reported long-term health conditions, impairments or disabilities: 2001 and 2006. *Australian Journal of Social Issues* 2009;44(1):39-53.