



Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services

2014

Introduction

The period of time in which young people with complex and chronic disability needs are transitioning from paediatric to adult services provides an important opportunity for the health system to respond to their changing needs.

“Transition” in the context of health care is “the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems.”ⁱ It is a formal process involving preparation while the child is attending paediatric services, conjoint activities as the adolescent matures, and appropriate and comprehensive orientation to ongoing adult care.

This position statement on young people with complex and chronic disability needs has been developed as a supplement to the RACP document *Transition to Adult Health Services for Adolescents with Chronic Conditions* (2007).ⁱⁱ It reiterates the principles articulated in the statement of the Paediatric Society of New Zealand (2003) *Position Statement: Meeting the Care and Support Needs of Young People with Complex and Chronic Health and Disability Needs as they Approach Adulthood*ⁱⁱⁱ and the RACP’s *Position Statement on Disability*^{iv}, both of which emphasise the principles of habilitation and rehabilitation of people with disabilities, as articulated in the *UN Convention of the Rights of Persons with Disabilities* (2010)^v.

Background

Between eight per cent and 11 per cent of children under the age of 14 years in Australia and New Zealand are estimated to be living with disabilities.^{vi,vii} These disabling conditions include developmental neurological disorders as well as acquired traumatic brain injury, spinal cord injury and amputations. While physical and psychological relationships, exposure to risks, and economic and vocational uncertainties are key issues for all young people,^{viii} there may be additional physical and psychosocial factors relating to personal image for adolescents with disabilities. These will be amplified during transition if not managed well^{ix}.

Young people with disabilities are a particularly vulnerable group due to the presence of coexisting risk factors for adverse health outcomes such as socioeconomic adversity, high rates of mental health problems, poorer rates of healthy lifestyles and widespread barriers to accessing services,^{x,xi} Vulnerable young people with disabilities for whom the transition to adult health care may be more difficult will include those with multiple disabilities, Aboriginal and Torres Strait Islander young people, Māori and Pacific Islander young people, those from ethnic minority groups and young people in the care of the state who require more intensive support during transition.^{xii,xiii}

Young people with disabilities are likely to have been seen regularly by generalist paediatricians, and been involved with sub-specialist paediatricians and their associated multi-disciplinary teams of clinicians during childhood. They will be transitioning to an adult health care system in which the treating general practitioner (GP) is the key doctor for their care and specialist health care is more likely to be dispersed. These young people are also transitioning from an environment in which their parents have been responsible for their

health and illness-related decisions to one in which they are taking those responsibilities themselves.

Principles of successful transition to adult-oriented health services for young people with complex and chronic disability needs

The RACP supports the following principles:

1. Young people with disabilities (and their families when appropriate) will receive developmentally and culturally appropriate medical and psychological care as they transition to adult health services.
2. Transition to adult-oriented health services is a formally planned and coordinated process which begins early in adolescence.
3. Transition is optimised when there is a specific health care provider who takes responsibility for active case management, helping the adolescent or young person and his/her family and/or carers through the process.
4. Health services for young people with disabilities need to holistically address the same health issues of concern to all young people transitioning to a healthy adult life such as growth and development, mental health, sexuality, nutrition, exercise and health risking behaviours such as drug and alcohol use.
5. Multi-disciplinary habilitation and rehabilitation services may be required for some young people to address underlying complex health conditions and new disabilities which may arise.

Recommendations

The RACP supports the following:

1. That the transition period be conceptualised as having three components: (1) preparation in the paediatric care system, (2) period of conjoint care and (3) ongoing care in the adult health sector:
 - a. The paediatrician should consider emerging health issues from early puberty through to adolescence, especially for those children with disabilities who are particularly vulnerable.
 - b. The transfer process should include close collaboration between treating paediatric and adult teams and should be delivered in one of the following care models in line with clinical complexity:^{xiv,xv} paediatric clinicians attending adult clinics; adult clinicians attending paediatric clinics; or attendance by both at a planned 'handover' case conference with the young person and her/his family or carers.
 - c. It is likely that a team approach will be required for young people with complex and multiple disabilities, and there should be a formal referral to the relevant lead clinician in that adult team.
2. That health care for adolescents/young adults during the period of transition addresses the following issues:
 - a. Physical health
 - b. Pubertal health

- c. Medications
 - d. Developmental/cognitive/academic progress
 - e. Sexual health and education
 - f. Nutrition, exercise, and other health promotion activities
 - g. Mental health
 - h. Relevant entitlements such as disability allowances and benefits, health care subsidy systems, insurance issues, medications, equipment and appliances and rules and regulations concerning driving licenses
 - i. Substitute decision-making and guardianship laws. The paediatrician should explicitly consider the capacity to give informed consent^{xvi} before the transfer to adult services.
 - j. Ethical decisions such as need for respiratory support, end of life decisions, major surgical interventions.
3. That the young person be supported during their transition to adult-oriented health services by the following activities:
- a. Active engagement and involvement of the treating GP
 - b. A personal health record that outlines specific health issues, including care plans as relevant
 - c. Formal letters of referral from paediatricians to adult health practitioners detailing summaries of the young person's health and disability management, including the clinical reasoning with respect to specialised medications or procedures. Copies of results of important investigations, and references for unusual procedures should also be included. Complex management or surgery offered but declined or deferred by the adolescent and/or family/carers should be included in the summary document, including discussions about palliative care where applicable.
 - d. The young person, or her/his family/carers if appropriate, should receive copies of this communication. They should also receive copies of correspondence from their new physicians to their referring paediatric clinicians and their identified GPs.
4. That services be developed in the adult sector for those with special needs who are ageing:
- a. Local Health jurisdictions^{xvii} should identify specialist physicians and other health professionals with expertise in disability to provide consultation for young adults with complex health care needs and support for other mainstream health care professionals.
 - b. Measures of health status for young people with disabilities should be developed and routinely used by health services.
 - c. Local Health jurisdictions should establish databases for determining health service requirements and for enabling better planning for young people with disability and complex health care needs.

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Document details

Publication name:	Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services
Author:	Australasian Faculty of Rehabilitation Medicine The Royal Australasian College of Physicians
Approved by:	College Policy & Advocacy Committee (CPAC)
Approval date:	23/07/2014
Review date:	2019

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^{xvi} In New Zealand health care providers must adhere to *The Code of Health and Disability Services Consumers' Rights Regulation 1996*. Online, available: <http://www.hdc.org.nz/the-act--code/the-code-of-rights> (last accessed 10.02.14)

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