

Transition of young people with disability

Allan Colver

Abstract

Transition from child-centred to adult-oriented health services occurs at a time when young people are going through adolescence, with all the excitement and uncertainty that accompanies it. Most elements of good transitional care for young people with disabilities are the same as those for all young people with long term conditions. The article discusses 'Developmentally Appropriate Healthcare', the NICE guidance on transition, and the implications of the NIHR funded Research Programme on Transition, 2012–2017.

However, additional consideration should be given to those with:

- physical impairments such as cerebral palsy
- mental health problems, including autism spectrum disorder, attention deficit disorder with hyperactivity or severe learning difficulties
- isolated sensory impairments
- very complex needs, requiring multi-sectoral packages of care

It is crucial to aim to retain the engagement of a young person, even if he or she may not always attach to their healthcare the importance their clinician's think they should. Three key practical points are:

- For child services: prepare properly young people from age 12 for transfer so that it is regarded as an exciting part of growing up, rather than a cliff from which to fall
- For adult and child services: keep parents involved in a manner that suits both young person and parent
- For adult and child services: ensure the young person and parents can meet the adult team at least once before transfer

Keywords Developmentally Appropriate Healthcare; disability; transition; young people

Introduction

All young people – defined by the WHO as any person between ages 10 and 24 – experience transformations in their lives and their understanding of the world as they grow older. Although it may not be possible for all, young people need to achieve four crucial developmental tasks: i) consolidate their identity, ii) achieve independence from their parents, iii) establish adult relationships outside their families, iv) find a vocation. A fundamental principle is that where young people have a need for healthcare, such care must be provided in a manner which is appropriate to their stage of development. Further, a young person with a long term condition has to move from child-centred to adult-oriented services. This process is called 'Transition' and is defined as the purposeful,

planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-oriented health care systems. 'Transfer' is the formal 'event' when medical care of a young person is moved from children's services to adults' services.

In the UK much transitional care is sub-optimal and responsibility to improve this lies with commissioners, provider organisations and clinicians. Recent policy and recommendations setting out the need for improved transitional care include: advice from the Department of Health in 2006 and 2008, the 2010 Kennedy Report; the 2015 Care Quality Commission report 'From the Pond to the Sea'; and NICE Guidance on Transition in 2016.

In the UK, some services to facilitate transition of those with chronic illness have improved, such as for diabetes, cystic fibrosis, congenital heart disease, chronic renal failure and rheumatological conditions. However, this is not the case for the topic of this article, those with disability – under which I will include mental health.

Why is transition important?

Transition is important because:

Many young people with a range of long term conditions have poor social outcomes following Transition in areas of social participation, employment or further education. For example, young adults with long term conditions, such as chronic illnesses or disability demonstrate delays in autonomy, and psychosexual and social development. Further, few young adults with neurodevelopmental disorders such as autism spectrum disorder attain their potential for participation in society.

Chronic illnesses, such as diabetes or renal disease, are prone to deteriorate during the adolescent years. Conditions such as cerebral palsy give rise to symptoms that interfere with daily living such as pain, spasticity or seizures. Most mental health disorders of adults develop during the adolescent years, just when commissioning and provision of services move from child and family-focussed to adult symptom-orientated mental health services. Disease control, continuity of healthcare, and co-ordination of care may also be compromised; this results in the need for (and hence cost of) additional healthcare in later life.

Some adult services may not be routinely provided. For example, for those with Attention Deficit Disorder with Hyperactivity. Further, in spite of the 2009 Autism Act, services for adults with Autism Spectrum Disorder are patchy. Other adult services, such as physiotherapy and mental health services, often have different and usually narrower entry criteria than do child services.

Transition of young people with disability

Grouping together young people with disability can be helpful for certain purposes but in relation to transition it is not. Improving transition for those with disability requires introducing changes which are relevant to:

1. all young people with long term conditions and
2. individuals with particular disabling conditions

Allan Colver MA MD FRCPCH is Emeritus Professor of Community Child Health Newcastle University, Royal Victoria Infirmary, Newcastle, UK. Conflict of interest: none declared.

Environmental aspects of developmentally appropriate healthcare

Consulting with the young person alone
Confidentiality explained
Flexible access and clinic times
Information about what to expect: navigation
Magazines, pictures, staff clothing

Table 1

Introducing changes which are relevant to all young people with long term conditions

Developmentally Appropriate Healthcare: those who work with the healthcare of young people need to understand and deliver Developmentally Appropriate Healthcare for young people; just as health professionals might currently do for babies and young children, or for elderly people with mental or physical frailty.

'Developmentally Appropriate Healthcare recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms Developmentally Appropriate Healthcare focuses on the approach of healthcare professionals to and engagement with each young person and their carers, alongside the structure of the organisations in which care takes place.'

There is not space to do full justice to this topic, but [Tables 1 and 2](#) highlight the main aspects relating to the environment and professional behaviour. Much qualitative research with young people indicates that they value the environmental aspects but what really matters to young people is their interactions with professionals. The key message is that professionals should be trained to adjust their professional behaviour, and that getting the magazines and clinic flexibility right can never substitute for this.

A toolkit to assist with introduction of Developmentally Appropriate Healthcare is available from: <https://www.northumbria.nhs.uk/quality-and-safety/clinical-trials/for-healthcare-professionals/>

NICE Guidance on Transition— February 2016: NICE guidance brought together guidance from previous government documents and the research literature. Its supplements are well referenced and informed. However, the guidance makes a large number of recommendations (over eighty) many of which are aspirational

or for which there is a relatively weak evidence. For example, its recommendation for a 'named worker' carries with it sixteen responsibilities for the worker; this seems unrealistic. Their recommendations are arranged under the following numbered headings:

- 1.1 Overarching principles, which cover: Involving young people and their carers in service design, delivery and evaluation; ensuring transition support is developmentally appropriate; ensuring transition support is strengths-based and focuses on what is positive and possible for the young person; using person-centred approaches to ensure that transition support treats the young person as an equal partner in the process.
- Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people. And these services should proactively identify and plan for young people in their locality with transition support needs.
- 1.2 Transition planning, which covers: Timing and review; having a 'named worker'; involving young people; building independence; involving parents and carers
- 1.3 Support before transfer
- 1.4 Support after transfer
- 1.5 Supporting infrastructure, which covers: Ownership; monitoring and reviewing the effectiveness of transition strategies and policies; planning and developing transition services; ensuring there are developmentally appropriate services for children, young people and adults to support transition. [Table 3](#) sets out the four challenges to implementation that NICE identified

NIHR funded Transition Research Programme 2012–2017: the author led a large programme of research in England over 5 years, with 12 co-applicants from clinical practice, academia, the voluntary sector and NHS Trust Management. Results and implications followed from a synthesis of the research undertaken in the Programme, which included qualitative work, quantitative work, health economics, and input from a Young People's Advisory Group which met monthly throughout the five years. The research examined the contributions Commissioners, Provider Organisations and Clinical Teams could make to improving transition. The main implications of the Research Programme and Open Access Publications to date can be downloaded from: <http://research.ncl.ac.uk/transition/resources/>

Introducing changes which are relevant to young people with particular disabling conditions

Any change of health service provider(s) may be particularly difficult to negotiate for young people with a disability such as

Professional behaviour for developmentally appropriate healthcare

Be approachable and welcoming. Adolescents appreciate friendliness, with much facial expression.
Allow graded opportunities for self-management and risk taking
Avoid asking a young person to make key decisions at times of excitement or stress
Set the consultation in a context of wider adolescent health: sexual health, substance misuse, body image etc.
Consider possibility of associated mental health problems
Health is just one of many upheavals for a young person: education, sexuality, separation from parents, friendships, etc. Health may not be the young person's priority. Show interest in all aspects of a young person's life, not just their health condition.

Table 2

Download English Version:

<https://daneshyari.com/en/article/8813064>

Download Persian Version:

<https://daneshyari.com/article/8813064>

[Daneshyari.com](https://daneshyari.com)