

SCIE RESEARCH BRIEFING

TRANSITION OF YOUNG PEOPLE WITH PHYSICAL DISABILITIES OR CHRONIC ILLNESSES FROM CHILDREN’S TO ADULT’S SERVICES

Definition of a briefing: A SCIE research briefing is a summary of information on a particular topic to update practice at the health and social care interface. It is a concise document summarising the knowledge base in a particular area to act as a ‘launch pad’ or signpost to more in-depth material. It is produced through a clear methodology involving identification of a focused question, comprehensive searching of multiple sources and filtering of materials for quality.

Definition of physical disability: a person “... with a physical ... impairment, which has a substantial and long-term effect on his or her ability to carry out day-to-day activities”. (1)

Definition of chronic illness: “... a disease or disorder that continues over an extended period of time and causes continuous or episodic periods of incapacity”. (2)

Scope of the briefing: This briefing focuses on physical disabilities and not learning disabilities.

What is the issue?	There are two key issues in transition: becoming an adult and achieving independence and changes in the actual services used. It is estimated that there are almost 156,000 adolescents (aged 16-19) with a disability in the UK: over 4,000 have a severe disability (3) and there is evidence that numbers are increasing (4). Most children with physical disabilities or chronic illness will survive childhood (5, 6, 7) and have improved life expectancy (8). During adolescence, they will experience change in a number of areas: from paediatric to adult health services (9, 10), school to higher education or work (11, 12) and childhood dependence to adult autonomy (13, 14). For disabled and chronically ill young people both the planning process and the actual move to adult services can be difficult (14), frightening (12, 15) and stressful (16). Associated problems can occur such as social isolation (17, 18, 19), a lack of daily-living skills (17, 20, 21), difficulties in finding work (21, 22, 23) and additional problems in family relationships such as over-protectiveness by parents (24) and low parental expectations (2). Transition can also cause considerable stress for families and carers (25). A method for helping young people manage the transition process and take their place in the adult world is effective transition planning: this will involve both life stage planning and planning in change from children’s to adult services.
Why is it important?	It is vital that transition planning is centred on the views, wishes and aspirations for

	<p>the future of the young person and that services and supports provided at the time of transition are both seamless and enable the young person to achieve greater independence. Ineffective transition planning can lead young people to ‘drop out’ and not access adult services (12, 16), others experience a deterioration in their health after a move to adult services and/or poorer quality services (12, 25). There is particular concern amongst paediatric health personnel that, for a group of young people with certain diseases, treatment expertise is lacking within adult health services (15, 26, 27). Provision of a range of more effective transition services covering health, social care, education and employment and planning mechanisms is a government priority (28, 29) but legislation and guidance are still evolving (5, 12). The aim is that young people with physical disabilities and chronic illnesses should receive effective, seamless transition services (28) that at least match those of their non-disabled peers, particularly as service transition adds to existing challenges of disability or chronic illness (26).</p>
<p>What does the research show?</p>	<p>Most research has been carried out into chronic conditions rather than physical disability. Individual research studies on transition often concentrate on specific conditions such as chronic arthritis (11), cystic fibrosis (14, 30), survivors of childhood cancer (31), juvenile idiopathic arthritis (10), diabetes (9, 32, 33), spina bifida (20, 34), cerebral palsy (19), chronic endocrine diseases (35) and epilepsy (15). A multi-method review to identify practices that promote continuity in transition has found that studies were largely descriptive (16), exploring the feelings and views of young disabled people themselves. Common themes identified in the transition to adulthood include: the apprehension of young disabled people as they approach and go through transition (33), the changing roles of families and carers (10) and difficulties in securing and keeping employment (22, 36) and in service transition include: the failure of different agencies to work and plan together (10, 34), and a recognition that transition is unique to the individual in terms of timescales (27, 36) and services needed (24, 27). Further research is particularly needed around the effectiveness of various transitional models (16), post-school outcomes and service satisfaction of users (37) and young people’s perceptions of what services should be offered and how they can be involved (36). Research around the role of a transition worker and teenage clinics is limited at present but might present a way forward in the future. A key element of research in this area is to give voice to the young people themselves in transition planning: this is included in the section on young people’s views below.</p>
<p>What are the implications?</p>	<p>Components of good practice for transition planning are likely to include: specific service provision (16) which is multidisciplinary (10, 12, 34), holistic (12), planned/anticipatory (35) and provides an element of continuity (16). Training for staff in transition planning and services is likely to be beneficial, particularly if they are motivated (38). Young people must be involved (34) and offered support (32, 36), choice (34) and information (4, 10, 36) in a confidential environment (36) to enable their involvement to be effective. This includes focusing on the young person’s strengths (16). The roles of carers and families will change during transition (10) even if they are still providing substantial levels of care (13, 32), they need to be involved, supported (13) and treated with sensitivity (12). The goal of transition planning must be to provide high quality services, offer choice and control to young people and maximise their education, training, employment and social opportunities (28).</p>
<p>What do I need to</p>	<ul style="list-style-type: none"> • Be aware of the provisions of the <i>Disability Discrimination Act</i> (1995),

<p>do?</p>	<p>particularly with regard to employment provisions and access to goods and services. See http://www.disability.gov.uk/dda/</p> <ul style="list-style-type: none"> • Be familiar with policies and services specific to young disabled people (such as the <i>Special Educational Needs Code of Practice</i> (2001), the <i>Learning and Skills Act</i> (2000) and the <i>Carers and Disabled Children Act</i> (2000)) and those directed towards young people in general (such as the <i>Quality Protects Programme</i> (1999) and the Connexions service). • Ensure that young people are at the centre of planning and participate in this process – this includes having their voice heard, individual assessments based on need, client-held transition documentation and transition to adult services taking place only when the young person is ready. (Refer to the innovative practice section of this briefing). • Develop links with supported and mainstream employment and education services, transition and adult health clinics, transport and housing providers and foster links between them, where necessary. • Ensure that young people receive free, independent support in making decisions including access to reliable and up-to-date information. • Recognise the importance of friendships, leisure activities and sexual relationships in young people’s lives. Support young people to build on already established networks of friends.
<p>Who can I contact?</p>	<ul style="list-style-type: none"> • Parent Partnership Service (based in Local Education Authorities) • Connexions – links to local services can be found at http://www.connexions.gov.uk/partnerships/index.cfm?CategoryID=8 • The Children and Young People’s Unit (developing an overarching strategy for all services for children and young people) within the Department for Education and Skills at http://www.cypu.gov.uk/
<p>Where can I find examples of innovative practice?</p>	<ul style="list-style-type: none"> • The SEN Regional Partnership (South West) has produced a number of guidance documents on transition planning. See: http://www.sw-special.co.uk/documents.html#Trans%20Plan • Great Ormond Street Hospital for Children has produced a factsheet on the transition from paediatric to adult cystic fibrosis services. See: http://www.ich.ucl.ac.uk/factsheets/services/cf_transition/index.html • Leeds Young Adult Team (Leeds West Primary Care Trust) has a website. See: http://www.leedsyat.nhs.uk/index.html • Southampton Council has developed a multi-agency transition policy for the move from children’s to adult’s services. See: http://www.communitycare.co.uk/articles/article.asp?liarticleid=27895&liSectionID=22&sKeys=Easing+the+pain+of+transition&liParentID=26 • London Borough of Waltham Forest has produced a comprehensive guide for young people and their parents to the transition process and issues such as health, education, independent living and advocacy, housing, finance and transport. See: http://www.lbwf.gov.uk/care/cf/cs103.pdf • Transition guides, produced by the US-based Institute for Community Inclusion, for professionals and young people/families can be downloaded at: http://www.communityinclusion.org/transition/ • The Family Fund has a website “<i>After 16 – what’s new?</i>” for school leavers with disabilities. See: http://www.after16.org.uk/ • “<i>Hurting into a Void</i>” by Jenny Morris covers the most important issues at transition and concentrates on quoting the voices and experiences of young disabled people. See a summary at:

	http://news.bbc.co.uk/1/hi/health/446891.stm
What are the views of users and users groups?	Young people commonly find that transition is a time of sadness (in breaking emotional ties with paediatric services) (15) and fear of an uncertain future (13, 15), such as a lack of social opportunities (17). Important issues for young people are gaining information about their condition (4, 33), being able to discuss their concerns in a confidential/private setting (9), gaining emotional support (4) and having hopes and dreams – their own home, a job, enjoyable leisure activities, a partner and maybe children (13). A formal transition programme can be beneficial in assisting the transition to adulthood and enabling disabled young people to recognise that there are different levels of independence (17). Young people also regard the existence of continuity of contact by people they can get to know and see regularly as essential (4, 9) and peer support and mentoring to help them cope with the uncertainties of adolescence. Consultation with a group of young people in Chesterfield revealed that the most important issues for them are developing practical experience and skills in order to be able to make informed choices, obtaining a range of information in different forms and from a number of sources, that transition planning is based on their strengths rather than their disability and that they have a say in the content of their transition plan.
Resource sites	<ul style="list-style-type: none"> • The Children’s National Service Framework website has a page of Useful Links at http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/fs/en • The Department for Education and Skills – Special Educational Needs web pages at http://www.dfes.gov.uk/sen/ • The Centre for Evidence Based Social Services – Transition Planning web page at http://www.ex.ac.uk/cebss/trans_planning.html • The Department of Health “<i>Integrated Children’s System</i>” has a list of resources on involving disabled children at http://www.children.doh.gov.uk/integratedchildrenssystem/involving2.htm • Search CareData freely available via the Electronic Library for Social Care • Search ASSIA
Comments	Please address all comments, suggestions or ideas for improvement to the ScHARR Library at scharlib@shef.ac.uk
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Australian randomised controlled trial of 108 GP's receiving an education programme on adolescent health with follow-up at 7 and 13 months.