

Transition to adult services for disabled young people and those with complex health needs

Patricia Sloper, Jennifer Beecham¹, Susan Clarke, Anita Franklin, Nicola Moran, Linda Cusworth

For many disabled young people², the process of moving from children's to adult services is problematic. Research has shown: problems in coordination of services and lack of multi-agency working; lack of information for young people and parents; insufficient attention to the concerns of the young person; and lack of appropriate services onto which young people can transfer. This research aimed to provide evidence of what works well in developing and implementing multi-agency coordinated transition services for these young people and their families. It also assessed the costs of the services.



Key findings

- A survey of all local authority areas in England identified 34 multi-agency transition services for disabled young people. There was considerable diversity in their structure, organisation, and funding arrangements, 23 had all three statutory agencies (health, education and social care) involved. On average, annual staffing costs were £220,000. Five services, encompassing different models of working, were selected for more detailed research.
- We looked at satisfaction with the service, parents' and young people's met and unmet needs, and effects on parental stress. These outcomes varied within and between the five services. The key factors associated with better outcomes were:
 - having a transition worker who supported the young person and parents
 - the family having a written transition plan
 - the manager of the transition service having strategic level involvement.

¹ Personal Social Services Research Unit, University of Kent

² For brevity we will use the term 'young people' throughout this publication to refer to disabled young people and those with complex health needs.

- Transition services were unlikely to reduce stress for the majority of the parents and over a third felt that contact with the transition service increased their stress. These problems were greatest where the factors noted above were not in place in the service the family received.
- Team costs varied between £22 and £52 per working hour. Based on parental reports of their contact with transition workers, and including transition workers non-contact activities, the average annual cost of transition support per family was £700 (2007-08 prices).
- High levels of unmet need were found in many areas of young people's lives, for example, leisure and social life, housing, career and employment opportunities, and planning future goals and aspirations.

Background

There is considerable evidence that for most disabled young people the process of transition from children's to adult services is problematic. These problems have been acknowledged in government policy and are highlighted in the *National Service Framework for Children, Young People and Maternity Services* (2004), *Improving the Life Chances of Disabled People* (2005), *A Transition Guide for All Services* (2007) and *Transition: Moving on Well* (2008), all of which promote the development of better coordination of services. Research points to problems in achieving a:

- coordinated approach to transition, including lack of multi-agency working
- lack of a holistic approach
- lack of information for young people and parents
- insufficient attention to the concerns of the young person
- lack of appropriate services onto which young people can transfer.

There is little evidence on which to build effective transition services, although Forbes and colleagues' review (2002)³ identified some of the essential components to success. Nor is much known about how transition services are currently provided and how they support disabled young people and their families, or at what cost.

This research aimed to provide evidence of what works in developing and implementing multi-agency coordinated transition services for disabled young people and those with complex health needs and their families:

- to investigate arrangements across local authority areas in England for multi-agency assessment for, planning of, and actual transfer from child to adult services for the young people
- to compare the implementation and operation of different models of transition services
- to assess outcomes for parents and young people arising from different models of transition services
- to investigate sources of funding and costs of transition services.

Findings

A survey of all local authorities in England, carried out in 2007-8, identified 34 multi-agency transition services for disabled young people. The majority had been set up within the last four years. There was considerable diversity in their structure, organisation, and funding arrangements. Twenty-three had all three statutory agencies (health, education and social care) involved, but in some areas, agencies were not consistent in their involvement.

Five services, encompassing different models of working, were selected for more detailed research. Key differences in the service models were between coordinating services, which supported generic workers working with disabled young people, and transition teams who had a designated role working solely on transition for disabled young people and providing direct support to the young people and their families. Both the survey and the case studies indicated that multi-agency transition services largely focused on young people with severe learning disabilities.

³ Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L. and Griffiths, P. (2002) *A Multi-Method Review to Identify Components of Practice Which May Promote Continuity in the Transition from Child to Adult Care for Young People with Chronic Illness or Disability*, Report for the National Coordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO), The Florence Nightingale School of Nursing and Midwifery, Kings College, London, URL: <http://www.sdo.lshtm.ac.uk/continuityofcare.htm>

Factors related to outcomes for young people and parents

The study explored outcomes for parents and young people relating to satisfaction with the service, parents' and young people's met and unmet needs, and impacts on parental stress. These outcomes varied between and within the five services. Box 1 shows the factors associated with better outcomes.

BOX 1

Key factors most strongly associated with better outcomes for young people and families:	Other characteristics of services associated with more positive outcomes for families:
<ul style="list-style-type: none">• having a transition worker who supported the young person and parents• the family having a written transition plan• the manager of the transition service having strategic level involvement.	<ul style="list-style-type: none">• transition workers setting up the adult care package for young people, negotiating funding for it and supporting them until they were settled in adult services• use of person-centred planning• having designated transition workers• having clarity on the role of the transition workers• having parents on the service's steering group.

Unmet needs

High levels of unmet need were found in many areas of young people's lives, for example, leisure and social life, housing, career and employment opportunities, and planning future goals and aspirations. In addition, transition services were unlikely to reduce stress for the majority of the parents and over a third felt that contact with the transition service increased their stress. These problems were greatest where the factors mentioned above were not in place in the service the family received.

Service issues

The research showed that dedicated multi-agency transition services could provide a valuable service for disabled young people and their parents and have a positive impact on meeting some of their needs. This was most likely to happen when transition workers worked directly with young people and families. Non-designated transition workers (that is, workers who work with some disabled young people in transition in addition their normal professional role) found that other aspects of their role often took precedence over their transition work.

The transition workers in this study often did not start working directly with young people until they were 16 years or over, and some of the services ceased to work with them at age 18 or 19. The workers felt that it would be valuable to start working with young people earlier and to continue to support young people until they were settled in adult services. However, staff shortages and lack of resources meant that this was not possible in most services. All five case study services had involvement from health, social care and education, but in some areas there was a lack of consistent involvement of all agencies. Staff attributed this in part to competing priorities and targets set by government for different services and limitations of different funding streams. These factors limited how resources could be used and prevented young people's needs being met in a holistic way.

Costs

A challenge to the economic component of this study was the unwillingness of transition services participating in the national survey and the case studies to provide data on expenditure, and indeed, some found it difficult to identify their full staff profile or the number of young people supported by the services. On average, annual staffing costs were £220,000 across the 12 teams that provided sufficient survey data, and their average cost per case was £1800 per annum. This figure assumes that each family on the reported caseload had received the same amount of transition support, and had received that support for the full year. Based on more detailed data from the five case studies, we found team costs varied in response to their staff profile; from £22 to £52 per working hour. To identify the way transition support varied between families we used parental reports of contact. Even when adjusted for staff reported non-contact activities, at £700 per annum the average cost was lower than that shown in the national survey.

Implications for policy and practice

Many multi-agency transition services for disabled young people are at an early stage in their development, and there is considerable variability in how they are being implemented. This study provides information on aspects of such services that are likely to have a positive impact on young people and families. It highlights the importance of properly resourced services that provide direct support to young people, provide timely and clear information and support young people until they are settled in adult services.

The findings indicate that information and good communication with young people and parents around transition are crucial parts of an effective service. This is in line with policy but is also an area where further development is needed. It is important that services facilitate young people's and parents' involvement in drawing up and reviewing transition plans, and that families have a record of all plans. Transition workers need time and training to be able to communicate and build a relationship with young people, and this should be a crucial part of a transition service.

Staff shortages and failure to replace staff who left caused problems in all five case study services, affecting the services' ability to support young people. It is important that these services are adequately staffed and systems are in place in all agencies to replace staff who leave. Services in which transition workers supported young people until they were settled in adult services were more likely to show positive effects. This model may help to ensure coordinated and timely funding decisions about adult care packages.

The study also points to the importance of a wide range of services in providing opportunities for disabled young people as they become adults. The current lack of such opportunities contributed to high levels of unmet need. Despite some positive findings about support from transition services, there were still substantial levels of unmet need, particularly around employment, housing and social and leisure activities, and in some areas access to further education college courses was problematic. It is important that transition services monitor unmet need and that this information reaches those with responsibility for commissioning. Transition service managers championing their services at strategic levels could help to ensure that the needs of disabled young people are better understood by the full range of services.

Both the survey and the case studies show that multi-agency transition services are largely focused on young people with severe learning disabilities. There is a need to extend such services so that young people with complex health needs and those with high functioning autistic spectrum conditions who do not have severe learning disabilities are able to receive coordinated multi-agency support.

A key area for policy is to reduce barriers to implementing a holistic multi-agency approach. Yet staff interviewed for this study reported that competing priorities and targets set by government for different services, and different constraints on the various funding streams, could limit the extent to which young people's needs were met. More recent policy initiatives, such as Individual Budgets for families with disabled children and *Total Place*, may help to address such problems.

More information on the cost and cost-effectiveness of transition services is needed to inform policy and practice. However, such studies are dependent on the willingness of services to release accurate information on their costs and activities.

Methods

The study used a mixed methods approach, gathering evidence from a variety of sources:

- A quantitative national survey of all local authorities in England to identify multi-agency transition services currently in operation, and their key features. From this survey, five differing models of services were selected for case studies.
- Qualitative interviews with 130 managers and staff in the five case study areas.
- A quantitative survey of parents and young people receiving the transition service, or having received the transition service during their recent transfer to adult services, in each of the five areas. This included measures of the respondents' perceptions of the effects of the service. 143 parents and 97 young people completed questionnaires. Multivariate analyses explored associations between variables relating to the characteristics of the services and outcomes for parents and young people, including unmet needs, satisfaction with the service, and impact on parental stress.
- Qualitative interviews with a small sample of parents and young people in six families who had made the transfer to adult services, exploring in more depth perceptions of the process and outcomes of the services they had received.
- Analysis of the costs of services and the support young people received.

This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

This publication should be cited as: Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. and Cusworth, L. (2011) Transition to adult services for disabled young people and those with complex health needs, *Research Works*, 2011-02, Social Policy Research Unit, University of York, York. Available to download from: <http://php.york.ac.uk/inst/spru/pubs/1903/>

The full report: Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. and Cusworth, L. (2010) *Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and costs*, Social Policy Research Unit, University of York, York. Available to download from: <http://php.york.ac.uk/inst/spru/pubs/1888/>



The Social Policy Research Unit is an independent research organisation at the University of York. Established in 1973, SPRU has an international reputation for excellence in key areas of social policy, especially health and social care, poverty, welfare and social work.

Its Director is Professor Gillian Parker.

SPRU is a winner of the Queen's Anniversary Prize for Further and Higher Education 2009.

For further information about SPRU visit our website at www.york.ac.uk/spru/

Social Policy Research Unit
The University of York, Heslington
York YO10 5DD, United Kingdom.
Telephone: +44 (0)1904 321950
Fax: +44 (0)1904 321953
E-mail: spru@york.ac.uk