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# Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and costs

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# Executive Summary

## Study aims

The research aimed to provide evidence of what works in developing and implementing multi-agency co-ordinated 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 young people with disabilities or complex health needs.
- To compare the implementation and operation of different models of transition services.
- To assess outcomes for parents and young people of provision of different models of transition services.
- To investigate sources of funding and costs of different models of transition services.

## Background

There is considerable evidence from descriptive research that for most disabled young people the process of transition from child to adult services is problematic. The problems in provision of appropriate services to support transition and in achieving positive outcomes for young people have been acknowledged in government policy and are highlighted in the NSF 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 a number of problems in achieving a coordinated approach to transition, including lack of multi-agency working; lack of an holistic approach; lack of information for young people and parents; insufficient attention to the concerns/priorities of the young person; and lack of appropriate services/provision onto which young people can transfer.

## Methods

The study used a mixed methods approach, gathering evidence from a variety of sources. These comprised: 1) A quantitative national survey to identify multi-agency transition services currently in operation in England, and their key features. From this survey, five differing models of services were selected for case studies. 2) Qualitative interviews with managers and staff in the five case study areas. 3) 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. 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. 4) Qualitative interviews with a sub-sample of parents and young people who had made the transfer to adult services, exploring in more depth perceptions of the process and outcomes of the services they had received. 5) Analysis of the costs of the services.

## Key findings

The survey, 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, 23 had all three statutory agencies (health, education and social care) involved. On average, annual staffing costs were £220,000 across 12 teams.

Five services, encompassing different models of working, were selected for more detailed research. Key differences between 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.

Outcomes for parents and young people varied between and within the five services. Key factors relating to better outcomes relating to satisfaction with the service, parents’ and young people’s met and unmet needs, and impacts on parental stress, were having a transition worker who supported the young person and parents; the family having a written transition plan; and the manager of the transition service having strategic level involvement.

Other characteristics of services were also associated with more positive outcomes for families. These were: 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; and having parental involvement in the service’s steering group.

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.

Team costs varied in response to the different staff profiles; varying between £22 and £52 per working hour. The mean cost per case, £1800 per annum, was similar when estimated from the national survey data and for these five case study sites.

## Results and relevance to policy

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 (i.e. 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, and it is important that they have protected time to undertake this work.

The findings indicate that, as policy emphasises, information and good communication with young people and parents around transition are crucial parts of an effective service, but 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.

The transition workers in this study often did not start working directly with young people until they were 16 years or over, and in 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, but staff shortages and lack of resources meant that this was not possible. Staffing issues were problematic to some extent in all five services, and it is important that these services are adequately staffed and systems are in place in all agencies which provide staff 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, and this model may help to ensure coordinated and timely funding decisions about adult care packages.

Despite some positive findings about support from transition services, there were still substantial levels of unmet need, particularly a lack of options around employment, housing and social and leisure activities, and in some areas there were difficulties in access to further education college courses. It is important that transition services monitor unmet need and that these data are fed through to those with responsibility for commissioning. The role of transition service managers in championing the services at strategic levels could help to ensure that the needs of disabled young people are recognised by the broader range of services.

Both the survey and the case studies indicated 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.

Although all five services had involvement from health, social care and education, there was a lack of consistent involvement of all agencies in some areas. This was attributed in part to competing priorities and targets set by government for different services and limitations of different funding streams which could militate against meeting young people's needs in a holistic way by limiting how resources could be used. More recent policy initiatives, such as Individual Budgets for families with disabled children and *Total Place,* may help to address these problems. A key area for policy is to reduce such barriers to a holistic multi-agency approach. The results concur with the recommendations in policies such as *Transition Moving on Well, A Transition Guide for All Services* and the developments promoted by the Transition Support Programme. However, they indicate that there is some way to go in implementing these policies in all local areas.

## Conclusions and further research

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 provide a more positive impact for young people and families, and 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. It also points to the importance of the wider range of services in providing opportunities for disabled young people as they develop into adulthood, and the lack of such opportunities at present which contributes to high levels of unmet need. More information on the cost and cost-effectiveness of transition services is needed to inform implementation. However, such studies are dependent on the willingness of services to release accurate information on their costs and activities.

The study was cross-sectional and research following young people over transition, including more in-depth research with young people, could help to further define good practice. In addition, further research is needed on the impact of transition services on other agencies, such as Youth Services and housing, and on models of support for young people who do not have a severe learning disability.

# Chapter 1 Introduction

There is considerable evidence from research that for most disabled young people or those with complex health needs the process of transition from child to adult services is problematic. The problems in provision of appropriate services to support transition, and in achieving positive outcomes for these groups of young people, have been acknowledged in government policy and guidance. Current policy developments and the growth of multi-agency working may lead to improvements in this situation. However, there is little research which can identify the components of models of good practice in transition services or the costs of such services. This research aims to address both these issues in order to inform good practice in services for disabled young people and their families at transition.

Transition is most often defined as the movement from childhood into adulthood and is a time of considerable psychological and social change. It can also be a difficult and challenging time for young people and their families. For disabled young people or those with a chronic illness, transition can be made more difficult because it is often accompanied by significant changes in their care needs and in service provision, and they will transfer from children's to adult services.

Whilst transition is often discussed in terms of transfer of responsibility from children's to adult services in health, social care and education, it is important to recognise that for the young person, the transition to adulthood also encompasses a range of different processes. These include, for example, leaving home, entering further education and employment, taking more responsibility for their own health, nutrition and finances and establishing themselves as autonomous individuals. It is important that transition is addressed in parallel with the young person's physical, social and psychological growth and development. It is clear therefore that supporting transition to adulthood for disabled young people requires an ongoing multi-agency approach which can address these different aspects of the young person's life.

## 1.1 Policy

The problems in provision of appropriate services to support transition and in achieving positive outcomes for young people have been acknowledged in government policy and guidance (Department for Education and Employment, 2000; Department of Health, 2001; Department for Education and Skills, 2004; Department for Education and Skills, 2005). A number of measures have been taken to address these, including the provision of personal advisors (PAs) through Connexions Services (Department for Education and Employment, 2000) to support young people through transition, with special educational needs PAs having a specific remit to support disabled young people through transition. The Learning and Skills Act (2000) required Connexions Services to undertake an assessment of any young person with learning difficulties and disabilities in the final year of compulsory schooling or when leaving sixth form provision (now contained in the Education and Skills Act 2008 section 139). In 2001, the *Special Educational Needs Code of Practice* (Department for Education and Skills, 2001), which supports the Special Educational Needs and Disability Act 2001, set out specific requirements for transition planning, including that young people of the age 14 and over who have a Statement of Special Educational Needs (SEN) should have a transition plan. Connexions PAs have a responsibility to attend the school Year 9 transition review and to coordinate and oversee delivery of the transition plan. In addition, Children's Social Care have a responsibility to ensure that a social worker attends the Year 9 review meeting and contributes to the transition plan for a 'child in need' (the definition of which includes disabled children).

Further measures to address problems of transition are contained in the *National Service Framework (NSF) for Children, Young People and Maternity Services* (Department of Health/Department for Education and Skills, 2004), in which Standard 4 specifically focuses on the need for age-appropriate services for young people as they grow into adulthood and Standard 8 recommends that:

- Local agencies set up a multi-agency transition group to take responsibility for overseeing arrangements for transition for disabled young people.
- Transition planning focuses on the meeting the hopes, aspirations and potential of disabled young people, including maximising education, training and employment opportunities, social relationships and independent living.
- Transition planning takes a person-centred approach.
- Young people aged 16 and above are supported to use direct payments.
- Specific arrangements are made for managing transition for young people with high levels of need, those living away from home, and those with rare conditions.
- Agencies develop local strategies to widen education, training and employment opportunities.
- Health services develop appropriate adolescent/young people's services to enable smooth transition to comprehensive adult multi-disciplinary care.

Similarly, *Improving the Life Chances of Disabled People* (Cabinet Office, 2005*)* highlights the problems around transition and the lack of evidence on what works, for whom and in what circumstances. It proposes better mechanisms for facilitating smooth transitions: integrated working to promote continuity, better support for families and personalised services. The government has placed transition high on its agenda in the *Aiming High for Disabled Children* programme (HM Treasury and Department for Education and Skills, 2007), and has demonstrated commitment to improving transition for disabled young people by allocating £19 million in the comprehensive spending review for a Transition Support Programme. The programme aims 'to help disabled young people and their families benefit from intensive, coordinated support and person centred planning' (p.7).

Other policy-driven developments also suggest improvements to services for disabled young people in recent years. In particular, the concept of person-centred planning promoted for people with learning disabilities by *Valuing People* (Department of Health, 2001), the growth of key worker services, and the use of direct payments all have the potential to engender more co-ordinated and young people centred transition services. More recently, three government departments (Health, Work and Pensions, and Children, Schools and Families) have set out a five-year joint strategy on the role of further education and training in supporting people with learning difficulties or disabilities to achieve the education they want and have the opportunity to fulfil their aspirations for adult life, including aspirations for employment and independent living (*Progression through Partnership,* HM Government, 2007). Unlike *Valuing People* which focuses on learning disability, this strategy covers the whole spectrum of disability, including people with mental health problems, autistic spectrum conditions, dyslexia, ADHD, physical, sensory and cognitive impairments, serious long-term illness, and any special educational needs that may or may not have led to identification at school under the SEN code of practice. As with other policies, this strategy, although focused mainly on further education and training, highlights the importance of a holistic approach, multi-agency working, early transition planning which then continues throughout college/FE/HE, and a person centred approach.

As noted above, there is a statutory requirement to plan properly for transition. There is also considerable information focusing on good practice guidelines. This includes new guidance under the *Every Child Matters* programme on transition for young people with long-term conditions moving from child to adult health services (Department of Health, 2006) and the transition care pathway for young people with life-threatening and life-limiting conditions (The Association for Children’s Palliative Care, 2007). The Department for Children, Schools and Families and Department of Health in collaboration with the Council for Disabled Children (CDC) have produced *A Transition Guide for All Services* (2007). This highlights the responsibilities of all agencies, provides an overview of legislation and guidance and provides examples of practice.

Since this project started in 2007, further developments and guidance have focused on transition. In 2008, the Department of Health and Department for Children, Schools and Families produced guidance for health professionals and their partners on transition planning for young people with complex health needs and disabilities. The National Transition Support Team for the Transition Support Programme (www.transitionsupportprogramme.org.uk) is now operational and between 2008 and

2011 is providing support, including funding and regional advisers, information, regional hubs and networking, to help local areas to improve practice. As part of the programme, the Transition Information Network (TIN) provides a useful signpost to resources and information (www.transitioninfonetwork.org.uk).

*Valuing People Now (*HM Government, 2009), building on the 2001 *Valuing People* strategy, is a new cross-government strategy for people with learning disabilities, including those with complex needs. The document acknowledges that although *Valuing People* has resulted in improvements in services for people with learning disabilities, services have not specifically addressed the needs of some groups of people who have learning disabilities. These include people with complex needs, people from black and minority ethnic groups, people with autistic spectrum conditions, and people who have offended. In addition, the impact of person centred approaches has been limited to relatively few people, and there has been little work on involving people with complex needs in person centred planning. The new three-year strategy aims for all people with learning disabilities to have personalised support and care plans, and better healthcare and health, and for more people to live in their own homes, have jobs, and live in their home community. This strategy is clear that these requirements will apply to young people in transition. In addition, the focus of the cross-government *Getting a Life* programme (www.gettingalife.org.uk) is initially on transition, and multi-agency teams in ten demonstration sites are working with young people aged 14-25 with severe learning disabilities to help them achieve paid employment and full lives. This is a three-year programme running from 2008 to 2011.

In 2009, Individual Budgets, which have been piloted and evaluated in adult services (Glendinning *et al*., 2008), are being introduced in a pilot with families with disabled children  and young people in six areas, with four of these focusing on transition. The Individual Budgets programme aims to give people a greater say in the assessment of their needs, and greater flexibility, choice and control in using resources to meet individual needs and priorities.

Although these newer developments will not have had time to impact on the experiences of the families in this research study (as the fieldwork was carried out between 2007 and early 2009), they clearly indicate the importance that is attached to having effective multi-agency transition services which address the aspirations of young disabled people and their families in a holistic and person centred way. However, so far there is little formal evidence on the effects of pre-2007 policy developments, such as the NSF, on transition.

## 1.2 Research evidence

### 1.2.1 Problems with transition

Despite the importance of transition, there is considerable evidence from descriptive research that for most disabled young people the process of transition from child to adult services is problematic (for example, CSCI, 2007; Cope, 2003; Hendey and Pascall, 2002; Morris, 1999, 2002; Hirst and Baldwin, 1994). Many young people and their families experience difficulty in gaining the health and social support required. This can have a negative impact on, for example, their longer-term health and social well-being. The experience of transition has been described by young people and parents using words such as ‘abandonment’ or a ‘nightmare’ (Fiorentino *et al.,* 1998; CSCI, 2007).

Research points to a number of problems in achieving a coordinated approach to transition: lack of multi-agency working; lack of a holistic approach; lack of specialist transition services and workers; lack of information for young people and parents; lack of user-involvement in the planning process; insufficient attention paid to the concerns and priorities of the young person and lack of appropriate service/provision onto which the young person can transfer (Cope, 2003; Dean, 2003; Forbes *et al*., 2002; Heslop *et al*., 2002; Morris, 1999, 2002; Fiorentino *et al.,* 1998; O’Sullivan, 1998; Pownceby *et al*., 1997). These problems are by no means unique to the UK, for example research in Australia and the US also points to similar problems, including fragmentation of services and limited involvement of young people and parents in transition planning (Ankeny *et al*., 2009; Winn and Hay, 2009; Powers *et al*., 2007).

Heslop *et al*. (2002) in their survey of 283 families of young people with learning difficulties found that one-fifth left school without a transition plan and nearly a quarter of young people were not involved in their transition planning at all. They also identified a discrepancy between issues that families wanted to address and those which were actually covered during any transition planning. Information on leisure and social opportunities, benefits, future housing opportunities, independent living skills, adult sexuality and relationships, further education and careers opportunities would have been beneficial but did not always feature highly. In addition, concerns that inhibited the move to greater independence were raised by young people and families, these included personal safety and risk, financial matters and transport issues. These were inadequately addressed in the transition process. Heslop *et al*. (2002) highlight two factors contributing to a lack of young people's involvement. Firstly, difficulties with facilitating young people’s involvement and lack of independent advocacy and secondly, a lack of real choices and options. This study was carried out prior to the 2001 SEN Code of Practice that set out requirements for transition planning, but later research with young people with SEN or learning disabilities also points to problems with young people's and parents' involvement in transition planning; lack of real choices and support for young people in making decisions about the future; failure of plans to address issues important to the young person and family; lack of coordination between services; plans being established too late and, in some cases, lack of awareness of any transition planning taking place (for example, Kaehne and Beyer, 2008; CSCI, 2007; Hudson, 2006; Dewson *et al*., 2004). Kirk (2008) found that young people with complex health needs also experienced a lack of involvement in, and information about, transition planning, both with regard to transfer to adult health services and to transfers from children's to adult services more generally. Those trying to negotiate multi-agency transitions referred to being 'in limbo', being confused by the differing age points for transfer for different services and uncertain about where to find support.

Heslop *et al.* (2007) highlight the problems concerning transition for young people with learning difficulties living away from home at an ‘out of area’ residential school or college (i.e. those placed outside their own local authority boundary). These young people are likely to be at greater risk of poor transition planning and outcomes because of the distance between their ‘home’ local authority and that which ‘hosts’ them. Supporting good, ongoing relationships between the young person and their family can also be problematic. In a study by McGill *et al*. (2006) of 73 parents whose children had learning disabilities and challenging behaviour and attended 52 week residential schools, 75 per cent of parents reported being ‘extremely worried’ about the availability of suitable, future services for their child. The mean age of the children was 15.2 years, with 86 per cent being 13 years and over, and parents typically wanted their child to live closer to them when they left the schools, yet they reported a lack of local planning for the child's future. These conclusions support the earlier findings of, for example, Pinney (2005), Abbott *et al*. (2000, 2001), Grove and Giraud-Saunders (2002). Heslop *et al.* (2007) suggest that there is often confusion or lack of knowledge by services involved about their roles and responsibilities. This has been addressed in the DCSF/DH transition guide published in 2007, which helpfully defines the roles of different agencies and professionals in the transition process. However, there is as yet no evidence on any impacts of this on transition for young people in out of area placements.

Underlying the challenges to positive transitions are shortfalls in the provision of adolescent and adult services. Research has found a substantial reduction in medical care and therapies for young people with physical disabilities (Fiorentino *et al*., 1998), widespread unmet need for equipment services (Audit Commission, 2000, 2002), paucity of post-school provision (Dee and Bryers, 2003) and shortages of accessible housing and supported employment (Morris, 1999, 2002). Parents play a key role in the outcome of transition (Hendey and Pascall, 2002; Morris, 2002; Pownceby *et al.,* 1997) yet evidence with regard to good practice in support of parents and carers is very limited (Forbes *et al.,* 2002; Heslop *et al.,* 2002; Pownceby *et al*., 1997).

Furthermore an arbitrary age point of transition assumes that chronological age alone indicates a readiness for transfer which may disregard the complexity of adolescent development and individual needs. Added complexity is produced by different services having different age points for transition to adult services. In education and in the remit of Connexions, there can be two key points of transition: from 16 into post-16 learning provision, and at the age of 18-19 the moves into adult social care services and the world of work or further college placements. Transition to adult health care can be at different ages depending on the young person's condition and the approach of different local services. However, the common thread for all agencies is that policy and guidance states that transition planning should begin at the latest by the age of 13-14 (Year 9) (for example, Department of Health/ Department for Children, Schools and Families, 2007, 2008). Against this backdrop is a changing population whereby increasing numbers of children with life-limiting and/or life threatening conditions are surviving into adulthood (While *et al*., 1996). There is also an increase in the prevalence of chronic diseases which emerge in childhood (for example, diabetes) and in children with a number of different impairments or conditions who require lifelong care (Morris, 1999; Betts *et al*., 1996). As noted in the *Moving on Well* guidance (Department of Health/Department for Children, Schools and Families 2008), adult services will need to plan and tailor services to accommodate the needs of this emerging group as they transfer from children’s services.

### 1.2.2 Outcomes

A ‘poor transition’ is likely to lead to reduced support. One study of 14 disabled young people during transition found substantial differences between the needs assessed and the services provided (Ko and McEnery, 2004). For the total sample, the need for 49 potential referrals to adult specialist services was identified, but 17 were not made as such services did not exist, in contrast to what had been available within paediatric services. Adult physiotherapy and occupational therapy services were particularly under-provided for young people with physical disabilities.

Hirst and Baldwin (1994) compared the outcomes on reaching adulthood for young disabled people and their non-disabled peers. They found young disabled people were less likely to have achieved employment, control of finances, moved out of the family home and to have the skills necessary for independent living. More recent research features young disabled people describing leaving the education system as a time of loneliness, with minimal contact with peers and few opportunities to engage in meaningful activities for personal development (Heslop *et al*., 2002; Morris, 1999; O’Sullivan 1998). Studies of adult outcomes for young people with autistic spectrum conditions suggest that very few adults are in paid employment, or have friends or intimate relationships (Rosenblatt, 2008; Reid, 2007; Howlin *et al*., 2004; Howlin, 2000). Burchardt (2005) analysed data from longitudinal cohort studies of young people who were aged 16/17 in 1986, 1998 and 2000 to compare aspirations and outcomes for non-disabled young people and those with physical or sensory impairments or mental health problems. The study found that although disabled and non-disabled young people held similar aspirations for post-16 education and employment, their experiences in early adulthood differed considerably. Disabled young people were less likely to attain their aspirations for education or employment: for example, they were nearly four times as likely to be unemployed at age 26, and for those who were employed their earnings were 11 per cent lower than those of their non-disabled peers with the same levels of qualifications. Aston *et al.* (2005) report a longitudinal study of post-16 transitions for young people with SEN. At age 19-20, disabled young people were more likely to still be in education and less likely to be in employment than those with behavioural, emotional or social development needs, and those with cognitive and learning difficulties were most likely to be NEET (not in education or employment).

These findings are also reflected in the international literature, where research to date has indicated that young people with disabilities and complex health needs have poorer outcomes of transition than their non-disabled peers in fields such as interpersonal relationships, academic achievement, social life and community participation, employment and health status (for example, Stewart *et al.,* 2007; Wagner *et al.,* 2005;).

These unmet needs may have prolonged and cumulative consequences for the young people’s education attainment, health and welfare, and costs to the economy. Godfrey *et al.* (2002), for example, calculated that the average per capita additional costs over a life time are £52,000 of Not Being in Employment, Education or Training (NEET) between the ages of 16 and 18. Many disabled young people may be in this group, for example, only 15 per cent of adults with autism are in full-time paid employment (Reid 2007). Knapp *et al.* (2008) calculated the costs to the economy of disabled people's unsuccessful transitions which do not enable them to achieve the educational or employment goals to which they aspire. These costs are substantial, for example losses in direct and indirect tax revenue and national insurance contributions when comparing actual and potential earnings (potential being earnings of non-disabled people with equivalent qualifications) are £76 per week for employed disabled males, and £128 for unemployed disabled males (2005-2006 prices).

As noted above, a number of studies have noted that parents play a key role in transition. The time of transition has also been shown to be one of the most stressful periods for parents, with difficulties experienced around coordination, availability, sufficiency and appropriateness of services; issues of dependence and independence; behavioural problems of young people; and concerns about their disabled son or daughter's vulnerability and well-being (Turnbull *et al.,* 1986; Wikler, 1986; Blacher, 2001; Rapanaro *et al.,* 2007). Such difficulties have negative impacts on parents, including impacts on emotional well-being, stress and burnout; pressures on time and financial resources; loss of freedom and independence; effects on family relationships; and loss of social networks (Rapanaro *et al*., 2007). However, parents in Rapanaro *et al.'s* study also reported some positive effects, including personal growth and increased assertiveness; a greater understanding of their child's needs and abilities; formation of new social networks for both themselves and their son/daughter; and increased maturity and confidence, and new coping skills for their son/daughter. There is little information on what can facilitate better outcomes for parents at transition. Good practice in supporting parents, for instance in timely, comprehensive and accurate information and parental involvement in transition planning, sensitivity to parents' role in the transition process, and provision of key workers could help to tip the balance from negative to positive effects for parents.

### 1.2.3 Effective transition services

Forbes *et al.* (2002) reviewed evidence on effectiveness of practice in continuity of care at transition focusing on five conditions: diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy. They found a paucity of high quality research. However, they found moderate evidence in support of a number of features of services as benefiting transition.

In relation to the **structures** of services these included:

- transition workers and transition teams in order to plan transitional care, connect between child and adult services, identify co-ordinated packages of care and facilitate greater co-operation and liaison between service providers;
- transitional services such as an adolescent health service to provide a bridge between child and adult services and prepare the young person and their family for adult life and probably responsibility for the care and management of their condition;
- formal intra and inter-agency liaison and agreements, for example, to foster improved communication, co-operation or collaboration;
- frameworks for fostering accessibility of services so that services are easily identifiable and that young people from different cultural backgrounds, or with particular health problems, are not disadvantaged.

Components for the **process** of transition included:

- preparation for transition including early planning;
- a systematic approach to managing the transition process, including multi-agency holistic assessment, care planning and review to identify readiness for transition, ongoing care needs and the young person's psychosocial development;
- active involvement of young people and their families;

- provision of information for both young people and parent/carers;
- advocacy to address differential power relationships and enable young people to express and take responsibility for their own needs;
- opportunities to visit future provision and meet adult providers;
- flexibility regarding the point of transfer;
- regular audit of services and case management approaches.

Positive features of **practice** for young people included:

- the development of independent living skills and self determination;
- support for personal growth and development;
- the involvement of young people in developing services;
- peer support;
- support for changed relationships with parents/carers;
- provision of choice and information;
- focusing on young people's strengths for future development.

Components of effective practice for parents/carers included:

- support for adjustment to a changed relationship with their child as they begin to 'let go' and allow their child greater responsibility;
- parental involvement in service planning;
- a family centred approach;
- the provision of information.

Furthermore, the conclusions of others (see for example, Heslop *et al*., 2007; King *et al.,* 2005; Ward *et al*., 2003; Bent *et al.,* 2002; Heslop *et al.,* 2002), are very much in line with Forbes *et al*. For example, Heslop *et al*. (2002) identify the five C's for a good transition experience: communication, co-ordination, comprehensiveness, continuity and choice:

*Communication*: which is open, honest and respectful between agencies and between agencies and families; independent advocacy for young people.

*Co-ordination*: effective interagency working, joint training initiatives, joint assessment procedures and a cohesive strategic approach to service provision.

*Comprehensiveness*: an effective transition plan for all young people; appropriate ethnicity and disability equality training for all staff; expectation that young people with learning difficulties will have access to the same opportunities to realise their aspirations as their peers.

*Continuity*: key workers to support individual young people and their families throughout the transition process; a seamless transition from children's to adult services; a range of options for young people to move into and between.

*Choice*: more and better involvement of young people and their families in the transition process; access to appropriate information on potential options; development of a range of local post-school alternatives in housing and employment.

A recent examination by the Commission for Social Care Inspection (2007) identified some progress being made in the areas of:

- planning with young people focusing on their aspirations and ambitions;
- improved co-ordination between social care, education, health, housing and other services to ensure a smoother, timely transition;
- planning ahead and commissioning the range and diversity of services needed for young people with complex needs.

However, the report concludes that good practice is not happening everywhere and that 'inadequate commissioning, poor co-ordination of services and a failure to properly plan with young people and their families are resulting in anxiety, delays, multiple assessments and confusion' (page vi). In line with previous literature, the report states that the six prerequisites for transition are: commitment, involvement of young people and families, effective strategic planning and commissioning of appropriate services, a multi-agency approach and regular monitoring of outcomes.

A large body of research has identified problems in the coordination of services for disabled children and young people and their families, and as noted earlier, these problems are particularly apparent during transition, when the need for multi-agency involvement includes both children's and adult services. Research suggests that well functioning multi-agency key worker services can relieve stress for families (Sloper *et al*., 2006; Liabo *et al.*, 2001), and Forbes *et al*. (2002) suggest that similar models with transition workers or teams may be an important part of successful transition services. Sloper *et al.* (2006) found that certain aspects of multi-agency key worker services were related to better outcomes for families: these were regular training, supervision and peer support for key workers; having a designated service manager and a clear job description for key workers; key workers carrying out more aspects of the key worker role; and families having appropriate amounts of contact with key workers.

The role of Connexions PAs in coordinating support is important in this context but there is little research to substantiate this. Work by Grove and Giraud-Saunders (2002, 2003) suggested that while the role of the Connexions PA is well placed to facilitate co-ordinated services and provide advice, information and support to young people, there were difficulties due to PAs' lack of specific skills and expertise in disability and insufficiency in the number of PAs. Rowland-Crosby *et al.* (2004), in a study of Connexions services in five areas, found that the service was of value to disabled young people and there were examples of good practice in services working together to support young people. However, they found that the role was often not clear to disabled young people and families, and that the service needed to do more to include parents and carers. They also point to large caseloads and lack of time, along with lack of training and skills in communication and training about autism or mental health problems, as factors impeding the ability of PAs to get to know young people well enough to help them make decisions. More general issues limiting the role of the service in supporting disabled young people included difficulties in multi-agency working and information sharing; lack of a single framework for planning, assessment and reviewing resulting in none of the areas having a single transition plan for a young person; variability in knowledge of, and lack of engagement with, person centred planning; and difficulties and variability in the quality of information from schools and LEAs. The study also found that some national policy priorities hampered opportunities for disabled young people. A key outcome for Connexions is to reduce the number of young people who are NEET, but this would not include many disabled young people, especially those with severe disabilities. In addition, the focus in colleges on a desired outcome of a level 2 qualification excluded many disabled young people who would be unable to attain this.

Tarleton and Ward (2005) investigated the information needs of young people with learning disabilities, their parents and supporters at transition and highlighted the aspects of transition that services need to address in information for young people and families. Besides general information about the transition process, 14 categories of information needs were identified. These were: work, college, where to live, money, friends, sex and relationships, safety, being in charge of your life, living independently, healthy living, having fun, music, sport and helping others. Information was needed to help families deal with the changes occurring and the impact they might have on family relationships, in particular issues such as increased independence, safety and risk.

A study by Cameron and Murphy (2002) illustrated how young people with learning disabilities and communication impairments can be fully involved and make choices during their transition planning. Using ‘Talking Mats’ (a light-technology augmentative framework), young adults indicated their likes and dislikes and expressed views previously unknown to their carers.

Person centred planning (PCP), which is a key element of policy for people with learning disabilities, has the potential to facilitate many aspects of good practice that are suggested above: by involving the young person more effectively in transition planning, by focusing on the young person's aspirations and development needs, by promoting family involvement, and by promoting collaboration and problem solving between agencies (Michaels and Ferrara, 2006). As yet, only a few studies have looked at the impact of PCP, the largest and most detailed being that of Robertson *et al.* (2005). They carried out an evaluation of the impact of PCP for 93 adults with learning disability aged 16-86 in four areas in England. The study followed the implementation of PCP in the sites for two years. Results indicated positive changes for those receiving PCP in: social networks, contact with family, contact with friends, community involvement, increased scheduled day activities, and increased choice. These results are extremely encouraging, but the study also found that impact varied across different areas of quality of life, and in different contexts. For example, PCP appeared to have no impact on employment, physical activity, and inclusive social networks. In addition, implementation was patchy, with only 65 of the 93 participants receiving a PCP within the two years of the study. Results indicate inequities in access to PCP, with certain groups of people being less likely to receive a plan: people with autism, people with mental health or emotional or behavioural problems, people with health problems and those with restricted mobility. Analysis of the factors related to having or not having a plan (Roberts *et al.,* 2007) showed that having a key worker at the start of the study was associated with increased likelihood of having a PCP. This suggests that more person-centred ways of working prior to the introduction of PCP were important in its implementation. Similarly, commitment of facilitators to PCP was also associated with likelihood of having a plan. There were also differences in impact of PCPs between different groups: people with mental health or emotional or behavioural problems were less likely to experience benefits when they did have a plan.

The recent CSCI study (2007) focused specifically on transition and also found that implementation of PCP was patchy, with only half of the professionals and managers interviewed saying that PCP was 'well-used' at transition, and social workers feeling that they lacked training in PCP and that there were not sufficient funds to commission independent organisations to carry out PCP.

### 1.2.4 Gaps in research evidence

Beresford’s (2004) review of the literature on transition concluded that there is limited evidence on what works to ensure smooth transition and positive outcomes for young people. However, what the evidence does show is the kind of support and service structures and processes needed to ensure a positive transition. Young people and their families have expressed many times what would constitute good practice. Beresford argues that research now needs to turn towards examining specific services and/or evaluating models of services, as well as holistic longitudinal studies to provide evidence on outcomes for disabled young people. Likewise, Forbes *et al*. (2002) recommend that further research should refine and explore the components of practice and models of promoting continuity in transition. In addition, the evidence base around the costs of supporting young people during transition, or the cost-effectiveness of different ways of providing this support is almost non-existent (Knapp *et al*., 2006). New developments in Individual Budgets for families with disabled children could also have an impact on the choices and support available to young people in transition, and results of the evaluation in the four pilot areas focusing on transition should add to knowledge on the value of this approach.

In conclusion, as Beresford (2004) argues, transition should not been seen as a means by which an individual is moved from one service to another. Rather it should be seen as a way to enable and support a young person to move towards a new stage in their life. This requires services to plan, work and develop together. Despite a lack of research, anecdotal evidence suggests that many services are making improvements and hopefully the priority given to transition in policy will make a difference.

## 1.3 Evaluating the impact of transition services

Building on the existing research evidence this research aimed to examine models of multi-agency services for transition.

Specific aims of the research were:

- To investigate arrangements across local authority area in England for multi-agency assessment for, planning of and actual transfer from child to adult services for young people with disabilities or complex health needs.
- To compare the implementation and operation of different models of transition services.
- To assess outcomes for parents and young people of provision of different models of transition services.
- To investigate sources of funding and costs of different models of transition services.

The objectives of the research were:

- To describe current arrangements for planning for and supporting transition to adult services in local authority areas in England.
- To identify the features of the services that contribute to improved transition for disabled young people.
- To inform standards of good practice in services for disabled young people and their families at transition.

In meeting these aims, the research set out to investigate the outcomes for families of the transition services and the specific characteristics of such services that were related to better or poorer outcomes. As the aim was to investigate multi-agency services which had transition teams and/or workers providing support for disabled young people and those with complex health needs and their families, part of the process was defined in advance – the study was not concerned with services that were not multi-agency and did not have transition teams or workers. However, even within these constraints there was likely to be considerable diversity in models of service and service processes.

Evaluating the outcomes of multi-agency services, which show considerable local variation in structures and processes, is complex (El Ansari *et al.,* 2001). The many and diverse factors that may contribute to the effectiveness of the process of multi-agency working are not easy to measure, but some assessment of these factors is vital if research is to answer questions about whether a service has a positive impact on young people and families, and also how it works. Evaluation needs to explore the mechanisms by which a service produces positive outcomes (or not) and the context (circumstances of the service and of recipients) in which these mechanisms operate to produce these outcomes, or ‘what works for whom and in what circumstances’ (Pawson and Tilley, 1997). The concept of an outcome also has a number of different meanings. Nocon and Qureshi (1996), distinguish between 'intermediate outcomes', such as the delivery of a particular service or effects on the knowledge and practice of professionals, 'process outcomes' that is the effects of the *way* in which the service is delivered on users, and the impact on users of the service, such as changes in well-being – sometimes termed 'distal outcomes' (El Ansari *et al*., 2001). Although intermediate outcomes are important and can help to explain the mechanisms by which the service impacts on users, they are not sufficient measures of effectiveness. In order to gain a picture of these different levels of outcomes, it is important that evaluation obtains the views of the different stakeholders in the services on the extent to which the services meet their desired objectives and the appropriateness of the service to the needs of users (Glendinning, 2002). As well as exploring outcomes, Glendinning notes that evaluation of multi-agency services should also look at efficiency, that is the relationship between costs and benefits.

Previous research, described above, on the experiences of disabled young people and their families around transition and existing studies of aspects of transition services, provides information to help define outcomes to be measured when comparing models of transition services. For example, questions about intermediate outcomes are: Does the service lead to better coordinated care for disabled young people and their families, and better relationships with services? Does the service facilitate early planning for transition? Does the service lead to better information provision for young people and families? Questions about impact on families are: Does the service result in fewer unmet needs for parents or young people? Does the service impact on parent stress? In order to understand the context in which these outcomes are produced detailed information about the services and the processes which affect them is needed.

These considerations lead to a mixed methods approach, gathering evidence from a variety of sources. Quantitative measures can provide information on some outcomes, but qualitative methods are required to explore some of the processes that may be important in producing such outcomes. A number of authors now advocate such a mixed methods approach to bring new insights in the study of joint working (for example, Popay and Williams, 1998; El Ansari *et al*., 2001).

The current project adopted a mixed method five-stage approach to the evaluation of models of transition services. These stages represent collection of different types of data and data from different categories of respondents:

- Stage One was a quantitative national survey to identify multi-agency transition services currently in operation in England, and their key features. From this survey, five differing models of services were selected for case studies.
- Stage Two comprised qualitative interviews with staff in the case study areas (transition workers/teams, service managers, members of multi-agency steering groups, and managers and practitioners in relevant services, including schools and colleges, who worked with the transition services).
- Stage Three was 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 survey included measures of the respondents' perceptions of the effects of the service.
- Stage Four comprised qualitative interviews with a sub-sample of parents and young people who had made the transfer to adult services, exploring in more depth perceptions of the process and outcomes of the services they had received.
- Stage Five analysed the costs of providing the services.

# Chapter 2 Research Design and Methodology

As noted above, a mixed methods approach was adopted in order to address the aims of the study. This chapter describes the methods used during the different stages of the project.

Ethical approval for the research was obtained from a Multi-centre Research Ethics Committee, and research governance approval was obtained from local R&D Committees in case study sites.

## 2.1 Stage One: Survey of local authorities transition services

A survey of all local authorities in England (n= 150) was undertaken, in the autumn of 2007, to determine which areas had arrangements for multi-agency assessment for, planning of and actual transfer from child to adult services for young people with disabilities or complex health needs.

In order to maximise response to the survey, a short one-sided screening questionnaire was initially sent to all Directors of Children's Services, asking whether there was a multi-agency transition service and if so, the name of the person to whom a more detailed questionnaire about the service could be sent. This strategy has been used in other studies carried out by SPRU and has resulted in good response rates (for example, Greco *et al*., 2005; Franklin and Sloper, 2006). Following this a detailed questionnaire was sent to the named contact, usually the Transition Manager or Service Manager for Disabled Children and Young People or Service Manager in Adult Learning Disabilities.

### 2.1.1 Content of survey

The detailed questionnaire included questions about partner agencies and organisations involved in the service; any formal links outside partner agencies, for example, with mental health services, benefits, employment, housing and leisure services; sources of funding; management of the service; existence of transition workers; their professional background and organisations from which they are drawn; transition teams and their membership and structure; arrangements for training and supervision of workers/teams; arrangements for assessment, care planning and review; involvement of young people and families; length of time the service has been in operation; eligibility criteria and age range of young people who receive the service, and case loads of workers/teams.

As there is so little information about how much it might cost to provide a transition service, the survey included questions that would allow an estimation of the costs of providing these services. Questions mirror the ‘nested’ approach taken in this and other service-led cost research (for example, Greco *et al.,* 2005; Beecham *et al.,* 2003) to ensure that even where services cannot provide the ideal data, enough quantitative information is provided to calculate closest approximations to long-run marginal opportunity costs (Beecham 2000).

### 2.1.2 Response rates

One hundred and five (70 per cent) authorities responded to the screening questionnaire (after one reminder). Fifty stated that they did not have a multi-agency transition service, of these 11 could be identified as being in development although this detail was not specifically asked for. Fifty-five reported having a multi-agency transition service, of which 50 were willing to complete the detailed questionnaire on the subject.

Detailed questionnaires were then sent to these 50 services. After a number of reminders and further investigation through discussions and correspondence with the services, it became clear that of the 50 who had received a detailed questionnaire, a number of services were indeed not multi-agency or were only in development. Despite the fact that the questionnaire had been piloted with three services, difficulties appear to have emerged in terms of the interpretation of ‘multi-agency’, ‘transition service’ or ‘transition worker’. For example, one service described themselves as multi-agency as their children’s and adults’ social care services were working together on transition but no other agencies were involved; another service did not consider that they provided a transition service as their transition worker did not work directly with families but provided a more strategic, co-ordinating role supporting others working with young people and their families.

After a number of reminder letters and follow-up telephone conversations, 34 services provided detailed information on the questionnaires.

### 2.1.3 Analysis

Results were analysed using SPSS and frequencies were calculated for the responses to each of the survey questions.

## 2.2 Difficulties with recruiting case study areas

The study aimed to have six case study services where the processes and outcomes of transition would be explored in more detail. However, an extremely prolonged period of negotiation was required in order to secure services, and thus a decision to undertake only five case studies had to be taken. This resulted in serious delays in the research.

Over a period of nearly ten months, 17 services were identified and approached. Twelve of these were identified through the survey and five, who had not responded to the survey, were identified through other contacts, such as the Transition Information Network. In nine cases negotiation took place over the telephone and in eight cases fact finding visits were made. A series of issues emerged which prohibited 12 services from taking part. Three services did not have service managers in post, which would have meant that the research would not have been able to be coordinated and prioritised locally; three services did not currently have any service users to sample for the research (two because they were going through re-organisation and restructuring and one was in development so identified that it was 'too soon' to take part). In three cases, services initially said they wanted to take part but after numerous contacts from the researchers had still not obtained 'sign up' from strategic managers. After further investigation in two sites it transpired that the service was not currently operating as a multi-agency service as there was no input from health agencies; and one service was not a transition team providing a regular service but only did project work with individual cases, this service also had no current social care input.

However, it should be noted that services were always supportive of the research, but circumstances and pressures of work prohibited them from supporting it in the way many of them desired.

## 2.3 Stage Two: Case-study areas - interviews with key staff

In order to investigate the process and outcomes of transition services in more detail, six case study areas were to be selected from survey respondents, representing different models of transition services and a range of demographic variables. However, as explained above, there were severe delays in recruiting sites and a decision was made to limit the case studies to five authorities.

Selection of case study services was informed by the findings and recommendations of Forbes *et al.'s* (2002) review and recommendations in Standard 8 of the NSF, and concentrated on services that had transition workers, key workers or transition teams to co-ordinate the services for the young person; multi-agency partnerships, that ideally include health, education, social services, housing, Connexions, Learning and

Skills Council and user representatives (although it was not possible to find five case study areas that had every one of these agencies formally involved with their service, two had all involved, one did not have housing, one did not have LSC, and one did not have housing or user representation); and a systematic approach to the management of the service. The case study areas were also chosen to ensure a spread of urban and rural areas and areas with high proportions of minority ethnic groups, in order to increase generalisability of findings.

In each case study area, a key figure in the Transition Service (typically the Transition Manager) was identified and contacted to ask if their service might be willing to take part in the research. If yes, a set-up interview was arranged whereby the researchers visited the key figure in the site to establish an overview of how the transition service worked in that site, which agencies were involved, and to explain in greater depth the demands of the research should they agree to take part. For sites which met the study criteria and then agreed to take part in the study, a partnership agreement was signed which set out the terms and obligations of all parties involved in the research.

The aim of the case-studies was to investigate both process and outcomes in order to understand the mechanisms and context in which successful outcomes are achieved or not (Pawson and Tilley, 1997). They examined in depth the different models of transition services and their effectiveness in meeting the needs of young people and families, in order to identify factors within the models contributing to greater or lesser effectiveness; and explored and estimated the service costs and the costs of supporting families.

### 2.3.1 Procedure

In each site, the transition manager contacted relevant managers and practitioners in the transition service, its steering group, and agencies with which the service worked and informed them about the research. The research team was then provided with a list of members of the transition service steering group, transition team members and managers and practitioners from other agencies involved with the transition service (schools, colleges, SEN workers, health, Connexions, leaving care, and so on). The research team then contacted each of those individuals by telephone and email to send them a staff information sheet and explain the study further and ask if they were willing to take part in the research. If so, a mutually convenient date and time of interview was arranged.

The majority of staff interviews were face-to-face, although a number were conducted over the telephone where a physical meeting was not possible. Interviews lasted approximately one hour and, with participants' permission, were tape-recorded. Signed consent to take part was obtained before the interview commenced.

### 2.3.2 Sample

In each area, in depth interviews were undertaken with managers and practitioners, including senior managers in all agencies closely involved in planning or implementation of the transition service and members of steering groups for the service; managers of the transition services; transition workers/team members and their line managers; and relevant staff in health, education, social care and Connexions, and in schools/colleges attended by young people receiving the service. In all, 130 interviews were carried out. Table 2.1 gives details of the roles of those interviewed and Table 2.2 gives details of the agencies they came from.

**Table 2.1 Interviewees by role in each site**

| *Site/Role* | *A* | *B* | *C* | *D* | *E* | *Total* |
|---|---|---|---|---|---|---|
| Transition Manager | 1 | 1 | 1 | 1 | 1 | 5 |
| Transition Team Members | 6 | 0[a] | 2 | 7 | 4 | 19 |
| Steering Group members[b] | 12 | 5 | 7 | 5 | 7 | 36 |
| School/College/ Education Staff[c] | 6 | 5 | 2 | 2 | 4 | 19 |
| Managers[d] | 3 | 5 | 4 | 6 | 5 | 23 |
| Practitioners[e] | 2 | 10 | 5 | 3 | 6 | 26 |
| Voluntary agencies/groups | 0 | 2 | 0 | 0 | 0 | 2 |
| *Total* | *30* | *28* | *21* | *24* | *27* | *130* |

[a] No designated transition team. Practitioners supporting some young people in transition as part of a larger caseload were interviewed and are included in 'practitioners'.
[b] All transition team managers were also on the steering group.
[c] Excluding those who were members of steering group.
[d] Excluding managers who were members of steering group.
[e] Practitioners who were not members of the transition teams; these included Connexions staff, speech and language therapists, physiotherapists, occupational therapists, nurses, children's and adults' social workers.

Schools and college staff represented three special schools and three FE colleges in area A, three special schools and one FE college in area B, one special school and one FE college in area C, two special schools in area D, and one special school and one FE college in area E. These schools and colleges were identified for us by managers of the services.

**Table 2.2 Interviewees by agency in each site**

| *Site/Agency* | *A* | *B* | *C* | *D* | *E* | *Total* |
|---|---|---|---|---|---|---|
| Child Social Care | 2 | 6.5[a] | 6 | 8 | 10 | *32.5* |
| Adult Social Care | 7 | 5.5[a] | 2 | 6 | 5 | *25.5* |
| Child Health | 1 | 4 | 5 | 1 | 4 | *15* |
| Child Mental Health | 1 | - | 1 | 1 | 1 | *4* |
| Adult Health | - | 3 | 1 | - | 1 | *5* |
| Adult Mental Health | 1 | 1 | - | 1 | - | *3* |
| Connexions | 8 | 1 | 2 | 2 | 2 | *15* |
| Education | 9 | 6 | 3 | 4 | 3 | *25* |
| Other[b] | 1 | 1 | 1 | 1 | 1 | *5* |
| *Total* | *30* | *28* | *21* | *24* | *27* | *130* |

[a] The Transition manager in this site was based half-time within Adult Services and half-time within Children's Services.
[b] Other includes two business support/administrative assistants, one employment strategy advisor, one parent representative who sat on the steering group, and one representative of a voluntary organisation.

### 2.3.3 Interview schedules

Interviews investigated the process of establishing partnerships, setting up and operating the service, addressing the following questions: which agencies are involved, and at what level, in partnerships to develop and deliver services? What difficulties/successes were encountered in establishing partnerships? How have barriers been overcome (or not)? How is the service funded and how was this funding negotiated? Is funding secure or short-term? What are the costs of the services and how are costs distributed between the activities undertaken? How does the service link to other programmes? How is the role of the transition worker/team defined? Does the service have designated transition workers or is the role taken on as part of an existing professional role? Which practitioners become transition workers? Who manages the workers and the service? What training and supervision is provided for workers? What types of relationships have developed between contributing agencies at different levels of the organisation? How is communication between and within agencies facilitated? To what extent do transition workers/teams liaise with the young people's schools/colleges/potential employers?

### 2.3.4 Analysis

The interviews were transcribed and two researchers each read a set of transcripts to identify *a priori* and emergent themes. A coding framework, consisting of main themes and sub-themes within these, was agreed and transcripts were then coded using the qualitative analysis programme MAXQDA, with any new emergent themes being added to the framework. Transcripts for each site were coded by a single researcher. The research team then developed a framework for reporting and two researchers each analysed data under a set of headings from the framework. Analysis was initially done by site and then was drawn together to produce a cross-site report.

## 2.4 Stage Three: Surveys of young people and their parents

The effectiveness of the services in providing co-ordinated care and in meeting young people’s and parents’ needs was investigated through questionnaires to all families going through, or recently (within the last two years) having gone through, the process of transition in these services.

### 2.4.1 Procedure

Questionnaires were sent to each service. Two versions of the questionnaire were used: one for parents of young people who were in the process of transition planning but had not yet transferred to adult services (pre-transition), and one for parents of those who had transferred within the last two years and had received the transition service (post-transition).

Although questionnaires are not always a suitable way to collect the views of many disabled young people who have cognitive impairments, it is important that young people’s views are included. Simplified versions of the questionnaires were designed for young people (one using symbol based language and one written).

The services were asked to post a pre-transition questionnaire package to all the families who were currently receiving the transition service. For these families, parents and young people's questionnaires were sent together. Each package contained a questionnaire for parents, a questionnaire for young people (both written and symbol version), an information sheet for the parents, an information sheet for the young person, a covering letter from the researcher, a postage paid envelope for return of the questionnaires, and a covering letter from the manager of the transition service. Parents were asked to give the young people's questionnaire and information sheet to their child if this was appropriate.

A similar procedure was adopted for post-transition families, except that young people's questionnaires were sent separately to the young person.

The design of the questionnaires incorporated aspects known to reduce non-response: questionnaires were made attractive by being printed on coloured paper, using clear fonts and well-spaced text. Questionnaires were piloted with four parents and their suggestions and comments were incorporated into the final version. The research team's consultation group of disabled young people were consulted about the young people's questionnaire and it was then piloted with two members of the consultation group and with one other young person recruited through a transition worker in a local service.

Two reminders were sent at three week intervals.

### 2.4.2 Content of questionnaires

Background data were collected in parent questionnaires on age, gender, ethnicity, diagnosis, educational placement and statementing, and daytime activity (for those not in full-time education) of the young person. Data collected on parents/carers were relationship to the young person, marital status, employment and effects of having a disabled child on employment, and socio-economic status.

An eight-item disability scale was used, measuring the type and level of difficulties experienced by the young person. These items were: communication, behaviour, learning, mobility, health, vision, hearing, and continence. Respondents were asked to rate whether their child had difficulties in each of those areas, either ‘not at all’, ‘some difficulties', or ‘a lot of difficulties’.

Questions were asked about the process of planning for transition, in particular whether they had a written transition plan; whether their son/daughter had a copy of this; the age at which transition planning started; how often it was reviewed, and whether this was regularly enough. Information provision on transition was covered by three questions about parent's information needs and three questions about the young person's information needs. Items were rated on a three-point scale, of 'Getting enough help', 'Need help' or 'Help not needed'.

Parents were also asked whether the young person and family had one person who supported them through the transition process and about their contacts with this person: the frequency and duration of their contacts with the key worker: 1) In the last three months how often have you seen this person? 2) Typically, how long do these visits last? 3) Would you like to see this person a) More often, b) About the same c) Less often? 4) In the last three months, how often have you spoken to this person over the phone? 5) Typically, how long do these contacts last? 6) Would you like to talk to this person a) More often, b) About the same, c) Less often? They were also asked whether the person was proactive in making contact, that is, whether they usually made contact regularly or left it up to the parent to make contact.

Coordination of transition was covered in six questions about the help parents had or needed in this area, which were rated on a three-point scale, of 'Getting enough help', 'Need help' or 'Help not needed'. Pre-transition questionnaires to parents also used the 20-item version of Measure of Process of Care (MPOC-20: King *et al.,* 1995) to determine whether parents perceived that the young person and family received co-ordinated multi-agency services more generally. Widely used across a number of countries, including Canada, the United States and UK (McConachie and Logan, 2003; Dyke *et al*., 2006), the MPOC comprises five sub-scales: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, and respectful and supportive care. The MPOC was only included in the pre-transition questionnaire for parents as it was thought that it would be too difficult for parents to recall the detail needed for this measure when it was some time since transition.

One item (drawn from Greco *et al*., 2005) measured how satisfied the respondent was with the transition service. The question was 'Overall, how satisfied are you with the transition service you receive?' The question was rated on a four-point scale from 'Very satisfied' to 'Not at all satisfied'.

Transition has been identified as a particular time of stress for parents, so a question was included on parents' views of the effects of the transition service on their own feelings of stress: 'Have your contacts with the transition service affected the amount of stress you have experienced in caring for your son/daughter in the past six months?' This was rated on a five-point scale: 'considerably reduced my stress', 'somewhat reduced my stress', 'not had any effect on my stress', 'somewhat increased my stress', 'considerably increased my stress'.

The extent to which services were meeting young people’s needs was assessed using a 22-item checklist based on one previously used in national surveys and research on families caring for a disabled child/young person (Greco *et al.,* 2005; Chamba *et al.,* 1999; Beresford, 1995), and adapted to suit this age group drawing on existing literature and consultation with SPRU’s Consultation Groups of disabled young people and parents. Items included needs related to self-care, leisure and social life, independent living skills, career/employment opportunities, preparation for changes ahead, and were rated on a three-point scale, of 'Getting enough help', 'Need help' or 'Help not needed'. For post-transition questionnaires these questions were asked both about past needs (during the transition process) and present needs.

The questionnaire also asked about the use young people made of transition services as well as other health, social care and education services. This part of the questionnaire was based on *Client Service Receipt Inventory* and records frequency and duration of service use (Beecham and Knapp, 1992, 2001).

Young people's written questionnaires asked whether they had one person who supported them through the transition process, how this person helped them and whether they would like to see this person more often or not. These questionnaires also included the section on the extent to which the services were meeting the young person's needs, including both past and present needs for those post-transition. The symbol questionnaires were briefer, focusing on whether the young person had one person to support them through transition and how this person helped.
All questionnaires included sections for open comments.

### 2.4.3 Sample

Questionnaires were sent to 717 families, 567 pre-transition and 150 post-transition. One hundred and forty three (20 per cent) completed parent questionnaires were returned (110 pre-transition and 33 post-transition). Ninety-seven young people completed questionnaires (73 pre-transition, of which 19 completed the symbol questionnaire; and 24 post transition, of which eight completed the symbol questionnaire). It is not possible to calculate a response rate for these as services were not able to give us information on the number of young people who would be expected to be able to complete a questionnaire.

***Response rates by service***
Response rates by service for the parent questionnaires are shown in Table 2.3.

### Table 2.3 Response rates by service and type of questionnaire

| *Questionnaire type* | *Service A* | *Service B* | *Service C* | *Service D* | *Service E* |
|---|---|---|---|---|---|
| Parent pre-transition | 22.4%<br>(41/183) | 15.3%<br>(11/72) | 15.2%<br>(28/184) | 21.1%<br>(16/76) | 26.9%<br>(14/52) |
| Parent post-transition | 23.5%<br>(8/34) | 31.6%<br>(6/19) | 6.6%<br>(2/30) | 18.1%<br>(8/44) | 39.1%<br>(9/22) |
| *Overall response rate* | *22.6%* | *18.7%* | *14.0%* | *20.0%* | *31.1%* |

Response rates were low in all sites, especially in Service C where there were some problems in posting out questionnaires. A number of reasons can be suggested for this: reliance on staff in sites who were already hard pressed to identify and locate users of the service and administer the questionnaire; problems with postage as noted above; some families may have had little contact with the service; and approaching families at a particularly stressful/busy time in their lives. One hundred and eighty-three questionnaires were returned uncompleted ticking the option for no further contact. Not all families gave reasons, those that did gave the following reasons: young people unable to complete questionnaires; young person has moved to a residential home or college; parents and/or young person cannot remember the service; family have not had much to do with the service; too soon to comment on the service; parent and/or young person is unwilling; not enough time to complete the questionnaire. Comments included:

> 'Snowed under with applications to charities for financial help with my son's accommodation and equipment.'
>
> 'Sorry too much to do and an added stress to fill in!'
>
> 'We have completed forms and undergone surveys on previous occasions all of which have caused us distress in one way or another and which my son in particular, found to be an invasion of his privacy.'
>
> 'My son cannot talk; he's too disabled to tell us.'

### 2.4.4 Analysis

Items for the disability scale, parental needs, and young people's needs were computed to comprise total scores for each of these scales. Scales were scored as follows:

1) Disability was scored by summing the responses from the eight items, which went from zero (not at all) to two (very much so) so that the higher the total score, the more severe the young persons's disability.

2) Parents' and young people's information needs were scored by summing the number of unmet needs, so that the higher the score, the higher the number of unmet needs. Parents' transition needs were scored in the same way.

3) Young people's needs during and after transition were scored by summing the number of unmet needs for each scale, so that the higher the score, the higher the number of unmet needs per young person.

Alpha reliability scores for the needs scales are given in Table 2.4.

## Table 2.4 Alpha reliability for needs scales

| *Scale/questionnaire* | *Alpha N ( )* |
|---|---|
| Parents' transition information needs/pre-transition parent questionnaire (3 items) | 0.88 (102) |
| Young people's transition information needs/pre-transition parent questionnaire (3 items) | 0.90 (96) |
| Parents' transition needs/pre-transition parent questionnaire (5 items) | 0.90 (95) |
| Young people's needs during transition/pre-transition parent questionnaire (22 items) | 0.91(71) |
| Parents' transition information needs/post-transition parent questionnaire (3 items) | 0.86 (32) |
| Young people's transition information needs/post-transition parent questionnaire (3 items) | 0.89 (29) |
| Parents' transition needs/post-transition parent questionnaire (6 items) | 0.90 (26) |
| Young people's needs during transition/post-transition parent questionnaire (22 items) | 0.88 (16) |
| Young people's current needs/post-transition parent questionnaire (21 items) | 0.93 (20) |
| Young people's needs during transition/pre-transition young people's questionnaire (19 items) | 0.90 (46) |
| Young people's needs during transition/post-transition young people's questionnaire (19 items) | 0.88 (13) |
| Young people's current needs/post-transition young people's questionnaire (20 items) | 0.94 (14) |

The MPOC-20 was scored using King *et al.'s* (1995) programme. If over half of the items were missing, the MPOC scale was not calculated for the individual. Although King *et al.* advise use of five separate scale scores, before computing the scale a factor analysis was run on its items to explore the scale's factor structure. The results showed a two factor solution with only one predominant factor, which was confirmed by Scree plot. The five scales of the MPOC-20 specified by King *et al.* were computed, in order to investigate the correlations among sub-scales, which ranged between 0.653 and 0.932 ($p<0.001$). These high correlations suggested that it may not be accurate to score the MPOC scales separately for these data. Rather a single factor appeared to be more appropriate for the data, and thus the MPOC was thus scored as a single scale. As each item of the MPOC has the possibility of being rated as not applicable, and items rated in this way are not scored, the mean of the items scored was used (as per King *et al.'s* programme). Alpha reliability for the total 20 item scale score was 0.97 (n= 98).

### *Coding of service context variables*

In order to explore the effects of different aspects of the transition service models on outcomes for families, characteristics of services that had emerged as important from the literature and/or from interviews with staff and managers, and on which the service models differed, were coded for each service. These covered eight criteria:

- Having designated transition workers.
- Transition workers having specific training for the role.
- Having clarity on the role of the transition workers/team.
- Transition workers setting up, and negotiating funding for, the care package for adult services.
- The manager of the transition service having involvement at a strategic level.
- Use of person centred planning for all young people.
- Having parent involvement in steering groups.
- Having young people's involvement in steering groups.

Coding for these criteria was binary (met or did not meet the criterion).

### *Statistical analysis*

Frequencies and mean values were calculated for demographic variables and variables about the characteristics of the service, and the main outcome (dependent) variables for the study: parent unmet transition needs, young oerson’s unmet needs, impact on parental stress, and satisfaction with the transition service. Where sample sizes allowed, one-way analysis of variance (ANOVA) and chi -square was used to test whether there were any significant differences between services on dependent variables and key independent variables. This was only possible for the parent questionnaires as the young people's sample was too small.

For the parent sample, the relationships between outcome variables and key descriptor variables - service context variables (see above) and a set of variables relating to the characteristics of the service and the young people derived from the parent questionnaires (see Table 2.5) - were then explored in bivariate (T-tests, ANOVA and chi-square for categorical descriptor variables and correlations for continuous variables) and multivariate analyses. First, differences between pre- and post-transition samples on outcome variables were investigated. There were no significant differences, so the samples were combined in order to increase sample size.

**Table 2.5 Descriptor variables from parent questionnaires**

| *Descriptor variables* | *Type of variable* |
|---|---|
| Difficulties score | Scale (0-15) |
| Has written transition plan | Binary (yes, no/don't know) |
| Has one transition worker | Binary (yes, no/don't know) |
| MPOC[1] | Scale (1-7) |
| Age transition planning started | Continuous |
| Type of school attended | Categorical 4-point (special school, mainstream or special unit in mainstream, residential, other) |

[1] only completed by pre-transition sample.

For each outcome variable, a subset of descriptor variables was identified for inclusion into a stepwise multiple regression analysis. Descriptors were included if they were related to the outcome at $p<0.05$.

The main merits of multiple regression are:

- It can provide a précis of the associations between descriptor and outcome variables by eliminating those descriptor variables whose covariance with the outcome measure is shared by other variables with more powerful associations.
- The regression equation indicates the maximum level of explained variance that is possible with the available information, and therefore the extent to which unknown or unmeasured factors may be important as predictors of the outcome variable.
- The equation identifies conditions and circumstances likely to predict the outcome. Although causality cannot be assumed from cross-sectional data, the data may suggest causal models with at least some of the variables in the final equation. In this study, the majority of the descriptor variables were chosen on the basis of potential causal order, i.e. that the key characteristics of the services could be (partial) causes of differences in outcomes for young people and parents.

## 2.5 Stage Four: Interviews with parents and young people

In-depth information on views of the process and outcomes of service provision provides a valuable addition to understanding the mechanisms by which outcomes are achieved. The original aim was to interview 30 to 40 families (5-7 families from each of six case study areas). However, the delays in recruitment of sites severely affected the project timetable and it was agreed with the funder (Department of Health) that a smaller number of interviews (c.10) would be undertaken. As an aim of the study was to find out about good practice, selection was focused on those families who indicated in the questionnaire that they were satisfied with the service they had received. In order to explore the whole process and outcomes of transition, selection also focused on families where the young person was post-transition. Families were then selected from those responding to the questionnaire who indicated willingness to be interviewed. The parent with main caring responsibilities and, where possible, the disabled young person was interviewed.

### 2.5.1 Procedure

Respondents meeting the above criteria who had indicated that they were willing to be contacted further were telephoned and asked if they were willing to consider participating in interviews. Families were also asked whether their son or daughter was able to participate in an interview, and if possible the researcher also spoke to the young person on the telephone. If the parent and/or young person was willing to be interviewed, a provisional date and time were set for the visit. Parents and young people were sent information sheets about the study and a letter confirming the provisional date and time of the interview. They were assured that they did not have to participate and they could withdraw at any time without having to give a reason. Interview arrangements were then confirmed and written consent was obtained before the interview took place. All interviews took place at the family's home or another venue of the family's choice. Parent interviews lasted approximately one and a half hours, young people's interviews lasted about 30 minutes. With respondents' permission, interviews were tape-recorded. One parent refused permission for the interview to be recorded so the researcher took detailed written notes.

### 2.5.2 Interview schedules

In order to get a picture of the young person's current situation, parents were asked, at the beginning of the interview, to describe a typical week in the young person's life - how they spent their time, what support they had received to set up these placements/activities and who had provided this support. Parent interviews then explored the extent to which transition plans had worked out in reality; any specific health or other needs the young person had and how these had been met (or not); experiences of adult services; what aims and desires the young person had and what parents' aims for their son/daughter were; how far the transition process helped them to achieve these aims; and if parents and young people disagree on desired outcomes, to what extent transition services helped them to negotiate and reconcile their views. Finally, parents were asked what improvements they would like to see in transition services.

Young people's interviews were shorter and simpler. They covered young people's current activities (college/work/day centre as appropriate, and activities in free time); likes and dislikes; who supported them and in what way; whether they needed more support in any areas of their lives; their views about where they currently lived; and their desires for the future in relation to activities, support and living arrangements.

The scope and the form of the interviews with the young people was dependent on the young person's abilities. Visual methods based on 'Talking Mats' (Murphy, 1998; Rabiee *et al*., 2005) were used where appropriate.

### 2.5.3 Sample

Eleven families met the criteria for selection for interviews. One parent could not be contacted and two refused, a further two were not available during the time that the interviews were being carried out and attempts to reschedule these for a later date were not successful. Interviews were carried out with six sets of parents across three different sites (three in one site, two in another site, and one in a further site). Two interviews were conducted with married couples, two with married mothers, and two with divorced or separated mothers. Three young people (one male aged 21 and two females aged 20) took part in interviews, all of which were facilitated with the visual materials, as the young people had limited communication and cognitive skills. In the other three cases, either parents stated that the young person was not able to take part in an interview (despite demonstration of non-verbal methods that would be used) or young people themselves did not want to take part.

### 2.5.4 Analysis

The process of analysis was similar to that in stage two. The interviews were transcribed and examined to identify *a priori* and emergent themes. A coding framework was developed and transcripts were coded using MAXQDA, with any new emergent themes being added to the coding framework.

## 2.6 Stage Five: The Economic Component

The economic component for this study was designed to link with Stages 1, 2, and 3 of the study with the following aims:

- To develop a national picture of the costs of transition teams and the support they provide.
- To develop a more detailed picture of the service-level costs for transition teams from those participating in Stage 2 of the research.
- To calculate the costs per family of transition support using data from Stage 3 of the research.
- To calculate the costs of the full support packages received by young people whose families participated in Stage 3 of the research.
- To explore whether the support costs for young people are associated with measures of the services' attributes, the family or young person's characteristics, the needs of the young people and parents or their outcomes.

### 2.6.1 Procedures and methods

At each stage of the research, questions were integrated into the schedules that would elicit the information required for each of these cost estimation tasks. The national survey included a 'nested' set of questions, based on earlier research on children's mental health services and key worker teams. The aim was to identify the expenditure on the team, and where this could not be provided, obtain accurate information on the staffing profile of the team. Information on activities – such as the team's caseload – would allow not only the full annual costs of the team to be estimated but also a 'unit' cost per case per year.

In a similar vein, the in-depth interviews with staff supplemented our request for expenditure information by including questions on the proportion of time staff spent on transition work, and how that time was split between eight categories of activities (such as liaison, face-to-face contact etc.). Importantly, these interviews allowed us to estimate a cost for the team that included inputs from the Steering Group. Together these data would allow a more accurate picture to be built up of the annual costs of each team and the costs per working hour, and also a means of 'weighting' that cost per hour so that a cost per contact could be estimated.

This 'weighted' unit cost would be used to convert the time families in Stage 3 reported *receiving* transition support (the amount of contact they had with the transition team) into the costs of *providing* transition support for families. The Stage 3 Family Survey also contained questions designed to find out what other types of services the young people received. With these data we could estimate the full costs of their support package.

### 2.6.2 Cost estimation and analysis

The cost estimation approach underlying this research takes the basic principles inherent in economics and applies them to the specific field of social care services. Our interest is in obtaining the best approximation of the *long-run marginal opportunity cost* of the services used, including the transition teams.

As transition services are intended as an important component of child and adult services so the cost of expanding the service is an appropriate measure. Thus, *short-run marginal costs*, which include only the costs of running the service on a day-to-day basis will underestimate the costs of providing *more* of the service. Our approach is to include these revenue (recurrent) costs as well as the overheads that accrue to the managing agency. Thus the full costs of providing the service are accounted for rather than the costs of squeezing just one or two more young people into an existing service.

Data on service use from the Family Survey were combined with information on the unit cost of the transition teams and other services so that the costs of the young person's care package could be estimated. It is perfectly reasonable that these support costs should vary; after all health and social care professionals intervene differently in response to their clients' very different needs. As the service response will vary, so too will the costs of that support. We explored the extent of this cost variation and whether it was associated with the characteristics or needs of the young people and their families, and measures relating to the transition service. Rather than look at the variation in the costs of individual services, the distribution of which would be skewed by the high number of people receiving no support, we focussed on ‘cost categories’ of services that approximated agency responsibilities: transition support, all social care, primary health care, community (specialist) health services, and the total costs of education, health and social care support.

These cost-related analyses provide descriptive results rather than definitive findings on the cost-effectiveness of any particular model of transition services. However, as these are relatively new additions to the care system the results can inform commissioners and providers who intend developing such a service or extending existing services.

# Chapter 3 Results of Stage One: Survey of Local Authority Multi-agency Transition Services

The section reports the results of the survey based on the detailed information gathered on 334 local authority transition services. Section 5 reports the results of the analysis of the information provided from the survey on the cost of the transition services.

## 3.1 Nature of services

The newly emerging nature of transition services became very evident in survey responses, with most services having been established fairly recently. Of the 34 transition services, 11 (33 per cent) had been established in 2007 (six in the last third of the year) and a further seven in 2006. Only seven had been in existence for four years or more (see Table 3.1). Six services reported that they were still at a pilot stage, the remainder stating that they were mainstream services.

**Table 3.1 Year multi-agency service was established**

| | *Number of services (n = 34)* |
|---|---|
| 2000 | 2 |
| 2002 | 3 |
| 2003 | 3 |
| 2004 | 3 |
| 2005 | 5 |
| 2006 | 7 |
| 2007* | 11 |

*6 in the last third of the year

### 3.1.1 Funding of service

Twenty-two of the services described their funding as ongoing and for some, funding of the service was part of their mainstream budgets. For many the funding situation was complex, for example as one described:

> 'The protocol and service relate to a number of different agencies/ services with different funding streams'.

and another stated

> ‘Key workers and social workers and manager funded by local authority, Connexions PA funded by Connexions and Transition Nurse funded by PCT’.

Funding difficulties might also occur as some described arrangements where part of the funding was permanent but some agencies were renewing their funding annually. Three services did not supply information on their funding status.

Funding, in terms of contributions of money or resources of staff time, was complex. Twenty-five services provided details on this. A number of agencies contributed to funding the services, although only a minority of services (n=5) had contributions from social care, health and education. In all these cases, both children's and adult social care contributed to the service, and in four Connexions also contributed. In all, nineteen services had funding from both children’s (children’s social care and/or Directorate of Children’s Services) and adult services (adult social care and/or adult learning disability service/learning disability partnership board).

**Table 3.2 Agencies contributing money or resources (staff) to the transition service in financial year 2006-7**

| *Agencies* | *No. of services (n=25)* |
|---|---|
| Health, education, children's social care, adult social care, Connexions | 4[a] |
| Health, education, children's social care, adult social care | 1 |
| Education, children's social care, adult social care | 1 |
| Health, Directorate of Children’s Services, Connexions | 1 |
| Health, children's social care, adult learning disability service | 1 |
| Children's social care, adult social care and/or adult learning disability service/learning disability partnership board, Connexions | 7 |
| Directorate of Children’s Services, adult social care, Connexions | 1 |
| Children's social care, Connexions | 3 |
| Adult social care, Connexions | 1 |
| Directorate of Children’s Services, adult social care and/or adult learning disability service | 3 |
| Children’s social care, adult social care | 1 |
| Children's social care only | 1 |
| *Missing data* | *9* |

[a] Two also had funding/resources from Directorate of Children's Services, and one of these from Adult Mental Health Service and a voluntary organisation as well. One also had funding/resources from CAMHS.

## 3.2 Models of multi-agency transition services

A complex picture emerged of a variety of different structures and multiple functions undertaken by these services.

### 3.2.1 Function and composition of transition services

It appears that authorities have chosen to organise their multi-agency transition services around two different main models. One is a coordinating role - a transition service whose main function is to track and monitor those eligible young people through the transition process and in addition to provide a transition specialist within the authority from whom others would seek advice and information. In the second model, workers were funded to provide direct support to a caseload of young people and families during transition. In some authorities both these functions were provided within one service. The situation is further complicated by the fact that authorities had either chosen to set up a distinct transition team to carry out these functions, or transition workers/key workers carried out these functions within other teams, most often social work teams (see Table 3.3).

**Table 3.3 Function and composition of transition services**

| *Number of services (n=34)* | | | | | |
|---|---|---|---|---|---|
| *Caseload* | | *Co-ordinating Role* | | *Combination* | |
| Distinct team | Transition workers part of wider teams | Distinct team | Transition workers part of wider teams | Distinct team | Transition workers part of wider teams |
| 5 | 10 | 6 | 3 | 4 | 6 |

Fifteen of the 34 authorities stated that they had a distinct transition team either performing the coordinating role, holding caseloads or undertaking both functions. The other 19 authorities chose to not have such a distinct team but to facilitate these functions within existing teams. Further questions illustrated that in the latter case, these workers were predominately based in social care, with the most common pattern emerging of having transition workers within both children’s and adults’ (mainly adult learning disability) teams. However, three authorities had chosen a different arrangement, with one having an arrangement within their Connexions team, another within the voluntary sector and one within their Specialist Child Health Team. The picture, however, is complicated and it is only through further qualitative investigation and the case studies which are being undertaken, that the complexity of the functions and compositions of transition services can be fully understood.

Twenty-four services indicated that they had a transition co-ordinator or manager who oversees the day–to-day running of the service (seven did not have such a manager; three did not supply any information). Of the 24 managers, five were employed by adult social care, five by Connexions, three by children's services, six had joint social care appointments, two had joint appointments between health and social care, and three only stated 'local authority' or 'council'.

The amount of time managers/coordinators spent working in this role varied from nine services which had a full time post, through to one area where the manager spent less than 15 per cent of time in this role. Only 11 of the multi-agency services indicated that they had any administrative support.

### 3.2.2 Lead agencies

Thirty-one services reported that they had a lead agency. Table 3.4 reports the exact terms used by services to describe their lead agency. Overall 13 were being led by children's services, seven by adult services and four by Connexions (two solely Connexions, a further two being Connexions in partnership with adult services). Unfortunately, seven were not specific enough to classify further as they described the lead agency using terms such as local authority or social care.

**Table 3.4 Lead agency for multi-agency transition services**

| | *Number of services (n= 30)* |
|---|---|
| Local authority | 5 |
| Children's Service | 3 |
| Children's Social Care | 3 |
| Children and Young People's Service | 4 |
| Adult Social Care | 2 |
| Connexions | 2 |
| Adult Social Care and Health Department | 2 |
| Social Care | 2 |
| Children's Disability Partnership (Health, Social Care and Education) | 1 |
| Adult Community Care | 1 |
| Children and Young People's Trust | 1 |
| Adult Learning Disabled Service | 1 |
| Connexions in partnership with Adult Learning Disability Services | 1 |
| Connexions and Adult Social Services | 1 |
| Adult Integrated Disability Team | 1 |
| Learning and Children's Service | 1 |
| *Missing data* | *3* |

### 3.2.3 Setting up and overseeing the service

A series of questions explored which agencies had been involved in establishing the transition service and those who were involved in overseeing it. Children's social care (n= 32) and Connexions services (n=31) were involved in the setting up of most transition services, followed by Education (n=27), Adult Learning Disability Services (n=27), Adult Social Care Services (n=26), and Primary Care Trusts (n=24). Learning disability partnership boards (n=17) and voluntary organisations (n=16) were involved in around half the services. However there was considerably less involvement of NHS Hospital Trusts (n=8) and mental health services, either children's (n=8) or adults (n=5) (see Table 3.5).

**Table 3.5 Agencies and others involved in *setting up* the service**

| | *Number of services (n=34)* |
|---|---|
| Children and Young People's Social Care Stream | 32 |
| Connexions | 31 |
| Education Stream/Service | 27 |
| Adult Learning Disability Service | 27 |
| Adult Social Care Services | 26 |
| Primary Care Trust | 24 |
| Learning Disability Partnership Board | 17 |
| Voluntary Organisations | 16 |
| Parent Partnership Services (SEN) | 9 |
| Learning Skills Council | 9 |
| CAMHS | 8 |
| NHS Hospital Trust | 8 |
| Adult Education/Further Education | 7 |
| Adult Mental Health Services | 5 |
| Supporting People | 5 |
| Housing | 3 |
| Schools/colleges | 1 |

Table 3.6 illustrates the agencies involved in overseeing the transition service. Not surprisingly a similar picture emerges as to those who were involved in setting up the service, although there are increases in the involvement of a number of agencies and organisations (for example, CAMHS, Parent Partnership Services, adult/further education).

### Table 3.6 Agencies and others involved in *overseeing* the service

| | *Number of services (n=34)* |
|---|---|
| Children and Young People's Social Care Stream | 33 |
| Connexions | 31 |
| Education Stream/Service | 29 |
| Adult Social Care Services | 27 |
| Adult Learning Disability Service | 27 |
| Primary Care Trust | 25 |
| Learning Disability Partnership Board | 19 |
| Voluntary Organisations | 16 |
| Parent Partnership Services (SEN) | 12 |
| CAMHS | 12 |
| Learning Skills Council | 12 |
| Adult Education/Further Education | 10 |
| NHS Hospital Trust | 7 |
| Adult Mental Health Services | 7 |
| Housing | 4 |
| Supporting People | 4 |
| Children's Disability Partnership | 2 |
| Person Centred Planning Co-ordinator | 2 |
| Young People's Partnership Board | 1 |

In order to fully appreciate the complexity of these arrangements the numbers of agencies involved in setting up and overseeing the transition service were also calculated. Table 3.7 indicates that one service had 14 agencies involved in the setting up of the service, although the average number of agencies was eight. In terms of overseeing the service, in two services there were 13 agencies involved although once again the average was eight.

**Table 3.7 Number of agencies involved in setting up and overseeing the multi-agency service (n=34)**

| *No. of agencies* | *Setting up* | *Overseeing* |
|---|---|---|
| 1 | 0 | 1 |
| 2 | 1 | 0 |
| 3 | 2 | 0 |
| 4 | 2 | 2 |
| 5 | 5 | 3 |
| 6 | 2 | 4 |
| 7 | 2 | 2 |
| 8 | 6 | 4 |
| 9 | 6 | 5 |
| 10 | 3 | 3 |
| 11 | 1 | 6 |
| 12 | 2 | 2 |
| 13 | 1 | 2 |
| 14 | 1 | 0 |

In the majority of cases (22) all three main statutory agencies (education, health and social care) were involved in setting up the services, with 18 of these involving both children's and adult social care; five services were set up by education and social care (four including both children's and adult social care); four services were set up by health and social care (three children's and adult social care); and three were set up by social care, with two including both children's and adult social care.

Similarly, 23 services were overseen by education, health and social care, 18 of which included both children's and adult social care; five were overseen by social care and education (four including children's and adult social care); three by health and social care (two including children's and adult social care); and two were overseen by social care, with one involving both children's and adult social care. Just one service was both set up and overseen by social care (children's and adult) without involvement of health and education, but had involvement of Connexions in both functions.

A further question on the survey explored whether the transition service had formal links with other agencies who may not be involved on a strategic level in terms of overseeing the service (see Table 3.8). Respondents reported that they had such formal arrangements with the Learning Skills Council, youth and leisure services, employment services, mental health services, benefits and housing. Although this should be viewed positively, it may be that changes to improve transition for disabled young people would be less likely to occur in these services if they were not part of the formal transition strategic partnerships involved in the service. As the literature indicates it is vital that services work together to ensure a smooth and positive transition, it is not possible from the survey responses to establish how formal, established or successful these links might be.

**Table 3.8 Formal links with other agencies**

| | *Number of services (n = 34)* |
|---|---|
| Learning Skills Council | 18 |
| Youth Services | 17 |
| Employment | 12 |
| Mental Health Services | 12 |
| Leisure Services | 10 |
| Housing | 8 |
| Benefits | 4 |
| No other links | 8 |
| Other* | 1 |

*Leaving Care Service Welfare Rights, Careers Service, voluntary and educational services

### 3.2.4 Transition protocols and service level agreements

Thirty-two of the 34 services indicated that they had a transition protocol, although in some cases it appeared that this was either still in development or was being updated. Only eight had service level agreements in place.

### 3.2.5 Involvement of parents/carers and young people in service planning and overseeing

Services were asked about the involvement of parents/carers and young people in planning and overseeing the service (see Table 3.9).

**Table 3.9 Involvement of service users in planning and overseeing the service**

| | *Number of services (n=34)* | |
|---|---|---|
| | *Planning the service* | *Overseeing the service* |
| Parents/carers | 26 | 24 |
| Young people | 15 | 12 |

Of the 26 services who had involved parents/carers in planning the service, 23 supplied further information. This indicated that 16 services had parents/carer representatives on their steering, working or strategy groups, or Partnership Boards.

Thirteen had involved parents/carers through consultations including workshop days or consultation events and one had set up a Parent Task Group. Involvement of young people in planning the service appeared more limited than that of parents/ carers, although some interesting examples were reported. These included a young people’s forum being involved in the recruitment process for a key worker. This authority was also looking at ways to involve young people in the planning that takes place within the Transition Board. One service had already achieved this, with young people's representation on their working group. One service prepared an accessible version of a transition strategy that had been developed and used it to consult with young people. Consultation in one service had taken place on the provision of activities and person centred planning, a further seven services mentioned undertaking consultation. One service had sought feedback from those young people who had participated in a person centred review pilot at a local special school, they also sought feedback from young adults who had been through transition in the borough. One service had innovatively involved young people in producing a CD-Rom to explain to other young people about the service. This was also used to consult them on how they wished to see the service develop and how they wished to be represented on the Transition Steering Group. Another service had produced a DVD of young people's experiences to inform good practice and had involved young people in development of their website.

The numbers of services involving parents/carers in overseeing the service (n=24) were slightly lower than those involving them in planning (n=26). Overseeing of the service by parents/carers was mostly through their representation on transition implementation, strategy or steering groups, membership of Learning Disability or Children’s Disability Partnership Boards and on working groups (n=18). Other forms of involvement were reported to be through sitting on interview panels (n=1) and through consultations or evaluations (n=3) and two authorities held an annual conference. Only 12 services involved young people in overseeing the service. Within one service a young people’s forum had been involved in the recruitment process for the transition key worker and this service was looking at ways to make sure that young people were involved in the planning that takes place through the transition board. Five services had a young person on various boards involved in overseeing the service (for example, the transition subgroup of the Learning Disability Partnership Board or Disability Partnership board), and in one of these young people and their advocates co-chaired the service's steering board. One service had involved young people through a series of consultations, workshops and events, whilst one had asked young people to join an advisory group. Two sought the views of young people when undertaking evaluation of their service, one of these held an annual conference each year to guide the service and one used the services of a local youth forum within a voluntary organisation to provide feedback. Another was linking into a pupil forum which they stated was representative of disabled young people. A further two stated that they would be developing this area of work.

## 3.3 Accessibility of the service to ethnic minority groups

Twenty-three services stated that they had made arrangements to make their service accessible to young people and families from black and minority ethnic groups. For the majority this involved a translation and/or interpreting service. Two services specifically mentioned that their assessments had been translated into other languages, one of these also updated their local BME forum with transition information. One service had produced a DVD which looked at working with black and minority ethnic groups, the DVD featured a young man going through transition. This service also ensured that all their workers undertook diversity training. One service identified that they had not completely addressed the issue of diversity and had recognised that the voluntary organisations representing the voice of parents/carers in their authority were not routinely representing the view of parents/carers from minority ethnic groups. They were considering how to address this issue. A further service was also examining their visual materials to identify if they were culturally appropriate and examining direct payments to see whether these would allow families to access more culturally appropriate services.

## 3.4 Young people supported by the services

The questionnaire explored which young people were supported by the transition services and how they were referred into the service. Table 3.10 indicates that all of the transition services were supporting young people with severe learning difficulties, and this appeared to be a key criteria for most services. Similar numbers of services supported the transition of young people with autistic spectrum disorders, complex health needs, physical or sensory disabilities, moderate learning difficulties, and life limiting/life threatening conditions. Half of the services supported young people with complex mental health needs, and only 12 supported young people with emotional and behavioural disorders or mild learning disabilities.

**Table 3.10 Client groups served by multi-agency transition service (n=34)**

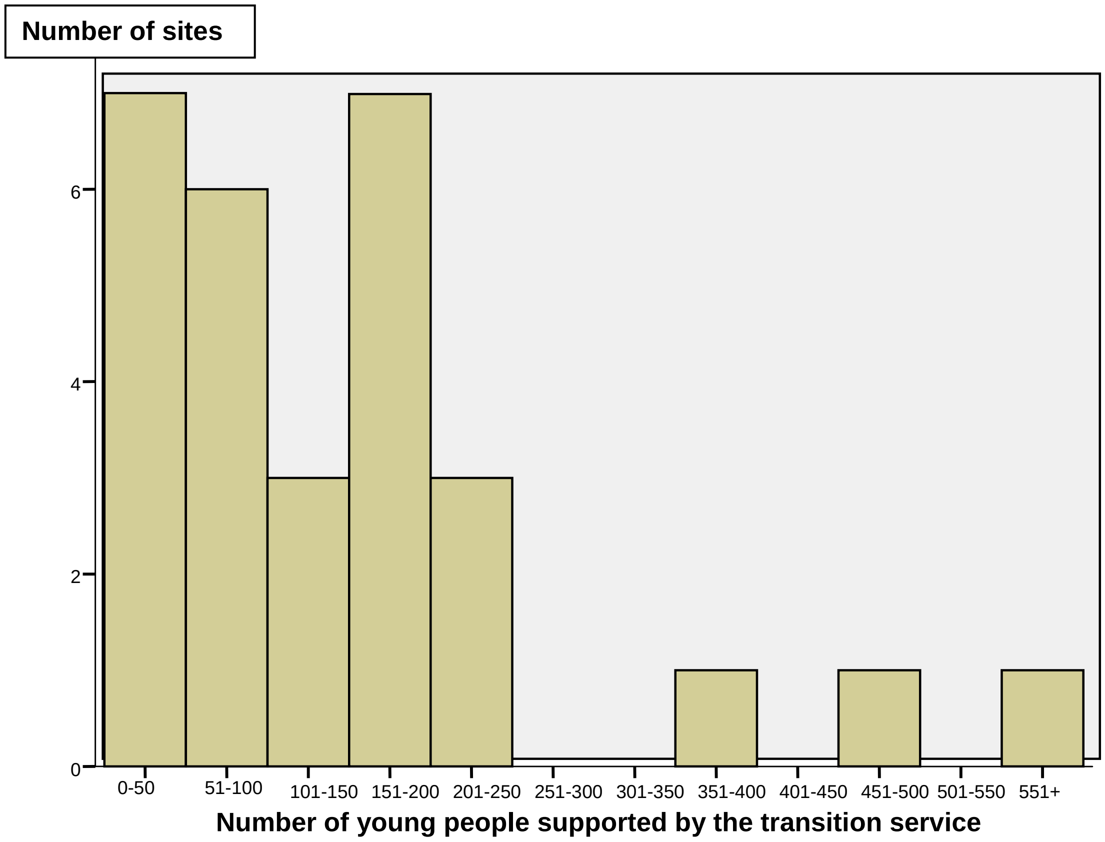
| | *Number of services* |
|---|---|
| Severe Learning Disabilities | 34 |
| Autistic Spectrum Disorders | 29 |
| Complex Health Needs | 29 |
| Physical Disabilities | 29 |
| Moderate Learning Disabilities | 29 |
| Life limiting/life threatening | 28 |
| Sensory Disabilities | 27 |
| Complex Mental Health Needs | 17 |
| Emotional and Behavioural Disorders | 12 |
| Mild Learning Disabilities | 12 |

A number of respondents added qualifying comments which included: '*all must have a learning disability as their primary disability in addition to all of the above'*; two stated that any young person experiencing, or likely to experience, problems with transition would qualify for a service. One reported that any young person with a statement of special educational need or eligible for a statement would be able to access the service. One respondent explained that the service predominately worked with young people with learning disabilities and physical/sensory impairments, however, they would work with young people in these categories if they *'had additional needs such as ASD, health or EBD difficulties'*. Another stated that they worked with young people with a primary diagnosis of learning disabilities although many had associated complex health needs.

One respondent specifically noted a gap in service for young people with Asperger's Syndrome (high performing) who would not be eligible for a service from adult learning disability services. Another service was planning to extent their practice further to include those young people with health needs who were currently within a separate process.

The number of young people being supported by the services varied widely, ranging from ten to 500, with one outlier service stating that they supported over 2,000 young people (see Figure 3.1). The median number was 135.

**Figure 3.1 Number of young people supported by the transition service in each site**



### 3.4.1 Eligibility for the services

Eligibility for the transition service varied across the services. For many, eligibility criteria was deemed to be aged 13 or 14 and above, and some form of disability, a statement of educational needs or eligibility for a statement. In three services, only those with a learning disability were eligible. In another three services, the threshold was slightly lower requiring school action plus or above or was stated in quite wide terms, such as 'any young person likely to experience difficulties with transition'. In four areas, to receive a transition service young people had to be already receiving a service from the children with disabilities team, most often described as young people with severe, profound, multiple or complex disability. Three services defined their criteria according to their adult service eligibility criteria, or used assessment under criteria for Fair Access to Care Services (FACS).

One service, which was undertaking this work as a pilot, had chosen to initially focus their attention on special schools within their authority and particularly those young people within the school identified as meeting FACS criteria. Another pilot was working with 100 young people attending two special schools and one college for young people with severe learning disabilities.

Transition services also varied as to the age at which they would start working, and cease to work, with young people. Five of the 34 services started the process at age 13, however, most (24 services) started at age 14. Three did not take on the role until a young person reached 16 and one service when young people turned 17.5 years old. One service did not provide a starting age. The situation was also complex as to when transition services stopped for young people. Six services stopped at aged 18 years, nine at 19 years, five at 20 or 21 years, and the remainder (14) reported that the transition service could continue until a young person reached 25 years old.

## 3.5 Referral to the service

Table 3.11 shows the routes through which young people were referred to the services. The findings illustrate numerous agencies which could refer young people and these included social care, schools, health settings, voluntary agencies as well as parents/carers and self-referral.

**Table 3.11 Referral to the multi-agency transition service (n=33)**

| | *Number of services* |
|---|---|
| Social Care | 31 |
| School | 29 |
| Connexions | 28 |
| Education Authority | 26 |
| Parents | 22 |
| Community Health Service | 17 |
| Voluntary Organisations | 15 |
| College | 14 |
| Self-referral | 13 |
| Mental Health Service | 10 |
| Open referral | 10 |
| Learning Skills Council | 8 |
| Hospital | 7 |
| *Missing data* | *1* |

## 3.6 Processes by which young people enter the service

The processes by which young people entered the multi-agency transition services varied. Services adopted a range of methods to track young people with SEN statements, or those who were receiving a service from their children with disabilities team or Connexions, and identify who would be best placed to support them through transition (if they met the defined criteria for a service). Often this tracking started following the Year 9 educational review:

> 'All young people with a statement of SEN are automatically referred to the service, those who meet certain criteria are then tracked by the service. All young people who are statemented receive a Year 9 review and a plan completed by Connexions in partnership with the school and any other agencies involved. There is a transitional operational group which includes children's and adult services, Connexions and SEN, meeting regularly to provide information about young people coming through the process and to aid joint planning and commissioning'.
>
> 'Joint Agency Teams have an assessment service who allocate an initial keyworker, when a young person requires longer term work at age 16+, a transitions keyworker will be appointed from the multi-disciplinary team'.

About a third of services also had open and self-referral systems in addition to access through existing services.

## 3.7 Planning and review meetings

Twenty-seven of the services reported that once a referral had been received, initial multi-agency planning meetings were held. There appeared to be two interpretations as to the focus of these meetings. First, some services reported this as being a meeting at the service planning level where the agencies involved would come together and discuss all cases. Others reported this as a meeting at an individual level with young people and families to discuss their individual case, often linked to their year 9 review meeting. This is not to say that transition services only held meetings at one of these levels but may illustrate differing interpretations of the question, which was 'Once a referral has been accepted, are initial multi-agency planning meetings held?' Three respondents mentioned both types of meetings being held.

Twenty services stated that they held individual review meetings regularly, this normally equated to an annual review or six monthly meetings. Twelve stated it would depend on individual need (see Table 3.12). The way in which planning and review meetings were held varied across the services and it appeared that some had not yet fully developed multi-agency arrangements for this. For example:

> ‘Allocated workers organise 6 monthly reviews, usually with young people and their families. Education also organise annual reviews, attended by multi-professionals. It is hoped that we will find ways to combine them’.

Others had linked into the education/transition reviews. Organisation of these meetings often fell to the key worker/transition worker to arrange. One service clearly described their process of review and planning:

> ‘During their [young person] time in education these reviews would be linked to school college reviews and involve the education establishment, young person, parent/carer and TPA [transition personal adviser] plus other agencies who might be appropriate e.g. health. The TPA would clearly be working with the young person in an ongoing way to prepare for the review and also draw together in a person centred way the information needed for Community Care Assessment which the TPA has to complete by the time the young person is 17.5. Similarly the young person and their parent/carer would be involved in the adult service reviews plus TPA and social worker prior to the hand over from TPA to social worker’.

### Table 3.12 Details of review/planning meetings

| | *Number of services (n=33)* |
|---|---|
| Yes, regularly | 20 |
| Yes, occasionally as needed | 12 |
| No | 1 |
| *Missing data* | *1* |

Table 3.13 shows who attended review/planning meetings, obviously this would depend on the individual needs of the young person. However, it is interesting to note the relatively low engagement of health services (Primary Care Trusts, NHS Hospital Trusts and Mental Health Services). In only 14 of the services was there a representative from further education/college attending the review/planning meetings. In addition, four services indicated that parents/carers did not attend and three that young people did not attend. In two of these services, neither young people nor parents attended.

### Table 3.13 Attendance at review/planning meetings

| | *Number of services (n=31)* |
|---|---|
| Connexions | 30 |
| Transition worker/ key worker | 29 |
| Young Person | 28 |
| School | 27 |
| Parents/carers | 27 |
| Children and Young People's Social Care Stream | 26 |
| Adult Social Care Services | 17 |
| Primary Care Trust | 16 |
| FE/College | 14 |
| Lead Professional | 11 |
| Advocate | 10 |
| CAMHS | 7 |
| NHS Hospital Trust | 6 |
| Voluntary Organisations | 5 |
| Adult Mental Health Services | 2 |
| Housing/Supported housing | 2 |
| Person-centred planning co-ordinator | 1 |
| *Missing data* | *3* |

### 3.7.1 Person centred reviews/planning with young people

Ten services stated that they offered person centred reviews/planning to all young people. A further 23 offered it to some young people depending on a number of factors. Only one service did not offer this to any young people they supported. Factors affecting whether a young person and their family were offered person centred approaches or planning appeared to be whether there were the personnel, resources or time to facilitate it, who was the lead agency, whether the school they attended implemented person centred planning, and whether the family themselves wanted this approach. However, it should be noted that 19 out of the 23 services stating that they offered this approach to some young people described how in reality this approach was in limited use at present, although most had plans to extend it. Some were piloting the approach in their special schools or in one particular special school, some were rolling out person centred planning across their year 9 reviews held at school, one service was rolling out the approach across all years in one school but planned to extend to other schools in the future. One respondent summed up what appears to be the case across many services: *'this work is in its infancy'.* Some reflected how time consuming the process was and how this affected its availability to families.

Services were asked which planning tools they used with young people and their families. Twenty-one of the services used the Valuing People planning model, and 17 used a transition pathway. However, only 12 used Health Action planning, although this is not to say that health issues would not be covered within other tools. In reality, services often used a number of tools and some reported that they had to be flexible to meet the needs of the individual young person and their family.

**Table 3.14 Planning tools used with young people and families**

| | *Number of services (N = 31)* |
|---|---|
| Valuing People Person-Centred Transition Planning | 21 |
| Transition pathway | 17 |
| Health Action Planning | 12 |
| Own tools developed | 6 |
| Other | 5 |
| *Missing data* | *3* |

A number of services stated that they used a variety of tools to facilitate communication with young people and their families, for example, photographs or observation. One respondent mentioned that their special schools developed tools for use with young people with communication impairments. Some services had developed their own planning 'booklets' for use with young people.

The 33 services who facilitated the involvement of person centred reviews or planning with young people were asked to rate the quality of person centred reviews/planning within their service. Only one stated 'very good', the majority 20 stated ‘good’, nine reported ‘not very good’, two did not know as the service had only just started and one did not respond.

### 3.7.2 Improvements to the involvement of young people and families in planning

Twenty-nine respondents provided comments on what improvements could be made to the involvement of young people and their families in planning for their transition (see Table 3.15). From responses it appeared that improved information was important, particularly for families and young people at an early stage, as well as accessible information for young people.

Eight services reported that there needed to be improved multi-agency working, particularly with education and further education providers, and employers. One respondent wrote:

> ‘Clearer information and preparation from education would empower families to be more pro-active at year 9 review meetings’, another stated that ‘year 9 reviews were not always well used or well advertised as tools for transition planning and families did not always realise that these had this purpose’ One respondent specifically mentioned the need for special schools to dedicate more time to this and more ‘acknowledgement that there is a need for a different approach placing the user at the heart of decisions about their lives’.

Three respondents particularly mentioned the need for more commissioned services for young adults, as one wrote:

> ‘Commissioning capacity to enable forward planning, developing supported living and education/employment options in advance, before the need becomes pressing’.

Likewise earlier planning was mentioned by five respondents. For two respondents a clearer strategic direction was needed which supported ‘young people to become as independent as possible with their local community’.

### Table 3.15 Improvements to assist the involvement of young people and families in planning

| | *Number of services (n=29)* |
|---|---|
| Improved information for young people and families | 9 |
| Improved multi-agency working | 8 |
| Earlier planning | 5 |
| More resources | 5 |
| Greater capacity of staff/more staff | 3 |
| More commissioned services for young adults | 3 |
| Strategic direction | 2 |
| Relaxation of some of the statutory demands | 1 |
| Core staff trained in PCP | 1 |
| Mentoring service for young people | 1 |
| More time for young person and family to engage in process | 2 |
| *Missing data* | *5* |

## 3.8 Information materials

When services were specifically asked if they produce information materials describing the service and what it had to offer, it can be seen that this was indeed an area for improvement, with only 27 services producing materials for parents/carers, and only 22 for young people themselves. In addition, only 25 produced information for other professionals describing the service they provided.

### Table 3.16 Production of materials describing the service and what it has to offer

| | *Number of services (n=32)* |
|---|---|
| For parents/carers | 27 |
| For young people | 22 |
| For other professionals | 25 |
| *Missing data* | *2* |

Of the 27 respondents who provided further details, 14 expressed that they were in the process of developing or revising their information materials, particularly accessible materials for young people. Others, however, had developed guides/ leaflets on:

- post 16 options for young people, parents and professionals;
- entitlements and rights;
- the transition team;

- ‘Moving on guide’/guide to transition;
- year nine reviews;
- transition standards.

Information was being provided in a number of forms. Two services had developed DVDs, another was using electronic passports and a pictorial pathway with young people, and one had a website that was accessible in schools and on the county council's website. One mentioned that their Connexions materials covered the basics, including information aimed at young people and information aimed at parents of young people with learning disabilities. Two respondents stated that there was a protocol and policy in place for professionals. One stated that they did not produce any specific transition information.

## 3.9 Exiting the service

As already described the age of a young person often determined when they both entered and exited the transition service, and this varied across services. Although chronological age does not necessary give a good indication of the needs of a young person or readiness to transfer, 17 services used age as a marker for exiting the service. Others appeared to adopt a more flexible approach which was linked to the nature of the young person’s impairment, their educational status or their eligibility for adult services. Table 3.17 gives a breakdown of responses.

**Table 3.17 Age at which young people exit the transition service**

| | *Number of services (n=33)* |
|---|---|
| Aged 25 | 8 |
| Aged 19 | 3 |
| Aged 18 | 6 |
| No set age | 10 |
| Dependent on disability* | 2 |
| Dependent on educational status** | 2 |
| Dependent on eligibility for adult services*** | 1 |
| Varies according to agency**** | 1 |
| *Missing data* | *1* |

*1 = 19 years for young people with learning disability and sensory impairment, 18 years for young people with a physical disability. 1 = end of academic year post 19 for SLD and on 18th birthday for sensory impairment or physical disability

**1 = 18 if no longer in full-time education, 19 years and 2 terms if in full-time education. 1 = within one year post education.

***If they do not meet the criteria for adult services then it would be 18, if accessing adults then it would be 25.

****On 18th birthday for social care and health and July of 19th year for education

No set age was often defined in terms of when the young person is settled into adult provision. As one respondent stated:

> ‘The spirit of the protocol is that the relevant agencies remain jointly involved in transition planning until plans/arrangements are established which can be reasonably judged as medium/long term adult ones. However, the protocol recognises and sets out specific transition points such as transfer from children’s social care to adult social care or from school to college’.

Others wrote, ‘*They exit transition when they are settled in an adult service. This could be at 18 or up to 25 but it is usually about 20 or 21’*, and *'They exit at the most appropriate time for the young person – when their support package is in place and stable or if they have moved into a college course post 19 years*'.

### 3.9.1 Arrangements for handover to adult services

It appeared from responses that practices regarding arrangements for handover to adult services were varied. A third of services had developed clear protocols on the procedures and timetable that should be followed and of the flow of information between the services:

> ‘Adult service link into reviews from 16 plus. The transition team send monthly information to adult services about people in transition. Once assessed and care plans made all documentation is sent to adult services. Case hand over at 18 years of age in the main’.

One service noted that this was made easier by having a specialist transition social worker on each side of the transition. A third had practices where children and adult social workers jointly work together on cases for a period of time, five held joint planning or operational groups where cases were discussed and passed across. Two transition services were based in adult social care, so reported that handover was simple:

> ‘Care managers work with children’s services for the last year or two years before handover. Person centred transition plans provide adult services with information needed and for some young people a person centred hand over meeting is held’.

However, for eight services this was not a clear process or the process was still being developed:

> ‘Still being discussed – currently regular meetings to highlight young people coming through the system and agreements made to refer via

children with disabilities team at 17. Hoping to develop arrangements – need to link in with Community Care Assessment process etc'.

## 3.10 Transition and key workers

Services were asked whether young people had one person as a transition worker/key worker, defined as a person who 'provides a single point of contact that the young person and/or family can approach for advice about any issues surrounding transition.... and [who] has responsibility for working with professionals from their own and other services'. Twenty-three services stated that they had such workers, 11 did not operate such an arrangement. Across these 23 services the numbers of young people who had a transition worker varied considerably, from none (as the service was just starting), through to all young people in SEN schools (see Table 3.18).

**Table 3.18 Numbers of young people who have a transition/key worker**

| *No. of young people with a transition worker/key worker* | *No. of sites* |
|---|---|
| 0 | 1 |
| 1-20 | 1 |
| 21-40 | 3 |
| 41-60 | 0 |
| 61-80 | 3 |
| 81-100 | 1 |
| 101-200 | 2 |
| 201-300 | 1 |
| 301-400 | 0 |
| 401-500 | 1 |
| All young people meeting eligibility | 2 |
| Not yet implemented | 1 |
| All young people in SEN schools | 2 |
| Not applicable | 11 |
| *Missing data* | *5* |

Four services reported that there was a waiting list of young people requiring a transition/key worker. The number of young people on these lists varied, from four to 29, as did time on the waiting list: one service stated that young people had to wait a month to be allocated a transition/key worker, two stated three months, whilst the other stated that all young people would be allocated a worker by the age of 17.

Most often young people were matched to a transition/key worker based on need and capacity/availability of workers, a small number of services were able to match workers and young people based on relevant skills of the worker, for example, skills in particular communication methods. However, in some services it was the case that there was only one transition worker, or one transition worker for the geographical area in which the young person lived or the school they attended. In only three of the 23 services did young people have a choice as to their transition/key worker.

### 3.10.1 Professional backgrounds of transition workers/key workers

Table 3.19 indicates the professional backgrounds of the transition workers across the services. It can be seen that the majority of workers were either social workers from children's or adult services, or Connexions workers. A small number of services were employing health practitioners, and a smaller number employed those with an educational background as transition workers. It should be noted, however, that the health and education staff were mostly part-time posts.

**Table 3.19 Professionals working within the multi-agency service as transition/key workers**

| | *Number of services (n=23)* |
|---|---|
| Social workers (Children's) | 10 |
| Social workers (Adults) | 10 |
| Connexions workers | 10 |
| Community nurses | 4 |
| Teachers (schools) | 2 |
| Paediatricians | 2 |
| Speech therapists | 1 |
| Occupational therapists | 2 |
| Physiotherapists | 1 |
| FE staff | 1 |
| Psychologists | 1 |
| Workers from voluntary agencies | 2 |
| Other* | 2 |

**Employment Service & Contact and Assessment Workers*

### 3.10.2 Numbers of transition/key workers

Survey respondents were asked to supply information on the numbers of transition/key workers they employed. Of course, the number per service will depend upon a number of factors such as the role and function of the worker (direct or indirect support to families), the size of the authority, scope of the transition service and level of need in the local area. Services varied in their transition workers from one to 14.5.

**Table 3.20 Numbers of transition/key workers currently within services**

| | *Number of services (n=21)* |
|---|---|
| 1 | 2 |
| 2 | 4 |
| 3 | 3 |
| 3.3 | 1 |
| 4 | 1 |
| 4.5 | 2 |
| 5.5 | 1 |
| 6 | 1 |
| 6.5 | 1 |
| 7 | 1 |
| 10 | 1 |
| 13 | 1 |
| 14.5 | 1 |
| Varies allocated by practice manager according to need | 1 |
| *Missing data* | *2* |

Of the 23 services with transition/key workers, 17 stated that they had ‘designated’ workers (workers employed exclusively in this role), three had ‘non-designated’ workers (workers working on transition but as part of a larger case-load and/or other role) and three had both. Thus the majority of services (86 per cent) had at least some designated workers.

Of the 20 with designated workers, the numbers of workers varied from one to 14.5 (see Table 3.21). These workers were employed by a number and combination of agencies; in nine services transition/key workers were employed by two or more agencies (for example, children's and adults' services; Connexions and children's disability service; Connexions, PCT and local authority; children's social care, adult social care and voluntary sector).

**Table 3.21 Number of designated transition/key workers**

| | *Number of services (n=20)* |
|---|---|
| 1 | 3 |
| 2 | 3 |
| 3-4 | 8 |
| 5-7 | 4 |
| 10 | 1 |
| 14.5 | 1 |

The numbers of young people supported by each full-time equivalent designated worker varied across services from five through to 50, with a median value of 20.

**Table 3.22 Numbers of young people supported by each FTE designated transition worker**

| | *Number of services (n=17)* |
|---|---|
| 5 – 10 | 3 |
| 11 – 20 | 6 |
| 21- 30 | 3 |
| 31 – 40 | 2 |
| 41 – 50 | 1 |
| Unknown – new service | 2 |
| *Missing data* | *3* |

Of the six services who had non-designated transition/key workers, one stated that they had two workers, another had five workers, one had eight workers and another had 20 workers. Two did not supply any information. Four services reported on the numbers of young people that workers would support in this role, two stated this would be three young people, one stated five and one stated 20 young people. Only two services were able to supply information on the proportions of time that non-designated workers spent on transition, in one this was 20 per cent and in another 50 per cent.

Services with transition/key workers were asked whether they had any such posts vacant within their service. Sixteen did not, five had one post vacant and one had two posts vacant, although this latter service had only just started.

All respondents were asked to report on whether there were key workers designated in adult services to take over a case following transition, 24 supplied information which indicated that 18 had designated workers in adults, four did not, one had a joint appointment between children's and adult services, and one did not know the answer.

### 3.10.3 Role of transition/key workers

Fifteen respondents provided valid information on what the role of transition or key workers covered. The roles varied considerably between services. Seven respondents described the role as including coordinating care, attending reviews and other meetings, liaising with other professionals, drawing up transition plans and care packages, and providing support to young people and parents. These are tasks that are seen as central to the role of a key worker in services for disabled children

(CCNUK, 2004). In addition, one respondent described the role as supporting young people to achieve their goals, including support with education, housing, employment and health needs, but was less specific about ways in which this was done. In three services, the role was one of support for the professionals who worked directly with the young people (for example, the social worker or lead professional). In these cases, the transition workers may coordinate, monitor and track cases but did not work directly with most of the young person receiving the service (although they may work directly with very complex cases). They often attended, and in some cases organised, reviews and completed or oversaw transition assessments and plans. In four further services, the role appeared to be mostly about assessment and completing transition plans.

Specific questions were asked about transition/key workers' direct contact with young people and parents. Data for one service was missing, but in all others transition workers did visit some young people at home, school/college or employment and did communicate with parents.

### 3.10.4 Training and supervision of transition and key workers

Within the 23 services, eleven stated that they provided special training for transition and key workers on appointment, ten did not and two did not answer. Mostly this training consisted of an induction training package, including child protection or safeguarding adults. In some areas where Connexions services were integral to the model, transition workers received a combination of generic Connexions training and social services training. Two services mentioned training on Person Centred Planning and Health Action Plans.

Nineteen services provided information on arrangements for ongoing training. Three provided no ongoing training. In the other services, training included having access to relevant courses, conferences or workshops as appropriate, Person Centred Planning, Heath Action Plans, generic Connexions training and social services training, child protection and safeguarding adults.

The supervision of transition workers also varied across services. Twenty supplied information, in 15 transition workers were supervised by the team manager of the service within which they were based. However, three reported joint supervision by managers of two or more of the services who formed part of the multi-agency service, and two reported supervision by a specific transition team manager.

## 3.11 Transition support for young people placed out of authority

A small number of questions on the survey sought information regarding transition support for young people placed out of authority. Only 14 of the 34 services provided support to all young people in residential weekly placements, 17 provided support sometimes and three did not have any provision.

Similarly, 13 out of 34 provided support to all young people in residential termly placements, for 17 services this depended on a number of factors, and one did not provide any support to these young people. Twenty services provided transition support for young people in 52 week placements, in 13 areas this depended on a number of factors, whilst one service had no provision available for this group. Across all of these types of placements where services stated that transition support was dependent on a number of factors this was most often defined as ‘cases would be assessed on an individual basis’, and whether they met services' eligibility criteria. Thus the majority of services did provide support to young people in out of area placements if those young people were assessed as needing such support and/or met the eligibility criteria for the service.

Services were also asked about the numbers of disabled young people from the authority who transferred to adult services from an out of authority placement during the last year (April 2006 – April 2007). Three services did not know and ten did not answer, whilst in the other services the numbers ranged from 0 to 30.

**Table 3.23 Number of disabled young people from the authority who transferred to adult services from an out of authority placement last year (April 2006-April 2007)**

| | *Number of services (n=24)* |
|---|---|
| 0 young people | 1 |
| 1 | 1 |
| 2 | 3 |
| 3 | 4 |
| 4 | 3 |
| 5 | 3 |
| 6 | 1 |
| 10 | 2 |
| 12 | 2 |
| 30 | 1 |
| Unknown | 3 |
| *Missing data* | 9 |

## 3.12 Improvements to services

Respondents were asked to comment on what they felt their service could improve upon. The majority of respondents wanted to see improvements in person centred planning, information provision and more transition workers to support young people and families, which in turn would allow the service to support a wider group of young people. Other suggestions were around improved processes such as hand-over arrangements, accessible assessments, more robust support systems and more engagement with parents and young people. On a strategic level improvements centred on improved partnership working, particularly with mental health services and schools, the need for improved steering groups, and improved clarity about roles and expectations. One respondent mentioned the need for more adult services and another noted the need to develop services for BME groups.

**Table 3.24 Suggested improvements to transition services**

| | *Number of respondents (n=32)* |
|---|---|
| More person-centred reviews/planning | 7 |
| Improved information for young people and families | 6 |
| More transition/key workers/lead professionals | 5 |
| Improved steering group | 3 |
| Improved young people's involvement | 3 |
| Improved hand-over arrangements | 3 |
| More engagement with parents | 3 |
| Supporting more young people and families | 2 |
| Mental health partnership | 1 |
| Extending service to those not meeting criteria for children with disabilities team | 1 |
| Use of individual budgets | 1 |
| More links with schools | 1 |
| Improved adult services | 1 |
| Improved clarity about roles and expectations | 1 |
| More accessible assessments | 1 |
| More robust support systems | 1 |
| Development of services for BME groups | 1 |
| Involvement of young people and families in design/ evaluation of service | 1 |
| *Missing data* | *2* |

## 3.13 Reflections on experience of multi-agency transition services

Respondents were asked to comment on what they had learned through their experience of the multi-agency transition service and would want to pass on to others, firstly as being particularly problematic, and secondly as being particularly useful.

**Table 3.25 Problematic issues within the multi-agency transition service**

| | *Number of respondents (n=29)* |
|---|---|
| Partnership working | 21 |
| Resources and funding | 5 |
| High levels of need | 4 |
| Lack of services | 3 |
| Need for a distinct team | 1 |
| *Missing data* | *5* |

*Note: Respondents could give more than one answer.

The problem most frequently mentioned concerned partnership working. Twenty-one respondents identified this as being a problem within their transition services. Examples of this included finalising agreement amongst all parties on a transition plan; ensuring communication between agencies; overcoming budget and expectation differences between partners; working with individual agendas; securing organisational commitment rather than on an individual level; the need for clear roles and responsibilities; partners delivering on agreed actions and attending meetings; overcoming cultural and practice differences; securing the involvement of some agencies (schools and mental health services were mentioned in this context); and the links between children's and adult services. Two highlighted the legislative context as being particularly difficult as it inevitably involves both the child and adult agendas. One described it as:

> 'Overlapping and complex, and agencies and professionals can get 'stuck' on their bit of legislation and defensive of their territory'.

One mentioned the problem of different services having different accessibility criteria for services and another, the difficulty of competing targets amongst partner agencies.

Five respondents reported that funding and resources were problematic: noting that financial insecurity of some services has an impact on their commitment; highlighting the difficulty of securing funding for posts; and citing access to funding in FE, especially for young people with high level need. Four respondents mentioned the problems of high levels of need and trying to establish a good quality service to all young people with such varying need. As one stated 'improving services uncovers more need and stimulates demands, with consequent resource pressures'. Another three reported on a lack of services such as mental health services and lack of further education options. One particularly mentioned the difficulty of reconciling good planning with realistic support plans and another noted difficulties in keeping interest and momentum in adult services due to staff changes. Finally, one reported the difficulties of running a service without having a distinct team.

Respondents identified a number of factors as being particularly useful and helpful to them in the establishment and operation of the multi-agency transition service (see Table 3.26). Partnership issues and multi-agency working were the most commonly identified factors. Developing a shared culture and working on relationships was described by many respondents as being valuable. This included developing understanding and knowledge about each others' role and responsibilities, legal requirements, targets, drivers and performance assessment frameworks. Good communication and sharing information across agencies, and joint planning were also seen to be of benefit to the services, as were shared goals and vision. As one respondent described:

> ‘[It is] crucial to establish shared expectations/vision of what a good service looks like.... We have had debates about the role of advocacy and person centred planning versus the need for best value – these things are compatible but require negotiation’.

Three respondents described the importance of having full strategic involvement at a multi-agency level:

> ‘Full strategic agreement at the start of a project which involves a number of partner agencies is a must, and a clear project management capacity and agreed focus maintains the direction of travel reporting to a multi-agency steering group’.

Three respondents mentioned the importance of accountability, described as ‘key people taking responsibility’, and ‘a strong steering group of senior managers to ensure discussions are actioned’. Another noted the importance of having a protocol in place to enable staff to work consistently across the authority.

Other factors focused on the team and service delivery levels. A couple of respondents mentioned the importance of involving young people and parents/carers and thus ‘check out your assumptions about your service’. Two respondents mentioned the importance of having designated workers to support transition, and one highlighted the importance of employing a coordinator for the service. Others recommended ‘start with a clearly defined small group and expand as the service develops, engaging other agencies in the process’, having a ‘can do’ attitude, sharing problem solving, and having an outcomes based approach. One noted the benefits of having regular multi-agency meetings bringing everyone involved in transitions together.

**Table 3.26 Helpful factors in multi-agency transition services**

| | *Number of respondents (n=26)* |
|---|---|
| Multi-agency partnerships/working: | |
| • develop shared culture and relationships | 9 |
| • good communication/share information | 3 |
| • all agencies involved | 3 |
| • shared goals and vision | 2 |
| • senior management from partner agencies involved at strategic/steering level | 3 |
| • share resources | 1 |
| • joint planning and protocols | 2 |
| • multi-agency meetings | 1 |
| Accountability | 3 |
| Involve young people and parents | 2 |
| Designated transition workers | 2 |
| Plan based on young people’s outcomes | 1 |
| Do not underestimate need | 1 |
| Share problem solving | 1 |
| Employ a co-ordinator | 1 |
| Positive/ can-do approach | 1 |
| Start small and expand | 1 |
| *Missing data* | *7* |

*Note: Respondents could give more than one answer.

## 3.14 Evaluation of transition services

Only 12 of the 34 services had undertaken any evaluation of their service. However, given the fact that most services had only been in operation for a short period perhaps this is not surprising.

## 3.15 Summary

The survey findings indicated a complex picture of multi-agency transition services with a wide variety of models and approaches being adopted across the country. At the time of the survey, many authorities had not yet established multi-agency transition services. For those who had, many services were in their infancy and were developing, with some transition services in a piloting phase. Funding was also not secure for a third of the services, which implies that the situation was uncertain and possibly changeable.

The findings also illustrated that the terminology surrounding multi-agency transition services had different interpretations. For example, authorities were using the same term of 'transition worker/key worker' to describe very different roles. Some roles involved little direct support to young people and their families but supported other workers who worked with the young people, while others held cases, worked directly with young people and families, liaised with other services and coordinated the full transition processes. Likewise, there were issues concerning definitions of 'multi-agency', where, for instance, one service considered they were multi-agency because their transition service bridged children’s and adults’ social care, but had no other agencies involved.

The eligibility criteria for young people to receive transition support appeared to be predominately based on severity of learning disability or statements of SEN, and thus questions still remain as to the support given to other disabled young people and those with complex health needs or high functioning autistic spectrum conditions who might not have a statement of SEN but would need support around transition.

Findings on which agencies were involved in setting up or overseeing the services suggested there was limited involvement from health partners in some of the multi-agency services and in a few, it would appear that education might also not have been as involved and committed as they could/should be. These issues were further explored in the later stages of the research. The lead agencies for around a third of the services were local authority children's services, and these services were involved in setting up and overseeing nearly all the services. This may be a result of the initial screening survey being sent to Directors of Children's Services. However, if services were truly multi-agency, it would be expected that Children's Services would be involved in all of them, so this appeared to be the best route through which to make initial contact. A slightly smaller proportion were led by Adult Social Care services, and only two services had health involvement in a lead role, in both cases this was as part of a partnership with local authority services.

Positively, the transition survey demonstrated that specific services were being developed and resources being made available to support transition. Specialist roles and workers were developing and the improvement of transition was high on the agenda.

However, the limitations of the survey must be acknowledged. It has been noted (for example, McConachie *et al.,* 1999) that reliability of survey responses is limited and responses from different professionals in the same service may not concur. In this study, it became apparent that this was the case during the further exploration of some services when they were approached to be case studies (see Chapter 2). The survey also provided only a 'snapshot' of multi-agency transition services in England, and did not provide information on the history and development of such services. In addition, although the response rate to the screening questionnaire (70 per cent) was good for a postal survey, only 34 of the 50 services identified by this went on to complete the detailed questionnaire. It was difficult to calculate a true response rate for this stage as for some non-completers this was because their current service was not multi-agency. Nevertheless, it is clear that the survey did not provide a complete picture of multi-agency transition services and some services remained undetected. The limited nature of the survey methodology prohibited any detailed exploration to establish which models and approaches produced the best outcomes for young people and their families or indeed provide a more satisfactory process of transition. The next stage of this research explored processes and outcomes of different models of services through detailed case studies in five areas.

# Chapter 4 The Transition Services

In this chapter, we provide brief details of the five services and the areas in which they are based. We then examine a number of aspects of the services in more depth, including:

- The characteristics of the services, including eligibility criteria and arrangements for referral, assessment, review, and transfer to adult services.

- The characteristics of the transition workers and teams including their professional backgrounds, their roles, use of person-centred planning, their training, management and supervision, case loads, and their perceptions of the constraints of the role and what worked well.

- The role of the transition services manager, and the overall management and oversight of the services.

- Multi-agency working and facilitators and barriers for this.

- How the services meet the priorities of young people that have been identified in previous research.

This chapter draws on findings from interviews with transition workers, managers and members of steering groups, and staff in other agencies who work with the services and the young people they support. We finish by examining their perceptions of the advantages and disadvantages of the services and areas for improvement.

## 4.1 Overview of the five services

### 4.1.1 Service A

Service A covers a predominantly rural county with a population of 498,093 (2001 census). At the time of the census, 24 per cent of the population were aged 19 years or under and just less than three per cent were from black or minority ethnic groups. Although there are significant areas of both rural and urban deprivation, the county overall has lower levels of deprivation than the national average.

The service was set up in September 2002 in response to Valuing People (Department of Health, 2001) and a subsequent local conference on transition that identified transition services/support as poor. Additional momentum came from the fact that adult services did not know who was coming up from children’s services and were therefore unable to plan provision. Transition workers were appointed initially and the protocols, structures and systems then addressed. These evolved as the service developed but the focus has remained on families having one transition worker to support them through the process.

The transition service is funded by Adult Learning Disability Services, Connexions and Adult Social Care. The transition workers are employed by Connexions. At the time we visited, the service had six people working as transition workers covering four and a half fte posts. Four of these posts supported young people with learning disabilities and were based in community adult learning disability teams. One half time post supported young people with a physical disability and/or sensory impairment across the whole county and was based within the Connexions service.

A manager (approximately 0.5fte) employed by Connexions oversees the day to day running of the service. A multi agency transition steering group meets quarterly to provide strategic guidance, develop and review policy/procedures, and trouble shoot.

In January 2009, the service supported 183 young people[1].

### 4.1.2 Service B

This service covers a small unitary authority comprising two urban centres and surrounding villages. At the time of the 2001 UK census, the total population was 118,208. The proportion of children under 19 was 24 per cent and the proportion of black and minority ethnic groups was 1.2 per cent. In national terms, the area suffers high levels of ill health, low employment rates, and life expectancy is lower than the national average.

The transition service was launched in June 2005 after publication of the government report *Improving the Life Chances of Disabled People* (Cabinet Office 2005) which set out a vision for improving the lives of disabled people, including facilitating a smooth transition into adulthood. A multi-agency strategic management group was set up to develop a transition strategy and action plan for young people with complex needs. A transition manager/coordinator, employed by social services, was then appointed to ensure this strategic plan was delivered and driven forward. Initially this manager was based in adult services but the post has been based 50/50 in children’s and adult learning disability services since April 2007 when the current manager was appointed. Other than the manager there are no other designated transition workers.  The transition manager has a coordinating role, and working around the transition manager is a virtual team of social workers from the children with disabilities team and the adult community care teams who work on transition as

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[1] Numbers quoted are based on those provided for the family survey in Jan 09.

part of a wider caseload. The service is jointly funded by adult and children's social care.

A Strategic Management Group oversees the service and regularly reviews the strategy and protocols for transition including the transition action plan. The group meets every two months.

In January 2009, the service supported 72 young people.

### 4.1.3 Service C

This service covers an inner city London borough with a population of 248,922 people (2001 census). Of this total population, 26 per cent were aged 19 years or under. Approximately one third of the overall population and 50 per cent of pupils in local schools were from black and minority ethnic communities. Deprivation is a major factor in this area, with the household income well below national average.

The multi-agency transition service was initially set up in April 2003 following a ten-year period of working groups, pilots and research and development programmes around transition within health, which found that transition could only be well-organised if new resources were created as practitioners in their daily working lives did not have time to liaise across service sector barriers (children’s to adult services, health to social care). Since its launch in 2003, the transition team, then based in adult services, has experienced chronic staff shortages. In June 2007, the transition team was re-launched in children’s services, however, staff shortages meant that the team continued to operate a reduced service. At the time of interview, the transition team had become fully staffed for the first time in its history, having recently increased from a lone transition worker to a team consisting of a transition manager, a transition social worker, a half-time social work assistant and a business support officer.

The service is mainly funded from social care budgets with some additional money (reviewed on an annual basis) provided by Connexions. Initially finance was also provided through Health Action Zone funds and Connexions.

The transition service is a coordinating service providing information and guidance on transition pathways to lead professionals from various agencies. The team is based in the Children and Young People’s Directorate in a multi-agency centre for children and young people. A steering group meets every six weeks to oversee the service.

In January 2009, the service supported 184 young people.

### 4.1.4 Service D

This service covers an outer London borough with a population of 263,464 (2001 census). The proportion of the population aged 19 and under was 25 per cent. It is one of the most culturally diverse areas in the UK, with more than 50 per cent of its residents from black and minority ethnic groups. In relation to the national average, the area has high levels of deprivation and a high transient population.

The transition service was set up in November 2007 following a joint area review that was critical of transition services for disabled young people and a period of work looking at issues around integration and joint working. As a result, the disabled children’s service was split into three age-based services, which included a transition team for disabled young people aged 14 to 18 that focused on transition-specific issues as well as generic social work for this age group.

The transition team is located within the education department in the new integrated disabled children’s service. The transition team comprises a manager, three social workers, two key workers, and a nurse. Also attached to the team are a trainee educational psychologist and two Connexions personal advisers. This service also benefits from having a designated social worker, senior social worker and nurse working on transition cases in adult services.

The service is funded by Children's Services, the Primary Care Trust and Connexions. A steering group is responsible for developing the transition service and raising issues such as gaps in provision with commissioners.

In January 2009, the service supported 76 young people.

### 4.1.5 Service E

This service covers a primarily rural county with a population of 668,553 (2001 census). Of the total population 23.7 per cent were aged 19 or under and 2.8 per cent were from black or minority ethnic groups. There is considerable variation in economic prosperity across the county, with deprivation in some areas above, and in others significantly below, the national average.

Transition support in the county is provided by three area-based disabled young people's teams: the western, northern and southern area teams. Our research focused on the western area where the transition service for the entire county was first set up as a pilot in 2004/2005 by managers within health and social care with a keen interest in transition.

At the time of the research the transition team comprised a senior social work practitioner, a social worker and a business support officer. However the team would normally also include a family support practitioner and a transition learning disability nurse. The wider transition team typically included a Special Needs Officer from Education, a Connexions Personal Adviser, and a Leaving Care worker who, in addition to their main jobs, had a remit for transition. The team is based in a drop-in centre for young people with disabilities.

Funding is provided by Children's Services and the Primary Care Trust. A countywide steering group meets termly to oversee the development and work of the transition teams.

In January 2009, the service supported 52 young people.

## 4.2 Aims and philosophy of the services

In all services, staff described the philosophy of the transition service in terms of empowering the young people to make the most of their future by putting their needs and aspirations at the centre of the transition process. In three services, staff also referred to an underlying principle of social inclusion and integration, and in two services to one of promoting and supporting disabled young people’s independence.

The basic aims of the services were also very similar across all five services. These were:

- To prevent young people from falling through the gap between children's and adult services.
- To enable better planning and projection of future service need by identifying young people early.
- To provide more direct support to young people and their families ranging from reducing parent/carer anxiety through early information sharing and planning, to assessing needs appropriately and preparing young people and families for the different service/culture within adult services.
- To ensure a smooth and seamless transfer from children’s to adult services.
- To manage a robust and well-organised process that is fair and transparent.
- To provide coordinated support and a more joined up service for families through inter-agency working.

Additional aims identified by staff in two services were to create more opportunities and choice for young people:

> ‘It’s about identifying where gaps are for young people and trying to… open more options for them’.

## 4.3 Key characteristics of the services

### 4.3.1 Eligibility criteria

Across all services, eligibility criteria only included young people at the high end of need, and specified disabilities or conditions that were severe, significant, substantial, life threatening or complex. Additionally, a guiding principle for all five services was the likelihood that the young person would meet the eligibility criteria for Fair Access to Care Services (FACS) in adult social care within their local authority.

***Physical and/or learning disability criteria***
All services supported young people with severe learning disabilities and/or substantial physical disabilities. However, in one service, young people with an IQ of 70 or less were eligible for the main service, and where necessary IQ tests were used to establish eligibility. There was a reduced service for young people with a physical disability and/or sensory impairment, which was provided by one half time transition worker post. In two services, eligibility was dependent upon the young person having a statement of special educational needs and having been assessed as having a high level of need or having complex needs that require multi agency input. In another service, frontline staff acknowledged that they only supported a very small minority of young people with physical disabilities alone, the majority were young people with a severe learning disability. In reality, therefore, whilst services did support some young people in mainstream schools, their main focus was on young people in special schools with a severe learning disability. More often than not, these young people were either being supported, or had previously been supported, by children's social care services.

Nevertheless in three of the five services staff reported providing some type of support to young people who did not meet the eligibility criteria for their full service. For example, one service continued to offer advice and guidance to young people until they were aged 25 if they were assessed as having a low to moderate special educational need and were not transferred to an adult social care team. This support was limited to twice yearly contacts to check if help was needed. In another service, monthly practitioner meetings provided a multi-agency forum for professionals to seek information and advice about young people in transition who failed to meet the eligibility criteria for support from the transition service.

***Excluded groups***
Across all five services, staff reported vulnerable young people who needed support in planning and adapting to adult life that fell outside the remit of their service. For example, the lack of support for young people with high functioning autistic spectrum conditions and no other difficulty was frequently mentioned by staff in all services. Other identified gaps in support were for young people with mental health issues in

three services, and young people in mainstream schools with a range of disabilities including visual impairments in one service. When not eligible for support from the transition service, young people were referred to other services for support, typically Connexions, but also mentioned were education and leisure services; local voluntary sector agencies; and other social care teams such as adolescent outreach or assessment and family support.

***Differing criteria***

Some staff reported a mismatch between eligibility criteria for children's and adult services, with some young people who met the criteria for children's services but not for adult services. They also reported a discrepancy between different ages at which children's services finished and the corresponding adult service began. One service had brought into line the age at which young people transferred to adult social care services and the age of transfer to adult health services.

It was also found in one service that eligibility criteria within the same transition team differed. Whilst the transition social workers worked with young people with either a physical or a learning disability, the transition nurse only worked with young people with health or behavioural needs if they also had a learning disability.

### 4.3.2 Age of young people supported

In all services, staff reported that transition support began at age 13 to14 years. This was consistent with statutory regulations that required the head teacher to call a transition review meeting to review young people's statements of SEN and draw up transition plans in Year 9. In practice, however, staff in every service reported not being actively involved in cases until the young person was aged16 and not usually linking in with staff from adult services until aged 17.

There was variation between services in the age at which transition support ended and young people exited the service. In two services, support for young people formally ended on their 18th birthday. However, in one of these services, young people were transferred to transition social workers within the adult social care team who continued to support them up until the age of 23, when they were referred on to generic care managers.

In another two services, transition workers continued to support the young person until they completed their education, including further education. In one of these services, involvement stopped when the young person was 'settled' into adult services as determined by social care managers, usually at age 20/21 but could have been up until aged 25. In the other, the transition service was involved until the young person's first review in adult services which could have been up until age 21. In the remaining service, the transition team was formally responsible for young people until age 25. However, in practice in this service, cases became ‘inactive’ once they transferred from children’s to adult social workers, and only remained ‘active’ if they did not transfer to adult care teams. Active cases were monitored through twice yearly contacts up until the young person was aged 25.

However, despite official protocols, staff in three services reported working with young people beyond their remit date – for weeks or months or up until a year. This was attributed to a lack of adult social workers to hand over cases to.

### 4.3.3 Identification and referral

In all services, most young people eligible for support were identified via lists provided by the local authority’s SEN service of young people with statements or receiving enhanced educational provision. These lists were also intended to identify young people in out of area residential placements who were returning to their ‘home’ authority because their placements had come to an end.

Individual cases from these lists were then discussed in multi-agency meetings to give an early warning to the transition team and to adult services about young people coming up who would be requiring their services in the future.

For all services, young people could be referred by anyone (including self-referral) but the majority of referrals were received from children’s social care teams and had already been identified in the meetings outlined above.

Other referral routes mentioned by staff included:
- LEA/SEN service
- schools and colleges
- community health service
- Connexions
- mental health services
- young people’s advocates
- other social service departments for out of area placements
- customer service departments.

### 4.3.4 Assessments and reviews

**_Assessments_**
In two services, transition workers carried out comprehensive multi-agency assessments to identify the package of care a young person would need in adult services, put together and secured funding for a care package, and care managed

the young person until they were ‘settled’ in adult services. In one of these services, a single assessment process (SAP) was followed, whereby the transition worker collected and collated any relevant information about the young person, but other professionals involved with the young person may complete specialist sections of the SAP form. In the other service, when in post, the transition learning disability nurse carried out Health Action Plans and input these to the assessment. Also in this service, where a case was complex, the transition social worker and the allocated social worker from adult services might work together to put a package of support in place.

In one service, transition workers carried out assessments of need in order to inform workers in adult services, who then completed separate community care assessments based on FACS policy. This was described as an ongoing process of information gathering rather than a formal form filling process.

In the remaining two services, which were coordinating services, transition workers were not directly involved in assessments but carried out a monitoring role to ensure assessments were completed by others. For one service, assessment was the responsibility of a social worker from the community team for adults, sometimes working in conjunction with the social worker from the Children with Disabilities team. For the other service, it was the responsibility of the lead professional working with the young person which could be a social worker, health worker or other professional involved with the young person.

***Reviews***

Across all services, transition services fed into existing review processes for young people rather than carrying out separate formal transition reviews. These included the annual school review from year 9 onwards where young people’s statements of SEN were reviewed and a transition plan first drawn up; Child in Need reviews for young people receiving support from social services; and LAC reviews for young people who were looked after by social services.

### 4.3.5 Transfer to adult services

There was variation between services in the process by which young people were transferred to adult social services.

In two services, transition workers were responsible for carrying out assessments for adult services, drawing up care packages in adult services and negotiating funding for these with adult service panels. In this respect these services took young people across the 'bridge' into adult services. In one of these services, when a young person required complex packages of care the transition worker would work jointly with an adult social worker to produce and implement an adult care package, and the transition worker would continue to support the young person until they were settled in adult services. However, responsibility for the transfer remained with the transition worker, with the adult worker taking on more of an advisory role.

In two other services, designated transition workers, or non-designated workers supporting young people in transition, either carried out transition assessments themselves or were responsible for ensuring assessments were carried out by others. These assessments then informed workers in adult social care when carrying out their own eligibility assessments based on FACS criteria, and when drawing up care plans. In this respect these services took young people to the 'bridge' to be met by adult services. It should be noted, however, that in one service, this transfer was facilitated through designated workers in both children's and adult services through whom all handovers were routed. In children's services, this designated worker was the transition manager, and in adult services it was a senior practitioner responsible for transition. Additionally, there were social workers in adult services with a designated transition role who supported young people until they were settled in adult services up until age 23.

The transfer process in the fifth service, depended on whether the young person was classified as having a high need under the SEN matrix and therefore eligible for intensive transition support, or a low to moderate need in which case only eligible for advice and guidance. In the case of the former, lead professionals from health or social care would manage the transfer to adult services directly with their counterparts in adult services, and transition workers would monitor this process to ensure it was happening. For those eligible for advice and guidance, the transition workers would continue to support them beyond 18 through twice yearly contacts up until age 25.

Transfers to adult health services were supported by:

- nursing staff on the transition team
- nurses in special schools in collaboration with the community matron
- individual health practitioners acting as, or on behalf of, lead professionals coordinating a young person's care
- transition workers coordinating input from health practitioners as part of the transition assessment process.

However, it appeared that this transfer was separate from the social care transition unless young people were transferring to joint health and social care teams for adults with learning disabilities.

### 4.3.6 Waiting lists

At the time of our visits, none of the services had a waiting list for their service.

## 4.4 The transition workers/teams

### 4.4.1 Transition workers' professional backgrounds

Although social work was the most common professional background of the transition workers, the professional make-up of each team or service was almost as diverse as the five services themselves.

Despite being based in adult social care, transition workers in one service were employed by Connexions and were not social work qualified. They came from a range of professional backgrounds: Connexions Personal Advisors (both general and those who specialised in working with young people with learning disabilities), learning disability nursing, learning disability services, teaching and careers advice, and one who had trained to be a social worker. The transition manager was similarly employed by Connexions and was not social work qualified. One of the transition workers in this service suggested that experience of working with people with learning disabilities (who made up the bulk of transition cases) and experience of contact with other services were the most important qualifications for the role of transition worker:

> ‘I don’t believe that you can do this job if you don’t have learning disability experience … And having some...background in a human service is advantageous and particularly...if that has brought you into contact with other agencies because then...you’ve got some kind of idea of how to work with them. But....I don’t think you can do this cold’.

There were no designated transition workers in one of the services that operated a coordinating role. Transition cases were worked with by social workers in children's and adult services as part of their generic caseload. The transition manager in this service had previously been a learning disability nurse. Senior managers in this service recognised the potential value of recruiting a manager from a different discipline as it was felt that this could encourage and support multi-agency working. For example, one senior manager noted:

> ‘… when we advertised the post....., we wanted a professional background, but it could have been health, education, social care, and ......she’s a learning disability nurse, which we found pretty good actually because it gives us, obviously each profession gives a slightly different focus… a slightly different understanding’.

In the other coordinating service, the transition manager and transition social worker were both social work qualified. The team also had a social work assistant. Although their role was mainly to liaise with the relevant lead professionals across children's services rather than to undertake direct work with young people and families, members of the transition team felt that their experience in work with children and families, including child protection, mental health and early intervention, was beneficial to their role as they understood the systems, processes, and pressures within children's social care, and had some prior knowledge and understanding of the potential challenges facing young people at transition age.

In the remaining two services, the transition teams were based in children's social care but were multi-agency. In one, the transition team was made up of qualified social workers, key workers (with backgrounds in consultation work and Connexions), a community nurse, a trainee educational psychologist, and Connexions Personal Advisers. In the other, the transition team included qualified social workers, a Special Needs Officer from education, and a Connexions Personal Adviser. At full capacity the team would also include a family support practitioner and a learning disability nurse. The transition manager in the latter service was social work qualified, while the transition manager in the former service, who did more direct work, had a background in managing advocacy services (latterly for disability rights organisations). Senior managers and practitioners within this service commented on the transition manager's drive and commitment to delivering the most holistic transition plan for each young person, a drive that several interviewees felt could be attributed to the transition manager's advocacy background.

### 4.4.2 Role of the transition workers

***Transition workers' roles with young people and their families***

The five services differed in the extent to which the transition workers worked directly with the young person and their family or had mainly a coordinating/liaison role. Transition workers/managers reported less direct involvement with young people and their families in the two coordinating services, and a more equal mix of direct work with young people and families and coordination and liaison with other agencies in the other three services.

In the three services which worked directly with young people and families, the transition worker met the young person at their Year 9 Transition Review in school and subsequent annual reviews, provided information and advice about transition and adult services to young people and their families, carried out the transition assessment (with specialist input from practitioners in other services), and worked with the young person to produce the transition plan. Their work included visiting young people and families at home to discuss transition issues and, in some cases, transition workers aimed to attain a more holistic picture of the young person and their needs and aspirations by also visiting the young person in school, at their placements, and through seeking the views of parents, schools and respite units.

In one of those services, the role differed according to whether the transition worker worked with young people with learning difficulties or young people with physical disabilities/sensory impairments. The former held cases, had the direct role described above, and effectively care managed the young person until they were settled into adult services and were then allocated to an adult social worker. By contrast, the sole transition worker who worked with young people with physical disabilities/sensory impairments had more of a coordinating role. This transition worker liaised with Connexions PAs in mainstream schools, requested that the PAs inform her about young people with severe disabilities who may require support from adult services, and offered support to the PAs who were writing the young people’s transition plans and/or the assessment in the final year of school. The physical disability transition worker also worked with groups of disabled young people in transition, to talk with them about various transition issues, for example, a session on further education or employment.

There were differences between the two coordinating services in the extent to which the role of transition workers/manager involved working with the young people and their families. In one service, the transition manager had a more direct role with young people and families. After being introduced to the young person and their family in Year 9 by the social worker from children’s services, the manager attended the Year 9 Transition Review; undertook some home visits to discuss any issues or concerns raised by the family relating to transition; attended reviews and Child In Need meetings for young people both in and out of area who met the eligibility criteria; occasionally worked alongside the social workers in child and adult services to look for services that may be suitable for individual young people; and introduced the young person and their family to their adult social worker prior to handover. In addition, the transition manager supported the social workers from child and adult services who undertook the assessments and transition planning for disabled young people amongst their generic social work caseload.

In contrast, transition workers in the other coordinating service had relatively little direct contact with young people or their families. Agencies involved with young people sent reports to the transition team and the team would build a general picture of a young person’s situation from those reports. Transition workers telephoned each young person twice per year to track their progress and check whether all services were in place. The transition workers would, for the most part, attend a young person’s review if that young person was not eligible for adult social care services and thus would soon be without a social worker. Transition workers in this service also worked with some disabled young people who were not known to any other services (for example, asylum seekers, see below).

***Transition workers' roles in working with other agencies***
Across each of the five services, the transition workers or transition manager played a key role in liaising with other agencies. This included identifying the agencies involved with a young person, obtaining any relevant documentation from other agencies that would contribute towards the young person's assessment, and requesting that practitioners from various agencies complete specialist parts of the assessment, for example a community or transition nurse may be asked to complete the health assessment.

In each of the coordinating services, part of the role of the transition worker/ manager was to liaise with all relevant agencies to ensure that workers were allocated, assessments completed, meetings were happening, planning was taking place, and adult services were aware of the young people who would be transferring over.  Much of the transition workers'/manager's time was spent contacting lead professionals and other practitioners to ensure that the necessary work was being undertaken. In one of the coordinating services, the transition manager supported those social workers in children's and in adults' social work teams who were working on transition cases as part of their generic caseload, and kept them up-to-date with what was happening with individual cases and at a strategic level. The transition manager discussed each case with the allocated adult social workers prior to handover. The transition manager could also make referrals to other agencies, for example the Benefits Agency. In the second coordinating service, although transition workers were generally not the case holders, they could co-work a case for a specific purpose then return the case to the lead professional. For example, if a young person was in an out of area placement and links with professionals in the home area had been lost, the transition team would get involved to help (re)establish links with health, social care and other relevant agencies in the home area to support the young person's return home. Further, transition workers would lead on a case if no other agency knew about, or was involved with, a young person, for example, an asylum seeker who had just entered the country. In such cases, the transition worker would call a multi-agency meeting to establish needs and get the relevant practitioners around the table to identify and delegate tasks, and review and monitor the situation.

In one service, the transition workers (based in children's services) were also responsible for developing the transition plan, ensuring that managers from adult social care agreed to support the proposed package, negotiating funding from the adult funding panels (including any joint health funding where necessary), ensuring that support packages in adult services were in place, and that the young person was functioning within their new support package. Transition workers in another service also had a similar role. This role was felt to be particularly challenging as transition workers were effectively required to understand and work with the documentation and systems in both children's services and adult services. In these services, transition workers presented cases eligible for adult services to managers at the regular transition sub-group meetings, so that the lead adult service could be identified and a either a named worker allocated or agreement reached regarding if or when an adult social worker would be allocated. Similarly, this role was undertaken by the transition manager in one of the coordinating services.

***Clarity of the transition worker roles***

Across four of the five services there was clear agreement and a shared understanding of the role of the transition workers/manager among transition workers, transition managers, steering group members, and practitioners from other agencies. In one of those services, there was a shared understanding between managers and practitioners that, due to under-staffing and the structure of the social work teams in children's services, the transition workers' role in practice was predominantly a generic social work role. This differed from the original conception of the role, and meant that the workers had less time to spend on transition planning than had been intended.

In the fifth service, accounts of the transition worker role were less clear. The recently recruited transition workers expressed a lack of clarity about their role, and a divergence between their perceptions of what the role should be and the reality of the role. For example, one of the transition workers noted that the role was very much an administrative, coordinating role, different in many respects from the direct role with young people originally perceived from the job specification.

### 4.4.3 Person centred planning and advocacy

Transition workers in three services reported that they had received training on person-centred planning (PCP). However, only in one service did transition workers report that they undertook person-centred planning with all the young people they supported[2]. In each of the other services, PCP was not universal.

Interviewees in one service reported that while PCP was good practice in transition, it was not yet embedded in transition planning and reviewing in children's services. However, the transition workers reported visiting young people in different settings (at home, at school, in a placement) and seeking the views of different people (the young person, their family, teacher, respite unit, and so on) in seeking to attain a holistic picture of the views and wishes of the young person. Armed with this information the transition worker took on an advocacy role and tried to give a voice to those young people who were unable to communicate their wishes themselves at their annual review. However, the transition team did make referrals for some young

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[2] This was limited to transition workers who worked with young people with learning disabilities. The sole transition worker who worked with young people with physical disabilities did not have the capacity to facilitate person-centred planning but worked closely with the Connexions Personal Advisers in schools who utilised person-centred planning in their own work.

people to a person-centred planner employed by the local authority. It was reported that some of the local authority's Aiming High grant would be used to fund the support networks that underpinned PCP, for example people to facilitate person-centred reviews in schools.

Transition workers in another service did not routinely use PCP but had begun piloting it with ten young people going through transition. The pilot was being supported and evaluated by the Foundation for People with Learning Difficulties. In the meantime, transition workers reported that their new transition assessments followed a person-centred format and would seek the views of young people, parents and a range of relevant practitioners to gain a more holistic picture of the young person, their abilities and their wishes. The service was also planning to bring in advocates to help make assessments and planning more person-centred for some non-verbal young people.

Transition workers in the latter two services expressed frustration that they did not have the resources or capacity to put their PCP training into practice. An interviewee in one service commented:

> 'We've had training on personal centred planning ... we've piloted it on a couple of young people. .. But again I think, in theory it looks like a really good idea and, you know, involving the young people, involving their family, it looked fantastic and what not. But looking forward, I don't think there'll be enough kind of staffing for it, I don't see that'.

Similarly, an interviewee in the other service argued that while transition workers were under-resourced, they did not have time to conduct person-centred reviews:

> 'I think because the bottom line is that they're dealing in crisis, and the two don't marry and .. if you're looking for housing or you're looking for opportunities it's...where's the person that's actually going to do the detailed work to actually understand what the person actually wants, rather than where the spaces are, and I think that's the awful thing. I upset people quite often because I say "We're back to just finding spaces again"'.

Person-centred planning was not universally practiced in the two coordinating services. In one of the coordinating services, PCP was reported to take place for some young people, depending on the lead agency. For example, one special school operated person-centred reviews with support from social workers from adult services. Interviewees in this service also reported that local self-advocacy groups run by young people with learning difficulties were involved with transition planning for disabled young people. In the other coordinating service, children's services had contracted a local advocacy organisation to facilitate PCP. The organisation had initially joined a pilot project run by the Valuing People team to develop person-centred reviews for young people at age 14 and had trained facilitators and project workers to do so. The advocacy organisation was in the process of facilitating a person-centred review for each young person at their Child In Need review. One interviewee suggested that using an independent facilitator was beneficial in that they could operate outside the (budgetary) constraints of adult services. The advocacy organisation also ran family support group meetings to help families keep the transition plans alive and updated.

In the other three services, one reported an advocacy service for adults but not for young people; another was planning to bring in advocates to work with a small number of non-verbal young people to make assessments and planning more person-centred; and the third reported that, although the transition workers acted as advocates for the young people at their annual reviews or at funding panels, the local authority was tendering for an advocacy service for young people between the ages of five and 25.

#### ***Challenges of undertaking person-centred planning***

Transition workers reported that the primary difficulty in implementing PCP was a lack of capacity to spend the time necessary to undertake thorough person-centred planning, as this would require numerous visits to the young person to build up a relationship and learn how to communicate with those young people who had little or no verbal ability. This situation was made more difficult where transition workers did not have adequate training on communicating with disabled young people (see Section 4.4.4 below).

### 4.4.4 Training

#### ***Training opportunities***

Interviewees in three services spoke of a lack of training opportunities for transition workers. In comparison, transition workers in another service reported an abundance of training opportunities and support from their transition manager to undertake appropriate training. The challenge was finding the resources and capacity to incorporate some of that learning into everyday working practices:

> ‘You do have the training, we just don’t have the resources to put it into practice. There is a lot of training in [service], that’s just one of the things, I think, you know, they do well, is the training side of it, but putting that training into practice in your job is, there’s no...overlap there… in theory...we’d love to be able to do these things … but for us to have the time to do that, no. Never going to happen’.

Transition workers in another service reported a range of training events and opportunities, however, staff shortages meant that there were few chances to undertake such training.

### *Transition-specific training*

Transition workers/manager in four services all reported that they had not received any training specific to transition. A senior manager in children's services in the fifth service suggested that there was no such thing as transition-specific training:

> '… there's nothing labelled transitions training. I don't know what it would look like if it did exist, because I guess at the end of the day we're doing social work and within that then you do things that are specific to that customer group, which is transition'.

However, surprisingly, this was the only service in which transition workers reported receiving training specific to transition. This included training on welfare rights, benefits, education support allowances, supporting people to find employment, and training around personal budgets (resource allocation systems, self-assessment questionnaires, and so on) as transition cases going through to adult services were required to have such assessments completed. It was also reported that all transition workers received training on adult sexuality and relationships, especially in relation to young people with learning difficulties.

### *Training in relation to the work of other agencies*

Transition workers in three of the services reported that they had received some training on the role of other agencies. For example, in one service transition workers reported that they were actively encouraged to learn from and about the work of relevant partner agencies and had attended training sessions led by CAMHS, Mencap and Housing. Such sessions were open to everybody within the children with disabilities team who could benefit from this information. The wider transition team, including the learning disability nurse and Connexions worker, had also attended away days which were designed to encourage multi-agency working and facilitate communication. Similarly, transition workers in another service reported attending multi-agency training days for all members of the transition team which focused on specific issues related to transition and team development. The transition manager also reported that the transition champion in adult services had received more extensive training, including a basic introduction to the processes in children's services and looked after children's services, in order to enhance understanding of how different teams operated. Training on the role of different agencies was reported to be very useful in each of the three services as it helped the transition workers understand referral routes, how different agencies operated, and which practitioners in which agencies to approach with particular cases, questions or concerns.

The transition manager in one of the coordinating services had not received any training on the role of different agencies but had taken it upon herself to visit other agencies to find out exactly what they did, as this would prove particularly useful in her coordinating role. Social workers who worked on transition cases as part of their generic caseloads in children's and adult services in this service reported that they did not receive any training on the roles of other agencies. The transition team in the other coordinating service had also not had any training on the role of other agencies.

#### *Gaps in training*

Where there was no transition specific training, transition workers and transition managers maintained that this was a significant gap which made their work more difficult.

Other gaps in training were also identified. A transition worker in one service felt that training on specific conditions and disabilities would be beneficial in helping the transition workers to better understand the potential, needs and limitations of some young people, which would assist with transition planning and help to maximise young people's future opportunities.

Two transition workers and the transition manager in one service reported a lack of funding to undertake training around communicating with disabled children, for example the use of Makaton symbols and/or British Sign Language (BSL) for those with communication or sensory impairments. The transition manager reportedly offered to lead some basic communications training with staff, however, in a team specifically working with disabled children and young people this was not felt to be sufficient. Another transition worker suggested that training or information about various non-governmental organisations and charitable organisations would be beneficial as transition workers could then signpost young people who were not eligible for adult services to such organisations.

One social worker in a coordinating service suggested that all social workers would benefit from training around transition, if only to raise awareness of the issues, while another social worker recommended joint training for social workers from adult and children's services and all others involved in transition, including colleagues in education and health.

### 4.4.5 Supervision

#### *Supervision of the transition workers*

In the four services with transition workers who were part of the core transition team, the transition managers were involved in supervising these workers, and the workers reported that they were happy with their supervisory arrangements. On average, formal supervision sessions between individual transition workers and the transition manager took place monthly and lasted approximately two hours. Supervisory sessions incorporated case supervision, where individual transition cases were discussed, issues were raised and next steps or targets were set, and also personal supervision, including professional development and training needs. All transition workers also reported an 'open-door' policy whereby they could seek advice or support from the transition manager and/or a particular service manager (if receiving joint or dual supervision, see below) as and when necessary, as typically cases could not be left on hold until the next formal supervisory meeting.

In three of these services, transition workers received joint or dual supervision. In the service where most transition workers were employed by Connexions and based within adult social care, transition workers received some joint supervision from the transition manager at Connexions and their team leader within adult social care. Such meetings were reported to be beneficial to all involved as they enabled each manager to fully understand the transition workers' role, pressures and constraints and also to learn about the challenges faced by the other manager's organisation, which supported more constructive dialogue. However, transition workers reported that the bulk of their supervision was one-to-one with their team leader in adult social care as their role was similar to a social work role and thus this was most applicable to their day-to-day work.

In another service, the transition social worker received case supervision from the senior practitioner within the transition team and supervision on professional development from the transition manager. The senior practitioner in the transition team was supervised by both the transition manager and the transition champion in the learning disability team within adult services. This was felt to work well as, between them, the two supervisors could offer advice and guidance on systems, processes and issues within both children's services and adult services. In a service where the transition manager did not have a background in social work, the manager provided case supervision to the transition workers and a senior manager within children's social care reported providing professional social work supervision to the transition workers, as and when requested. Also in this service, the transition social worker in adult services received case supervision from the senior practitioner/ transition lead within adult social care.

In the two services, where the wider transition team included practitioners from other agencies (Connexions, nursing), supervision of those practitioners was provided by a manager from within their home agency.

### *Supervision of the transition managers*

Transition managers in three services were supervised by senior managers from children's social care. Supervisory sessions tended to occur monthly, though informal discussions were often held more frequently. Sessions focused on discussion of particularly complex transition cases, identifying priorities for the transition manager or transition team, ensuring that any targets were being met and policies implemented, and ensuring the smooth management of the transition team. In another service, the transition manager was employed by Connexions and supervised by the Head of Operations in Connexions.

In one service, the transition manager received joint supervision from a senior manager within children’s social care and a senior manager from the adult learning disabilities team. At these sessions, each active transition case was discussed, enabling the transition manager to gain some input from senior managers within both children’s and adult services. However, each manager reported that this arrangement did not always work well as it was difficult for a mutually convenient meeting date and time to be arranged and also as such joint supervision left no room for discussion of the transition manager’s personal development issues. Thus, one-to-one supervisory sessions were becoming more commonplace.

### 4.4.6 Case loads

Caseloads differed quite substantially both within and between services with designated transition workers and services with a coordinating role. In one service, many of the 183 transition cases were simply tracked. The number of active cases requiring support on any one (fte) transition worker’s caseload ranged from about 25 to 30. For example, one transition worker had a caseload of 52 but was only actively involved with 30. In another service, with a total of 76 transition cases, transition social workers within children’s services each worked with up to 17 active cases; the transition key workers each reported having a caseload of approximately 20 cases; the transition nurse in adult services reported a caseload of approximately 30 young people who met the criteria for adult services and thus required full health assessments; and social workers in adult services reported working with between 12 and 18 transition cases each. In the third service, the transition team reportedly held 52 cases which were allocated to individual transition social workers depending upon their capacity, ability and experience.

The remaining two services had coordinating roles. Of the 72 transition cases in one service, only 32 were receiving active support (the remainder were tracked by the transition manager). The generic social workers within children and young people’s services reported that their caseloads included between four and 20 transition cases, while the generic social workers in adult services reported working with between three and six transitions cases each. The transition team in the other coordinating service were working with 184 cases. The majority of these were tracked, for example the transition workers would contact other practitioners to ensure that particular assessments had been carried out or referrals made. As noted in section 4.4.2, the team worked more actively with some young people, for instance those not known to other services, usually on a short term basis. The team (transition social worker and social work assistant) were working with 47 of these cases.

Across all services, transition workers and transition managers all referred to under-staffing, heavy workloads and a lack of capacity to dedicate as much time as they would like to each young person going through transition.

### 4.4.7 Constraints and problems of role

A number of constraints and problems of the transition worker role were highlighted by interviewees across different services:

- Across all five services, a key constraint and source of frustration was the limited range of options available to most young people in adult services (see section 4.10), particularly those on the autistic spectrum, and the consequent restrictions on the ability of transition workers to be as creative and person-centred as they would like during transition planning. In addition, transition plans could be rejected by funding panels in adult services leading to frustration about the perceived wasted time and effort invested in planning by transition workers, the young people and their families. Thus the transition workers could feel stuck in the middle between funding panels who refused to fund a particular placement or package and the families who believed this would best meet their young person's needs.

- Transition workers also reported difficulties in trying to plan in advance which adult services the young people might access since, in some cases, processes and budgetary pressures within adult services meant that adult practitioners could not start to plan for a young person until they had reached the age of 18 years. This was particularly problematic in relation to adult health services.

- Under-staffing was reported to be another key constraint on the transition worker role as limited capacity meant that transition workers could not spend as much time, and thus explore as many different possibilities or opportunities, as they would like with each young person. Further, staff shortages meant that if a transition worker was on leave or off sick there was nobody else to cover their work. This had led to some backlogs and delays and some complaints from families.

- A number of transition workers felt that they did not have the time, capacity or skills to fully access the views of young people with communication difficulties.

- Another common constraint was reported to be the lack of administrative support for the transition workers, as the administrative tasks were relatively time-consuming and ate into the already limited time that transition workers had for transition planning. Transition workers reported feeling constrained by the volume of paperwork they were required to complete. This appeared most problematic in the service where transition workers were employed by Connexions but based within adult social care teams and had to complete paperwork for each organisation without administrative support.

- In the two large rural counties, transition workers reported that different adult social care teams operated differently, or had recently restructured, and this complicated and slowed down transition planning while the transition workers got to grips with such differences and (re)established referral routes.

- In two services, it was reported that a key issue was the need to have knowledge and experience of systems and processes within both children's and adult services, as in one service the transition manager spanned child and adult services, and in the other service transition workers (based in children's services) were responsible for negotiating the support package and the funding that would take young people into adult services. This requirement significantly increased the workload of transition workers.

- Constraints were also reported in two multi-agency transition teams where team members outside social care were typically not co-located with the transition social workers, did not have access to the transition team's database, were not always kept up-to-date with what work the transition workers had undertaken with individual young people, and were not managed by the transition team manager and thus faced competing demands from their line managers and the transition team.

A few of the reported constraints and problems were service specific:

- In one coordinating service, the single transition manager role was reported to be a lonely role as there was no other person who could fully understand the challenges and pressures of the role. It was also reported that there was no way to record electronically the transition manager's input with the wider group of transition cases who were not eligible for social care support. Consequently, other practitioners were not always aware of the latest updates and could end up either duplicating or inadvertently counteracting the work of the transition manager.

- In the other service with a coordinating role, the lack of clarity about the transition worker role was problematic as some young people and their families had reportedly believed that the transition worker would be acting as their social worker. Further, many practitioners outside the team reported a lack of knowledge and understanding of the transition worker role. This had led to confusion for all concerned.

- In another service, the transition workers were non-designated workers who worked with some disabled young people on transition along with their generic social work caseload for disabled young people aged 14-18. They felt that their generic responsibilities, including child protection, reduced the time available for transition work. In this service, the transition worker role was also somewhat hampered by the fact that many different languages were spoken in the area and thus transition workers had to work around interpreters and wait for documentation to be translated.

### 4.4.8 What worked well?

Interviewees reported several key benefits of the transition worker role:

- greater multi-agency working
- increased communication between agencies
- increased clarity of role for all agencies and understanding of the role of other agencies
- having a central point of contact for young people, their families, and practitioners to seek information and guidance in relation to young people in transition.

Interviewees in different services highlighted different key benefits of the transition worker role in their service. One transition manager argued that the best part of the transition worker role was the continuity that the transition workers offered to the young people, their families and also to practitioners from other agencies as, typically, the transition worker worked with a young person from the age of 14 up until possibly 25 years of age. This enabled relationships to develop and allowed the transition workers to gain a deeper understanding of the needs and wishes of the young people, which in turn assisted with transition planning and helping the young people to access the most suitable services and support available. This stability was also believed to help practitioners in other agencies as they had a central point of contact (the transition worker) that could keep them up-to-date with developments, help them to make links with other practitioners and agencies, and encourage joint-working.

Interviewees from two services reported that one of the key benefits of their teams was their multi-agency, multi-disciplinary nature, with membership of each including social workers from children’s services, Connexions Personal Advisers, and a nurse. This was reported to be an improvement for the young people and their families as there was less repetition and duplication of assessments due to greater inter-agency dialogue and, in one of these services, due also to the increase in joint visits and joint assessments between practitioners from health and social care, and between children’s services and adult services.

Interviewees in the two services with a coordinating role reported that the transition service benefitted from the co-location of transition staff with other teams or agencies. In one service, the fact that the transition manager was based half-time with children’s social workers and half-time with adults’ social workers gave the transition manager a presence in each and encouraged dialogue and joined-up working. In the other service, the co-location of the transition team in an integrated centre, with children's social work teams and some child health teams, eased the logistics of multi-agency working and meant that practitioners from other agencies were more accessible. In both services, this co-location reportedly led to informal discussions between the transition manager/team and practitioners from other agencies where issues could be raised and ideas discussed without the need for an official meeting.

Interviewees in the coordinating services also argued that what worked well in those services was the fact that the transition manager and the transition team typically did not hold cases, and thus were able to focus on supporting good communication between agencies, ensuring that assessments and referrals had been undertaken to smooth the transition from child to adult services, and identifying and raising awareness of gaps in information and support. They maintained that this focused role also meant that practitioners from all agencies were clearer about their own roles and responsibilities in relation to transition cases and had a clearer idea of what was happening with young people in transition and the involvement of other agencies. In one of these services, it was also acknowledged that the transition team provided a valuable service in picking up young people who were not known to other agencies (for example, young people who had been out of area for a number of years and were not/no longer known to local services). Having this capacity in the system to deal with such cases was felt to be of great assistance to the young people concerned, their families, and other practitioners who may not be in a position to coordinate the assessments and services that such a young person may require.

## 4.5 Role of the service managers

All services had a manager with responsibility for the transition service. In the two coordinating services, this was a full time role. In the remaining three services, the managers spent between 25 and 50 per cent of their time managing the service. Three of the five services also had designated administrative support.

The service managers came from diverse professional backgrounds. Two were from a social work background and one of these also had experience in mental health. The others came from learning disability nursing; youth work, advocacy services and disability rights; and careers advice work with young people with learning disabilities.

In all cases, the role of the manager was to lead and develop the service, with the support of a multi-agency steering group and line management from senior level managers within children's social care services, adult services or Connexions. In all but one service, where the manager was the only designated transition worker, the service managers took charge of the day-to-day running of the service, and provided support to transition staff both informally when required, and formally through regular supervision meetings. In three services, interviewees reported that the manager’s role included raising awareness of the transition service amongst families and/or other professionals through information sessions in schools or presentations to colleagues.

The primary role of the manager in the two coordinating services was to monitor and coordinate transition planning and to act as a reference point for others supporting young people through transition. Their main focus was on liaising with the different professionals working with the young person, rather than providing direct support to families. However, both of these service managers did carry out short term work where necessary to support young people in transition. In one of these services (as detailed in Section 4.4.2), the manager’s role also included providing information to families embarking on the transition process, attending education and social care planning and review meetings, and producing projected costs of future adult care packages to inform the planning and commissioning of services.

In some cases, managers reported providing a ‘bridging’ function between children’s and adult services. Indeed in one service, all young people transferring to one of the adult community teams were routed through the transition manager and a designated transition worker in adult services. In another case, the manager reported supporting transition workers to move cases across to adult services by putting pressure on adult services to identify workers to take on cases. In three services, managers attended various multi agency strategic groups and through membership of these were able to provide two-way communication between operational and strategic levels of the transition service. Table 4.1 summarises the main components of managers' roles in the different services.

**Table 4.1 Role of service managers**

| | *A* | *B* | *C* | *D* | *E* |
|---|---|---|---|---|---|
| Leading and developing the service and feedback to the transition steering group | ✓ | ✓ | ✓ | ✓ | ✓ |
| Supervising the transition team both informally and through regular supervision meetings | ✓ | N/A | ✓ | ✓ | ✓ |
| Taking charge of the day to day running of the service | ✓ | ✓ | ✓ | ✓ | |
| Attending multi-agency strategic groups, providing two-way communication between operational and strategic levels concerning the transition service | ✓ | ✓ | | | ✓ |
| Raising awareness of the service amongst families and/or other professionals | | ✓ | | ✓ | ✓ |
| Providing information and signposting support to families, and generally preparing them for the move to adult services | | ✓ | ✓ | | |
| Liaising with other professionals and other agencies involved with the family | | | ✓ | ✓ | |
| Acting as a reference point for others supporting young people through transition | | ✓ | ✓ | | |
| Carrying out short term work where necessary to support young people in transition | | ✓ | ✓ | | |
| Acting as a link between children's and adult services | ✓ | | | ✓ | |
| Liaising with adult services if the team are having problems moving a case across or identifying an adult worker to take it on | | | | | ✓ |
| Working directly with families, including carrying out core social work tasks such as statutory assessments and child protection work. | | | | ✓ | |
| Producing projected costs of future adult care packages to inform the planning and commissioning of services | | ✓ | | | |

## 4.6 Management of the multi-agency transition services

Each of the five transition services was managed through a multi-agency steering group, along with a number of transition sub-groups.

### 4.6.1 Steering groups

***Role of the steering groups***

The transition steering groups aimed to develop the strategic direction for the transition services; support and ensure the active engagement of all relevant agencies and professionals; encourage communication and problem-solving between agencies in attempts to ensure smoother transition processes for young people; ensure that strategies and protocols developed within the steering group were operationalised; quality assure the work of the transition team; review transition protocols; and identify and respond to gaps or difficulties within services or more broadly within the transition process. Steering group members from particular agencies were also seeking to ensure that their voice, and that of the organisation and/or young people whom they represented, were heard.

Some challenges were noted by members of three steering groups. Steering group members in one service reported that the recent policy focus on transition in health services and the recruitment of health professionals to the steering group had meant that work was necessary to establish how health could be integrated into the systems, policies and protocols already developed by the transition steering group.

In another service, difficulties with staffing the transition team had resulted in the steering group needing to input at a more operational level and this had reportedly diverted attention away from more strategic issues. In addition, steering group members had been debating whether young people with moderate learning difficulties should be included within the remit of the transition team, in order to gain a better understanding of the transition support needs and future commissioning requirements of all young people within the area. In a third service, the steering group had a large and broad membership and some members argued that this made the group unworkable as too many viewpoints needed to be represented and positions agreed.

### ***Membership of the steering groups***

Membership of the steering groups varied between services (see Table 4.2). The steering groups in all five services included managers from children’s social care (including the service managers for the children with disabilities/child in need teams), adult social care, Connexions, education (including SEN team managers, an SEN champion and strategic coordinator for education and training), the transition manager or coordinator, and practitioners from health (including a transition nurse, consultants, specialist adult LD healthcare staff, and representatives from general community health services). Three of the five steering groups also included managers from health: adult mental health, child health and/or nursing. Three of the steering groups included representation from CAMHS.

Senior managers of Children’s Services were members of the transition steering group in three services, for example, the Head of Children and Young People's Specialist Services. Three of the steering groups included commissioners of children's and/or adult services and one of these also included a health commissioner. Representation from local schools and colleges was only reported in two services.

Two of the steering groups included members from employment services. Three steering groups included representation from leaving care services. Two steering groups included a parent or carer of a disabled young person, while only one steering group included a disabled young person. Two services included a range of other steering group members: representatives from Mencap, the local carers centre, housing, and a sports/recreation inclusion adviser.

**Table 4.2 Membership of the Steering Groups**

| *Steering group member/Service* | *A* | *B* | *C* | *D* | *E* |
|---|---|---|---|---|---|
| Children's Social Care | √ | √ | √ | √ | √ |
| Adult Social Care | √ | √ | √ | √ | √ |
| Connexions | √ | √ | √ | √ | √ |
| Education | √ | √ | √ | √ | √ |
| Service manager for children with disabilities/child in need teams | √ | √ | √ | √ | √ |
| Transition Manager or Coordinator | √ | √ | √ | √ | √ |
| Health practitioners | √ | √ | √ | √ | √ |
| Health managers | √ | √ | √ |  |  |
| CAMHS | √ | √ |  |  | √ |
| Senior managers of Children's Services |  | √ | √ |  | √ |
| Commissioners | √ |  | √ |  | √ |
| Representatives from local special schools |  |  |  |  | √ |
| Employment |  |  |  | √ | √ |
| Leaving care | √ | √ | √ |  |  |
| Parent/carer | √ |  |  |  | √ |
| Young person |  |  |  |  | √ |
| Voluntary organisations |  |  |  | √ |  |
| Housing |  |  |  | √ |  |
| Leisure services |  |  |  | √ |  |

***Frequency of meetings***

Steering groups met regularly in each service, varying from once every six weeks to once per term. Meetings lasted approximately two hours, but this could stretch to a half day in the service where concerted efforts were made to engage young people in the meeting.

### 4.6.2 Transition sub-groups

In addition to the steering groups, a range of multi-agency transition sub-groups had been set up in each of the five services. Typically such groups reported back to the steering group and any issues that they could not resolve were taken to the steering group for further discussion. These included the following systems in the different services:

- Manager-led *Area Transition Meetings* that aimed to identify the likely support needed in adulthood for each young person going through transition, identify which adult team the young person would be allocated to, and estimate the cost of an adult care package. This group reported directly to the service's steering group.

- A practitioners' *Transition Sub-Group* addressed broad issues around transition, such as what leisure activities were available for young disabled people locally, gaps in information and provision for young people and their families, and concerns over young people's further transition post-college. The group reported back to the *Adult Learning Disability Partnership Board* on issues that needed to be addressed at senior level. The practitioners' *Transition Tracking Panel* tracked the progress of all young people with a statement from Year 9 onwards, discussed the detail of each case and what provision was available locally. Issues raised at the *Transition Tracking Panel* meetings could be taken up to the *Transition Sub-Group* or the *Transition Steering Group*. The *Operational Managers Group* complemented the work of the steering group in its remit to guide, review and problem-solve at the operational level (typically in response to individual cases), and reported directly to the main steering group.

- Operational transition leads discussed individual cases and made decisions as to which young people would be allocated to which team in adult services at the *Referral Meetings*. The detail of each individual case was then discussed with the relevant team, agency or service at the *Individual Planning Meetings*. *Management Group Meetings*, attended by the Transition Manager, the Service Manager for Children in Need and the Joint Commissioner for Adult Learning Disabilities were used to resolve issues around difficult referrals and smooth the path into adult social care. They were a forum in which cases coming through to adult social care could be tracked and costed to inform future commissioning. Requests for services for young people with complex needs, that is, those with multiple disabilities and/or complex health needs, had to be approved by the managerial *Complex Needs Panel*.

- A practitioners' *Transition Tracking Group* confirmed which young people would be transferring over to adult services, which agencies needed to be involved with each young person, and which individuals from which agencies would take the lead on which aspects of the case. The Tracking Group reported to the steering group if there were operational, principle or policy issues which needed to be addressed.

- Practitioners' *Transition Cohort* meetings were designed to ensure that all eligible young people were known to adult services. Cases would then be presented to the *Transition Panel* meetings to identify the lead agency, discuss difficult cases, and ensure that all agencies were happy with the agreed plans. The *Transition Practitioner* meetings were a forum for practitioners to present information about their service to practitioners from other agencies, to seek advice and guidance on particular cases, and to provide networking opportunities.

### 4.6.3 Driving change

A majority of interviewees across all sites spoke of the transition service, in particular the steering group, having a key role in driving change in adult services. To some interviewees, this was a facilitating role in the sense that the transition steering group and the transition sub-groups existed to ensure that the transition process was set up, individual agencies understood the role of the transition service, as well as the role of the other agencies, and that any challenges were addressed. As a consequence, the transition service could function which in turn could affect change in adult services.

To other interviewees, the steering group and sub-groups were perceived to be fora where specific issues around individual young people, cohorts of young people, gaps in services and/or other challenges to commissioning could be raised and addressed by senior managers from each agency involved in transition. This increase in communication between different agencies and services was expected to lead to an increase in joined-up problem solving. This could drive or encourage changes in commissioning in adult services, for example a reduction in block contracts in adult services to enable greater flexibility with support planning.  Issues that could not be fully addressed or resolved within the transition sub-groups or steering group could be referred higher. In some sites, interviewees were able to give specific examples of how the transition service had influenced changes in adult services. For example, in one service steering group members had been alerted to the fact that a local college was not accepting young people with special needs and as a result a consortium of transition workers, Connexions and special schools were acting together to encourage the local college to be more inclusive. Interviewees also noted the role of person-centred transition planning in driving change, as only through finding out what young people actually wanted to do could appropriate services or support be commissioned in adult services.

In three sites, a small number of steering group members suggested that adult services were responsible for driving change in the transition service and/or in children’s services, as the role of the transition service was to prepare young people, their families and carers for the changes ahead in adult services. For example, it was reported that some of the good practice in transition, notably person-centred planning, had been passed down from adult services. This argument was strongest in those sites where adult services were implementing a model of self-directed support and thus where young people in transition were being introduced to self-assessment questionnaires, resource allocation systems, support planning and Direct Payments or individual or personal budgets. In two of these services, a reciprocal relationship was reported, with developments in adult services reportedly driving changes in children's services and vice versa.

In one service, a number of interviewees reported their disappointment that the transition steering group lacked the necessary authority to influence the types of services that were commissioned, with one referring to this as 'a missed opportunity'. They felt that the key drivers of change were national policies:

> '… the big drivers come from legislation and policy really, and that's where we start - things like Valuing People and Valuing People Now. CSCI are there in part as well…'

## 4.7 Involvement of young people and parents in planning or overseeing the service

Across the five case studies, one service included parents and young people on their transition sub-group, one included parents on the steering group, one included parents and young people on the steering group, and two did not include either parents or young people. The service which included both parents and young people was also seeking to appoint a young disabled person to co-chair the steering group meetings. A majority of steering group members across all services reported that they had some contact with young people and their parents through their day-to-day roles which they could feed into the steering group meetings, and members from four services explained that they or the agencies they represented had held various consultation events with parents and young people, views from which were also fed back at steering group meetings. Steering group members in one service did not report having consulted with young people or their families and this service did not have young people or parents on their steering group.

Steering group members in services both with and without parents and young people on the steering group expressed concerns about representativeness. Some members felt that no parent or young person could possibly represent the multitude of views, experiences, conditions and needs of disabled young people and their families within the local authority area and thus that the inclusion of one or two parents and young people would be superficial. Linked to this were concerns that a core group of parents tended to sit on various groups and this further minimised representativeness. The second most frequently cited concern about including parents on the steering group was that parents of young people with disabilities already led difficult and complex lives and often would be unable to commit to attending regular meetings or would not have the capacity or energy to do so. Further concerns about including young people on the steering group focused upon (a) the resource implications of making the meetings accessible for disabled young people, for example, producing accessible copies of the meeting minutes using symbols, or the need to support the young person before, during and after the meeting; (b) concerns that pitching the meetings at a level that would enable young people to engage could limit how useful or productive the meetings were; and (c) that young people would struggle to engage with much of the discussion (for example, discussions around agency systems and processes, eligibility criteria, and community care assessments), and would not gain much personal benefit from attending formal meetings which they may find intimidating. However, other steering group members felt that some representation was better than none and that the cost of supporting parents and young people through the meetings was justifiable and worthwhile.

## 4.8 Multi-agency working across transition

### 4.8.1 Knowledge of the role of the transition service amongst agencies

***Knowledge of the role in schools and colleges***

In each area, we interviewed key staff in schools and FE colleges attended by young people with whom the transition services worked. In each area, between one and three special schools and one and three FE colleges were involved (see Chapter 2).

Knowledge of the transition worker role in schools and colleges was generally mixed across the five services. Interviewees reported greatest knowledge and understanding of the transition worker role in the service where the transition manager had made a concerted effort to visit the schools and introduce the work of the transition service, and least knowledge of the transition worker role in the service which had been under-staffed for some time and thus probably not in a position to be actively promoted.

In the service where interviewees in the special schools reported good knowledge and awareness of the transition service, the transition manager had visited the schools to introduce the service and attended open-evenings at the schools to introduce the role of the transition service to young people and their parents. The schools' databases included the name of each young person’s transition worker (where appropriate) which aided communication around individual young people. Further, interviewees reported that the transition team updated the school with relevant reports and information to keep the school aware of the current situation, prevent unnecessary difficulties for the young people, and to prevent the need for the young person to repeat information.

In the other services, knowledge tended to differ between different schools and colleges. For example, in one area this ranged from a good relationship with the transition team and good knowledge of the service in one special school, to simply the receipt of some basic information on the transition service in another school, and very little knowledge or understanding of the transition service's role in the third school. Interviewees from one FE college and one special school expressed concern that they were not notified of changes of personnel in the transition team and were unclear about the roles and responsibilities of different workers. Similarly in another service, senior figures from one special school and from the local college reported that they had a good knowledge and understanding of the transition service and felt able to contact the transition manager if they had any queries or concerns, but an interviewee from another special school reported a lack of knowledge about the role and function of the transition service. In a number of cases, it appeared that where there was good knowledge of a service, a particular school or college was involved at a formal level with the service, through having a representative on a sub-group, or that a school head had contact with a key figure relating to the service. It was clear therefore that communication with schools and colleges about the transition service was patchy in most areas.

### *Knowledge of the role amongst health and social care*

Again knowledge was mixed across the five services. Knowledge of the transition service's role among managers and practitioners in both child and adult social care, and among health interviewees, was reported to be good in four of the five services. These transition teams were all based within children’s or adult social care and the transition workers worked closely with social workers from children’s and/or adult services. In contrast, knowledge of the service's role was poor in both health and social care for one service, even though this service was co-located with some child health teams. For a considerable time this team had only had one person in post. In the other four services, communication with health and social care agencies appeared to have been better than communication with schools and colleges. For example, in one area the lead for person-centred planning reported being regularly consulted and updated by the transition manager, and social workers in both children's and adult services reported that the transition manager was very clear about her role. In another area, interviewees from health services reported there had been a lot of promotion of the transition service when it was launched. There had also been a recent awareness raising campaign to boost the profile of the service among other practitioners in social care. These measures appeared to have contributed to better knowledge of the role of the service among health and social care. Three of the transition teams had a community nurse or designated transition nurse attached to the team (although this post was vacant at the time of interview in one service) and liaison with health was primarily facilitated through this nurse.

### 4.8.2 Facilitators and barriers for multi-agency working

Across the five case study services, interviewees from all agencies reported broadly similar factors that they believed had helped facilitate multi-agency working in their areas or had acted as barriers to multi-agency working.

Factors that were commonly believed to have *helped* multi-agency working were:

- A model where transition was the work of a designated team rather than an ‘add-on’ to existing posts. It was argued that the designated workers were able to specialise in issues and options around transition; gather and disseminate information to young people, parents and other practitioners about what provision was available locally; provide more support for young people and their families as they were solely working on transition; and act as a central point of contact for other practitioners working with young people of transition age. Interviewees within such services felt that this specialist knowledge could not have developed in the same way within generic children’s or adults’ teams.

- Co-location of transition workers, or the co-location of numerous agencies within one building, was felt to be conducive to multi-agency working as the transition team could build relationships with practitioners from those agencies that primarily work with the same group of young people and thus with whom they would have most professional dealings, and gain a better understanding of the work of other teams and the demands placed on other teams.

- A better understanding of the roles of colleagues in other agencies, and the eligibility criteria of other agencies, could aid multi-agency working as practitioners had a better understanding of when, or whether, to refer to other agencies and/or to suggest to families that other agencies might get involved, and this could encourage agencies to work together to deal with issues more constructively.

- The dedication, authority and strong leadership of senior management and the multi-agency strategic group, which kept the dialogue going between the various agencies and sold the transition message to a wider audience.

- The commitment and enthusiasm of key individuals, including transition managers, senior practitioners and steering group chairs, and their ability to ‘sell the message’ of transition to get other agencies on board had helped the transition services to develop and maintain their profile.

- The establishment and work of transition sub-groups helped to keep practitioners and managers up to date with general issues relating to transition, and with individual cases, and maintained the profile of transition within the areas.

- Good communication, working relationships and clear processes helped practitioners from different agencies know exactly what they were expected to do and in what timescales, and this could also reduce duplication.

- Systems in place to support multi-agency working such that links would not break down if key personnel left.

- A history of partnership working and multi-agency forums at senior level, which meant that much networking and relationship-building had already taken place and a strong ethos of multi-agency working already existed.

Factors that were commonly believed to *hinder* multi-agency working were typically the lack of the factors listed above. Additional factors reported as hindering multi-agency working were:

- Under-staffing and lack of capacity: interviewees across all services reported that either not enough staff had been recruited to the transition team or that posts had been left vacant when team members had left. This had put a strain on the services and meant that some young people had not received as much input from some agencies, as they might otherwise have received. For example, in one service the transition nurse post had been left vacant for ten months. This had led to a gap in service provision for young people and reduced the input of health in transition planning. Staff shortages also meant that current staff faced a heavier work burden which reduced their scope for creative planning and multi-agency working.

- Issues around funding decisions: interviewees maintained that funding decisions were often made too late which meant that multi-agency transition plans could not be agreed until the last minute, creating anxiety for the young people, their families and the transition workers. In addition, there was often conflict and uncertainty as to whether part of the funding for particular young people should come from social care or continuing healthcare.

- A lack of service provision which inhibited certain services from fully engaging with the transition process as they had little service to offer.

- The lack of consistent engagement of certain agencies with the transition steering group or transition in general, particularly health in four services and adult social care in one service.

- Poor information sharing between agencies (see section 4.8.3 below).

- Lack of a clear definition of what was meant by ‘transition’ and how this was interpreted by different agencies.

- Competing priorities of different agencies, for example, child/adult protection in children's/adults' social care, educational achievement in education.

- In two areas, some of the special schools were thought to be less engaged with the transition service as they operated their own transition process and were not convinced of the need to adapt.

- Multi-agency working was reportedly hampered somewhat by the different ages at which different organisations became involved or ceased to be involved with a young person. Although it could be argued that transitioning between different child and adult services at different ages could be inefficient and complex for both families and practitioners, one health practitioner suggested that by staggering transition in this way there remained some continuity and the young person did not wake up on their 18th or 19th birthday with a new social worker, nurse, teacher, Connexions worker, health practitioners and so on, which could be overwhelming for some young people and their families. However, in another area a senior manager within children's services reported that joint working had been made easier for practitioners and clearer for the families since the transition age was now the same for health and for social care.

- The fact that funding for services and support came from different funding streams, which tended to impose their own limitations on how resources could be used, impacted upon the flexibility and creativity of transition planning.

- The lack of a common transition assessment document across all agencies was also regarded as problematic. A senior manager within children's services suggested that such stream-lining of assessments was prevented by the competing demands and targets of different government departments:

  > '… everybody's got a different set of forms to complete, you know, because you have a looked after form, you work out a transition form here, education will have a transition form, health will have forms....I think we haven't managed to get the columns streamlined into one form, and I think it's partly also because we're working to different government departments, so they're expecting different things'.

- Organisational restructuring could lead to a loss of continuity of personnel, processes and referral routes causing important links to be lost.

### 4.8.3 Information sharing

The benefits of information-sharing were recognised and advocated by interviewees across all agencies: reducing duplication, saving time for both practitioners and for families, and building a more holistic picture of a young person, their family and their environment.

Only one service reported relative success with sharing information. In this service, information could be shared between children’s social workers, adult social workers, the special educational needs assessment service team, occupational therapists employed by the local authority (though not those employed by health) and the transition nurse, as all could access the same database. Access tended to be on a ‘read-only’ basis, however it was at least accessible to all those within the transition team, irrespective of their discipline. This service was also in the process of establishing ‘transition episodes’ on the local authority database whereby all transition assessments from social care, Connexions and health action plans could be placed together. This was expected to be of particular benefit to adult services which could immediately see the latest ‘episode’ of what was happening in a young person’s life, track when assessments had taken place, and thus reduce the number of duplicate assessments. This service also had a ‘transitions broker’ within the adult social care team. This was someone who could work with the transitions team, young person and their family to devise an appropriate package of support for the young person upon moving into adult services. The broker had access to the same information system as the social workers and could view all relevant reports from children’s services, health and Connexions and had easy access to other transition team members. Although information on health databases could not be shared within this service it was reported that local information sharing agreements between health and the local authority enabled both to place information on a single database and to view one another’s case notes (outlining which interventions/treatments were taking place, not detailing the sensitive content of those interventions). However, it was reported that the school nurse and the transitions nurse had to use different forms for recording data about individual young people, which was felt to be inefficient.

Interviewees from across all agencies in the other four services spoke of the challenges they faced in attempting to share information with colleagues from other agencies as IT systems from different agencies were incompatible. In services where the transition team were co-located or could access a single office it was possible for practitioners from different agencies to log into their own database from neighbouring computers within one office and share information verbally with colleagues from other disciplines. However, not all agencies were able to log in from the same office and even where they could the fact that a single young person was allocated a different identifier by each agency, for example, a pupil number or health service number, proved particularly time-consuming when practitioners attempted to cross-check their records or verbally share information on a particular young person.

Interviewees also reported service-specific challenges to information sharing. For example:

- In one service, the local authority database (accessible by all relevant local authority employees, including education, social care and occupational therapists) reportedly held only basic information (school attended, name of GP, and so on). However, the database was to be upgraded so that practitioners could add more detail, for example whether the young person had a statement or whether the social worker had given advice around transition.

- In another service, one interviewee reported that the information systems between the PCT and the Mental Health Partnership NHS Trust were incompatible. It was reported that adult social workers were not able to access reports on the children's social care database which impacted on the sharing of information between child and adult services (although plans were in place to train adult workers to use the children's system).

Incompatibilities in information systems were argued to be a 'huge hindrance to multi-agency working' and remedying them would have financial and organisational implications. Although practitioners attempted to share basic assessment information in a bid to reduce duplication, one interviewee noted this was ineffectual while information systems, assessment tools and statutory requirements varied so much between agencies.

### 4.8.4 Links with other programmes/initiatives

Each of the five transition services linked into related programmes or initiatives in their areas. For example, one site was a pathfinder for the cross-government *'Getting a Life'* initiative (see Chapter 1, section 1.1) and was aiming to create and fund individual pathways for young people with learning disabilities to access various pieces of education, training or job coaching to help them enter into employment. Another service linked with Connexions to run a young ambassadors' project whereby young people attending particular colleges visited the special schools to promote the colleges and encourage young people and their parents/carers to apply to the local college rather than to out of area placements. Interviewees in four of the five services reported links with initiatives aimed at increasing local resources and facilities in order to reduce the number of out of area placements.

Interestingly, the most links to other programmes and initiatives were reported in the service which had a transition manager who did not hold cases and did not manage a team of transition workers. This transition manager had the flexibility to concentrate on information sharing and drawing upon other resources at a strategic level. In addition to running a project to promote local college provision, this service ran a transition conference for all statemented young people in both mainstream and special schools to provide families with information and support ahead of the transition planning process; linked in with a local authority commissioned service that helped young people (particularly those who would not be eligible for adult services) tap into voluntary services, supported employment and training to develop their independent living skills; and had commissioned a piece of research to identify any gaps in the curriculum in local specials schools that could impact upon a young person's competencies and preparedness for adult life.

## 4.9 Evaluation and monitoring

Steering group members across each of the five services were asked whether their transition service had been formally evaluated. All managers and practitioners were also asked about the role and function of any transition sub-group in monitoring the service.

### 4.9.1 Evaluation of the transition services

Not all of the transition services had been formally evaluated. Interviewees in two services reported that their transition service had been evaluated by external consultants within the past two years. In one, consultants had been commissioned by the Children and Young Person's Directorate to look at transition processes. This had reportedly revealed various strengths and weaknesses (one being the number of protocols in existence). It was also noted that the Children's and Adult Directorates had been working together in preparation for taking the transition service to the internal scrutiny committee earlier in the year and that had involved a partial evaluation of the service. One steering group member expressed concern that only processes were reviewed, while outcomes for individual young people were largely overlooked. In addition, interviewees in this service reported that Connexions and the Adult Learning Disability Service (who jointly supervised the transition workers) had undertaken evaluations of the transition workers' role and that feedback from the families and agencies that the transition workers had worked with was positive. In the other service, an external consultant, commissioned by Children's Services, was brought in to look at the policies, protocols, and finances of the transition service and develop a pathway to simplify what was a fairly complex transition process. The consultants had developed a set of milestones around what should have happened at different ages for the young people, who should be doing what at various points, and when a referral should start to be made to adult services. The service manager for Adults with Disabilities reported that having those milestones in place was useful.

Two of the transition services had recently been reviewed as part of their local Joint Area Review (JAR). Interviewees in one service stated their transition service had received a good report, in part because there was an area transition team with a transition manager that provided good communication and liaison between partner agencies. In the other service, interviewees reported that their recent JAR had highlighted the need for more attention to be focused on those with more moderate difficulties and those who may end up in the NEET population.

Interviewees in two services reported that no formal evaluation had taken place. However, in one there were suggestions that an evaluative role may be added to the work programme or the terms of reference of the steering group.

### 4.9.2 Monitoring of the transition services

Managers and practitioners from each of the five services reported some degree of monitoring of the transition service. In each service, the transition manager provided regular progress reports to the steering group. The progress reports were informed by feedback from the various transition sub-groups and included issues such as gaps in service provision, and any operational or policy issues which needed to be addressed. Interviewees from three services reported that the steering group regularly monitored the transition service against the action plan and any review points detailed in their transition protocol. In all services, the transition manager or members of the various sub-groups also provided feedback to the relevant senior managers within children’s services and adult services.

## 4.10 Meeting priorities of young people

As noted in Chapter 1, previous research undertaken with families and young people has continually identified areas of concern and issues that need to be addressed in the transition process. These include provision of information about the transition process, support for the transfer to adult services, and information and support in a number of areas: equipment and therapies, social and leisure opportunities, finances and benefits, future housing opportunities, post 16 education, career and employment opportunities, independent living skills, short breaks, adult relationships and sexuality, healthy living and emotional changes, and planning future goals. Therefore, across the interviews, questions were asked about how the transition services met these needs.

It should be noted that whilst staff reported many innovative services and exciting developments for young disabled people in transition, they also shared a frustration at the lack of accessible services and opportunities for them. As one senior social care manager said:

> ‘..you can get the assessment process right, you can get a dedicated team set up and you can try and improve, you know, information and communication between different agencies, but the bottom line is actually our young people need access to services when they leave school in terms of employment, housing, ....education, learning, leisure…’

### 4.10.1 General information about the transition process

The need for information about services by families of disabled children and young people, and for information to be accessible in different formats has been highlighted in previous research (for example, Tarleton and Ward, 2005; Mitchell and Sloper, 2001). All services provided verbal information about the transition process to young people and their families, and staff would seek out additional information for them if and when needed.

With regard to printed information about transition, two services, which had been in operation for less than two years, were in the process of developing information packs for families and staff recognised that there was currently a gap in information provision.

One service had a transition information pack with information designed for both parents and young people that was comprehensive, up-to-date and routinely given to all families using the service. The guide to transition for parents and carers included information about what transition is, post 16 options, organisations which might be involved locally, money matters, and useful contacts. It also included an evaluation form at the back of the guide for parents to feedback any comments or suggestions they may have to improve this. The transition information for young people used pictures and simple language to explain what transition is, the transition review and plan, the transition meeting, money, and having fun. There was also a guide to person centred planning for people with learning disabilities in a comic strip format.

In another service, transition workers gave young people and their families a transition pack comprising information leaflets on transition meetings and transition planning, work and education choices post 16, changes on becoming an adult at 18, benefits for young people aged 16 plus, health and social care support, homes and housing, and leisure. These leaflets were produced in a range of colours and designed to be stored in a plastic pocket within the cover of the pack. Pictures and symbols were used alongside the text to facilitate understanding for young people with learning disabilities. A poster-version for young people was also provided. At the time of the research, the pack and poster were being updated and re-printed.

A further service produced a variety of printed information for young people with additional needs. This included a guide to transition for young people aged 13+ with learning difficulties or disabilities and their parents and carers, with information on transition planning, the Youth and Connexions Service, learning, employment and training, advocacy, health, social care, direct payments, benefits, housing, transport, and person centred planning. It also included a section answering parents' queries about transition planning, and a feedback page. This service also produced a leaflet promoting a database register for young people with additional needs aged from birth to 19 years. By registering with this database, families received a newsletter four times a year with information about services, events, opportunities and support. This register could then be used by the local authority to help plan future services. Local schools also distributed a *Transition Toolkit* designed to support everyone involved in the Year 9 transition process for young people with a statement of SEN. There were transition checklists for health, education, and social care representatives, Connexions personal advisers, and voluntary organisations, as well as a section for parents, carers and supporters, and a young person's proforma for drawing up a transition plan. Nevertheless a senior manager in this area commented that information for parents and young people about the transition process was fragmented and not well-coordinated.

In two areas, information about the transition process was also available in DVD format. In one of these areas, the DVD focused on young people with learning disabilities and addressed further education and transport, employment support and independent travel training, and leisure services. In another area, young people with a variety of physical and/or learning disabilities had produced a DVD guide to transition featuring themselves. Topics covered included transition reviews and planning, work experience and employment, further education, housing, driving lessons, specialised equipment, support workers and leisure opportunities. The DVD was up-beat and aspirational in demonstrating what could be achieved by young people with disabilities.

Web-based information was available in one area, with a website dedicated to young people in transition which included information on issues ranging from health to education, work and money, as well as a *Service Finder* of useful local and national organisations able to help with such things as benefits, leisure activities, support groups etc. It should be noted however that some pages, including the one on the transition team, were in need of updating.

Finally, staff in two services referred to information events held in special schools about the transition process. In one service, these were run by the transition manager in collaboration with the local Connexions service for young people primarily, but parents were also invited. From the autumn it was planned to show the transition DVD referred to above.

**Table 4.3 Information about the transition process**

| | *A* | *B* | *C* | *D* | *E* |
|---|---|---|---|---|---|
| Verbal information | ✓ | ✓ | ✓ | ✓ | ✓ |
| Written information packs | ✓ | ✓ | | | ✓ |
| DVD | | ✓ | | | ✓ |
| Website | | | | | ✓ |
| Information events | | ✓ | | ✓ | |

### 4.10.2 Transfer to adult services

Responses from staff with regard to how well the service met the needs of young people in managing the transfer to adult services were varied. Some focused on the transfer to adult social care services, some on the transfer to adult health services and some on the transfer to adult services generally.

***Transfer to social care services***

In two services, some transition workers remarked upon how well the transfer was managed from children's social care services to adult social care services: '*I think we do that exceptionally well and I think families appreciate the smoothness of it*'.

In one of these services, the transition manager attributed this success to forward planning, the expertise of transition workers, and flexibility in the age of transfer. In this service, a panel agreed when a young person would be transferred and to which team, and when an adult services worker should be allocated to facilitate joint working between children's and adult services. One of the transition workers within this service noted how transfer works best when there is a period of co-working between social workers in the transition service and social workers in adult services.

In another service, a transition worker noted that social care transfers were only smooth for young people eligible for adult care services, which ruled out many disabled young people who were not assessed under FACS criteria as having critical or substantial needs:

> 'Unless you've got severe profound needs, you're not going to really get a service, and that's talking from experience and people on my caseload'.

***Transfer to health services***

For the service with a nurse in the transition team and a nurse in the adult social care team, the transfer to adult health services was reportedly relatively smooth. The transition nurse would coordinate health assessments and health action plans for the community nurse on the adult's team to take forward.

In another service, a member of staff from children's social care noted that the fragmentation of adult health services made it difficult to establish strong links with health practitioners, unlike in children's health services where care was coordinated by the community paediatrician.

In all services, the transfer to mental health services appeared to be a separate process. Staff from different services reported that difficulties arose with mental health transfers because of the different thresholds of care and eligibility criteria between children's and adult services. Many who did not qualify for adult mental health services had to rely on the voluntary sector for support.

Additionally in three services, some staff identified the transfer from children's to adult services as particularly problematic for young people with autistic spectrum conditions. An interviewee in one of these services expressed frustration:

> 'I have definitely hit a brick wall. I mean I haven't even tried to do an ASD, cos... there's no team says they'll work with them'.

In another service, staff reported that a clear referral process was lacking and adult mental health staff seemed reluctant to engage in proactive planning for young people who had cognitive impairments and were not 'in crisis'. In this service, there were a few non-statutory specialist providers locally for young adults with autism but these services were expensive and therefore not generally available. As a senior manager in children's services from another area commented:

> '…ten/fifteen years ago were saying, crikey all these kids being diagnosed with autism and so over the years we've developed services to respond to that within our schools and within our respite provision... But those young people are now becoming adults and it's like, you know, wake up and smell the coffee, time isn't it?'

### ***Transfer to adult services generally***

Some interviewees were critical of the lack of services for young disabled people to transfer to on leaving school. Interviewees from two different sites stated:

> 'Well sometimes when they leave school, they don't have anywhere to go…they're not suitable for colleges, they're not suitable for the day centres. There is nowhere for them to attend and some of them haven't got any day care placement'.

> 'It just seems to me that once you reach 16, I think a lot of parents really do feel like people are dropping off the edge, and certainly when they leave college at 19 parents definitely feel they've rather fallen into the abyss I think'.

### 4.10.3 Equipment and therapies

Transition workers reported that young disabled people’s needs for equipment and therapies such as physiotherapy, occupational therapy and speech and language therapy, were addressed in transition planning and assessments. However, in one service, a transition worker for young people with learning disabilities explained that whilst referrals were covered as part of the single assessment process, control as to when these cases were picked up was with the health practitioners within the adult learning disability team in social services. In another service, the transition manager said that transition assessments such as speech and language assessments needed to have been completed within the six months immediately preceding transfer in order for the adult social care funding panel to take these assessments into account.

In one service, the transfer to adult services in relation to equipment and therapeutic support was facilitated by health practitioners in children’s services linking directly with their counterparts in adult services. What was not yet happening was incorporating this into a multi-agency transition plan coordinated by the transition team. In this area, there was also a speech and language post that was shared by one of the special schools and the adult learning disability team, which facilitated a smooth transfer from children’s to adult services.

Within three services, staff reported that equipment and therapeutic services for children were accessed through community paediatricians and largely provided within special schools or special units within mainstream schools. Some staff in these services reported a gap in provision for young people who left school at age 16 which remained until they were picked up by adult services at age 18 or above. In one service, staff also reported that even for those remaining in special school until age 18 or 19, the pressure on resources meant that school-based therapeutic services were frequently withdrawn from age 16.

Whilst many staff reported that equipment and therapies for young people with learning disabilities were provided through integrated health and social care teams within adult learning disability services, none reported similar services for young people with physical impairments or mental health problems who did not have learning disabilities. This may suggest that transfer to adult services for these young people might result in gaps with regard to equipment and therapies. The transition manager in one service reported that a half time post had just been created to try to address this gap in provision for young people without learning disabilities.

### 4.10.4 Leisure and social opportunities

Staff in all services reported that they provided information to young people and their families about the leisure and social opportunities available locally, although they also noted that provision was scarce, particularly in rural areas. In one service, staff said they did not have enough information themselves about what sport and recreational activities were available locally, and had to rely on searching the internet for this information. This service was working with Mencap to develop a web-based information resource about the leisure activities available to young people with disabilities. As well as being an important source of information for young people, it was envisaged that this would also be a useful tool for professionals working alongside them. The same service was using Learning Disability Development funds to produce resource packs for young people in collaboration with local community groups, as well as a DVD made by young people themselves about what they liked doing in the local neighbourhood (see Section 4.10.1). The service that had an information pack for families, included within this a section on social and leisure opportunities locally. Another service had a website for disabled young people, which included a section on leisure, with a facility to search for local sports and entertainment opportunities.

Specialist provision, such as youth clubs for disabled young people, ‘buddy’ schemes for disabled teenagers, and summer playschemes, was largely provided by the voluntary sector through organisations such as Mencap and Barnardo’s and other local charities, as well as by special schools in the area. However, staff noted that many of these activities and schemes were only available to young people up until aged 18 or 19. In one area, staff mentioned a summer camp for young disabled adults aged 18 or over run by the Council’s community bridge building service. In another area, the transition team was based in an Info Bar in the centre of town, which was a drop-in centre for teenagers and young adults with a learning difficulty or disability. This provided a base to meet up with friends or take part in community activities and its facilities included a coffee bar serving light snacks, computers with internet access, and an activity room where a variety of courses were taught, such as arts and crafts and skills for daily living. However a senior manager acknowledged that this facility was not very well used and this poor take-up needed to be addressed.

Staff in all five areas reported that mainstream leisure services provided some opportunities through leisure centres, swimming pools and youth clubs, but noted that these were not always accessible to young disabled people. Barriers to participation highlighted by staff included the cost of the leisure or social activity, including transport costs; the lack of suitable transport to and from activities; the lack of specialist support for young people with more complex needs (such as young people who do not use speech for communication) to be able to truly participate; and negative attitudes in society generally about disability and inclusion. As one interviewee put it: ‘*We need more inclusive services but society in general aren’t very receptive to that’.*

Nevertheless, in several areas staff talked about current or planned initiatives to develop inclusive provision for disabled children in mainstream settings and to encourage young people to take part in inclusive activities. In one service, Leisure Services had introduced free taster sessions to enable disabled young people to try out a sporting or leisure activity. They were also hoping to use Aiming High money to introduce a mentoring/befriending service to provide one-to-one support to enable disabled young people to participate in mainstream leisure activities. The same service had appointed a Disability Youth Officer in 2008 to develop a range of leisure provision in the community. This led to a ‘summer university’ of inclusive courses for young people aged 12 to 19 years ranging from academic courses to courses in computing, dance and art. Free transport was provided and disabled young people were supported to participate by workers recruited from their own schools, with whom they were already familiar. Similarly in another area, two staff were responsible for identifying gaps in leisure provision and developing opportunities for disabled young people to take part in leisure and social activities within mainstream services. This was a longstanding initiative which had been running for eight years that had been given additional impetus recently from the government’s Aiming High strategy.

It was reported that the government’s personalisation agenda had also created new opportunities for young adults to participate in leisure and social activities in the community via direct payments or individual budgets. In one service, a transition worker, with a remit to take forward ‘In Control’, had undertaken more proactive work looking into hiring village halls so that young people could choose their activities and use their individual budgets to pay for someone to come in and facilitate that activity, for example, rapping, mixing, and so on.

However, with reductions in day services and closures of some day centres, there was also concern about where young adults would be able to go to meet up with friends and take part in community activities:

> ‘We’re told we’ve got to reduce the people [who] go to Day Service, they should be doing other things in the community, which I fully support. However...the other things aren’t there in a lot of cases’.

Worried that young disabled people may become isolated in the community, services were trying to encourage young people to maintain links with school and college friends. For example, one service was working with schools to promote the value of friendships and staying in touch, and through transition assessments, was trying to match young people with others wanting to do similar activities so they could share a support worker to do things like bowling. In another service, a transition worker was encouraging young people themselves to organise trips out with friends (for instance, to the cinema or swimming pool) because ‘we can’t facilitate everything’.

### 4.10.5 Information about benefits

Transition workers in all services were able to provide basic information about benefits and sometimes got involved in assisting with applications such as claims for Disability Living Allowance. Some referred to the Department for Work and Pensions and other websites for information when advising families. However, generally transition workers advised families to seek specialist support from organisations such as the Citizens Advice Bureau, Mencap or other disability or carers organisations, or from the council's welfare rights service or local job centres. Staff reported that welfare benefits for young people in transition was a complex issue, particularly when young people were living in supported or residential accommodation, and they were anxious not to misinform families.

### 4.10.6 Future housing options

One interviewee noted that where their children will live when they grow up is often a source of great anxiety for parents of disabled children. Housing options for young disabled people in transition put forward by staff included supported living accommodation, shared ownership, residential homes, residential colleges, adult 'foster' care and remaining in the family home (facilitated by housing adaptations if necessary) along with short break accommodation. However staff frequently highlighted the chronic shortage of housing in their local area, particularly a lack of supported housing and housing that was fully wheelchair accessible. In one service, with other options no longer available, staff advised young people to apply to go on waiting lists for social housing.

Most commonly reported as a housing option was supported housing, where young people live independently in flats or shared housing with support from visiting support workers. In two areas, staff commented on the drive to move people from campus or residential settings (often in expensive out of authority placements) into independent or supported living facilities. In one of these areas the transition service had run a joint workshop with Mencap to inform young people about supported living as a possible housing option. This service had also provided young people with a 'taster' of supported living by placing young people in supported living facilities for a short residential break. In the other area, the local authority was hoping to set up a two-stage housing scheme where young people with learning difficulties and complex needs are initially housed in a residential home, where they are encouraged to develop skills and abilities to enable them to move to supported living accommodation nearby. This scheme had been successfully introduced in a neighbouring area by an independent provider.

In all services, transition workers reported signposting young people for housing advice and support to the local authority's housing advice service or to local voluntary agencies such as Mencap. In both the state and the voluntary sector, staff noted there were specialist advisers for young people with learning disabilities. In one service, transition workers reported doing a lot of work around housing, including liaising with the council's preferred housing providers and supporting young people to make housing applications and sign tenancies. Transition workers in this service were based in adult social care. In contrast, a children's social worker from another area, who supported young people in transition, said that she did not provide support in relation to housing as most young people lived at home – this was something that adult social workers addressed.

### 4.10.7 Post 16 education

***Options for post 16 education***

Most young people in special schools, with whom the transition services primarily worked, remained in school until aged 18 or 19 when they completed Year 13. However, for those young people choosing to leave school at the end of Year 11, possible options for post 16 education noted by staff in all areas included sixth form at another school or college, a mainstream further education college (often enrolled on segregated courses), or for those whose needs could not be met elsewhere, a specialist college (often a residential placement due to the distance from home).

***Role of Connexions***

At the time of the research, for young people with statements intending to move on to further education or training, Connexions were responsible for completing a Section 140 assessment during their last year of compulsory schooling. These assessments resulted in a written report of the young person's educational and training needs, and the provision required to meet them, which was then passed to further education providers. Unsurprisingly given this responsibility and their specialist knowledge in this field, Connexions personal advisers, rather than transition workers, often took the lead in supporting young people in relation to their further education. However, in three services, the transition teams included Connexions workers.

***Provision in local special schools***

As previously noted, special school sixth forms were a popular choice for young people already in special schools who wanted to continue their education. In one area, a new sixth form facility had just opened which was a joint provision for two special schools catering for pupils with both physical and/or severe learning disabilities. Nursing support was still to be put in place, but it had been agreed that the transition service's Connexions worker would have a permanent base on the premises and would introduce transition topics within Personal, Social and Health Education (PSHE) lessons. In another area, the first co-located special school and mainstream school was due to open in January 2010, and there were plans to develop specialist ‘hub’ schools across the county to cater for young people with the most complex needs.

### ***Provision in local further education colleges***

College staff reported providing a range of ‘pre-entry’ courses for post 16 students with learning difficulties and disabilities, which were designed to encourage independence and confidence, to teach new skills, and to prepare students for higher level courses or for work. However, interviewees reported a number of problems with provision in further education colleges in their areas.

Both frontline staff supporting young people in transition, and senior managers, reported a lack of suitable courses in local colleges for disabled young people, particularly for those with profound learning or severe physical disabilities. In three services, some staff also noted a gap in further education provision for young people with autistic spectrum conditions.

Young people with disabilities often require specialist support to access college courses, such as a personal support worker. Some interviewees noted that local college courses were not accessible to disabled young people. In one service, staff reported that local colleges were unable to support young people with profound and multiple learning disabilities who needed a multi sensory curriculum and a high staff to pupil ratio. In another service, a manager hoped that young people would use direct payments to pay for personal assistants to provide one-to-one learning support in college. In a further service, it was also reported that further education provision was not accessible to some severely disabled young people. On leaving school, these young people were placed in day services or supported by direct payments.

In three areas, there was only one local mainstream further education provider. In one of these areas, parents had historically rejected the local college, and staff supporting young people in transition discussed the difficulty of reversing this trend despite improvements in courses for those with moderate learning disabilities. In another area, there was frustration at the failure of the local college to provide accessible courses when many colleges in neighbouring boroughs seemed able to deliver these. In this area, one manager argued that what was needed was for the local college, local employers and local transport providers to work together to develop appropriate further education provision in the authority.

However, it was also suggested by some staff that the lack of appropriate further education provision for disabled young people was also attributable to government funding policy which linked learning to academic attainment and to NVQs specifically. This policy supported vertical rather than horizontal progression with an accreditation or qualification needed to progress to the next level. On the other hand, some staff referred to the 'revolving door' of college courses for young people with disabilities, with young people repeating similar courses without progressing to anything new:

> ‘.. you’ve literally got people just sitting on the course for year after year after year and there’s no kind of outcome’.

In relation to further education funding, the transition manager from one area viewed the proposed disbanding of the Learning and Skills Council as a positive development. By transferring responsibility for commissioning and funding education and training for 16 to 19 year olds to local authorities, local councils would be able to determine their own education priorities: ‘*So it, it gives the Council a lot more control about funding priorities really and developing local provision’*.

However, in another area, a transition worker expressed concern about what would happen to many of the lower level further education courses with the demise of the Learning and Skills Council.

In four of the five areas, staff also commented on the importance of ‘link courses’ to help young people transferring from school to college. Sixth form pupils in special schools would attend college for one day a week to introduce them to, and prepare them for, the new learning environment. However, in one site, none of the seven young people from one school who had attended the local college link course that year had been given a place after interview. This was because the pupils had only been able to access this course with the support of the teachers from school who accompanied them; and the college was unable to provide comparable learning support.

The contrast between full time education provision in schools for young disabled people and part-time provision in colleges, was mentioned by a few staff from different agencies in three areas. This required considerable adjustment for a lot of families, because if young people were not able to remain at home on their non-college days, alternative day care provision needed to be put in place.

There was also praise for existing further education providers. In one area, several staff referred to their local college as a 'centre of excellence'. This college provided courses for young people with complex disabilities, such as cerebral palsy and brain injury. However because of their popularity, these courses were often oversubscribed, with lengthy waiting lists.

***Provision in out of authority placements***

A lack of suitable local provision meant that some young people with disabilities had to find residential college placements out of their home authority. Staff reported that these were often very expensive placements, taking up a large proportion of the overall education budget:

> ‘I know that the Learning and Skills Council review showed that actually they’d spent the majority of money on a very small number of young people, funding very expensive out of borough placements’.

In this area, a commissioner reported working with senior figures from child and adult services to bid for funding to increase facilities for disabled young people locally in order to reduce out of area placements.

In another area, the local authority was an *Improving Choice* Pathfinder, and had received funding from the Learning and Skills Council to improve post 16 Education for young people with learning difficulties and/or disabilities. Two key elements of this were the establishment of a Development and Training Unit to train college staff in complex disabilities, and a brokerage programme to put together bespoke packages of learning for young people. It was hoped that this would help to reduce the number of young people placed out of authority because of inadequate local provision.

In a different area, the transition service linked with Connexions to run a young ambassadors' project whereby young people attending particular colleges visited the special schools to promote the colleges and encourage young people and their parents/carers to apply to the local college rather than to out-of-area placements.

### ***Transport***

Travel training was an integral part of many of the specialist courses provided post 16 for young disabled people. A few staff remarked on transport provision in relation to post 16 education.

There was variation across the five areas in the age at which free transport ceased. In two areas, interviewees reported that free transport ceased when the young person’s statement ceased. In another area, a senior manager reported that beyond age 19, transport provision to college was a huge issue for young people, and one that was exacerbated in a predominantly rural county. In the same area, another interviewee noted that problems arose if a young person was staying in respite accommodation rather than at home, because this was not covered in the local transport policy. In two areas, individual staff noted the difficulty in securing transport for young people attending out of area further education colleges. Two staff from two areas reported that young people awarded the mobility component of Disability Living Allowance were expected, or would shortly be expected, to use this for transport to and from college.

In one service, transition workers reported that they liaised with the education department about home to school transport, and also provided information and advice to families about what transport was available. This included information about the *Buddy* travel training service which provided trained ‘buddies’ to accompany disabled young people on bus journeys.

### 4.10.8 Career and employment opportunities

***Lack of opportunities for paid employment***

In all areas, staff reported few opportunities for the young disabled people they supported to get a paid job. In one area, this had been the finding of a recent Special Education Needs Review. In another area, interviewees noted that employment was a conspicuous gap in young people’s transition plans, reflecting the lack of employment opportunities available. In this relatively young service, two transition workers were unable to recall any young disabled person who had left school to go into employment. This was echoed by a member of staff in another area, where the transition service was well established: *'Nobody goes to nothing…but nobody goes into employment*.'

Unsurprisingly, given the lack of employment opportunities generally for disabled young people, some staff in two areas reported that opportunities to work were even fewer for young people with profound and complex needs. On leaving education, the principal options for these young people were to go to a social services day centre where activities may include work-type pastimes such as gardening or helping in the café, and/or to employ a personal assistant through self-directed support funds.

***Voluntary work or work experience***

In all areas, staff reported opportunities for young people with disabilities to increase their employability by volunteering or work experience. In three areas, the local Mencap ran an employment service for learning disabled young people, which included finding them work experience placements as well as travel training, mock interviews and job searching skills.

In another area, a work preparation service based within adult learning disability services provided training and support into work for adults with learning disabilities. This was primarily done through a number of its own businesses and projects in, for example, catering, gardening and recycling, which provided work experience for young people with learning disabilities. Drawing on its links with local employers, this service also provided coaching and job search support for adults with learning disabilities. However, in this area, the transition worker supporting young people with physical and sensory disabilities reported that there were no supported work placements for young people with physical impairments. Specialist disability organisations, such as the Royal National Institute for the Blind or the Royal National Institute for the Deaf, did provide employment services, but these were not based in the local area.

Similarly in another area, a work preparation service was provided by the council’s supported employment team for disabled people of working age. This included helping young people find voluntary work or job tasters. This council had also set up a community bridge building service to ensure mainstream services were accessible to people with disabilities. Through this service, young people were supported to find voluntary work. Also in this area a 'Taste for Work' project had funded work tasters with a local employer progressing to an unpaid work experience placement for 11 young people with learning disabilities. Additionally, 'Routeway to Employment for People with Learning Difficulties and/or Disabilities', was a two year LSC-funded project to place 21 young people in jobs with a local employer.

***Connexions and Disability Employment Advisers***

Connexions were also tasked with supporting disabled young people to find employment, and transition workers in all areas reported signposting young people to Connexions for employment advice and support. Connexions personal advisers, including transition personal advisers in one service, may then refer young people on to Disability Employment Advisers (DEAs). Based in local job centres, DEAs were responsible for helping disabled people to find work or gain new skills. They carried out employment assessments to identify skills and abilities, and made referrals to work schemes and programmes such as Access to Work and New Deal for Disabled People.

***Future plans***

In two areas, transition workers highlighted the importance of developing links with local employers to create more opportunities for disabled young people to participate in the workplace. In another service, the chair of the Transition Sub Group hoped to broaden the group’s membership to include representatives from disability employment specialists, like Remploy or the Shaw Trust, or from the council’s employment service.

Staff also reported local initiatives which they hoped would improve job prospects for young people with disabilities. In one area, these were the newly created post of an employment transition champion within the Learning and Skills Council, and the proposed development of social enterprise schemes within the local authority. In another area, a new employment strategy was about to be implemented for all disabled people in the borough, with particular emphasis on young people aged 16+ in transition from children's to adult services. A performance framework was being developed to monitor this strategy, which included targets relating to the number of people with learning disabilities or mental illness in sustainable employment.

### 4.10.9 Independent living skills

Across all services, staff reported that independent living skills, such as managing money, travel and safety issues, were delivered through the curriculum in special schools and colleges of further education. In some special schools, staff described specialist facilities for young people to learn about food preparation and cooking. Where particular concerns were identified, transition workers or those supporting young people in transition, would refer to other practitioners or organisations for help with teaching life skills. These included:

- outreach workers attached to social care teams for children with disabilities or adults with learning disabilities
- specialist disability organisations such as Mencap or the National Autistic Society
- voluntary organisations providing outreach support to enable people with learning disabilities and/or mental health problems to live independently, or providing advocacy services for adults who have learning difficulties
- local organisations supporting young people's independence by helping them to go out into the community and access inclusive services.

Some staff reported that opportunities to develop independent living skills were provided through short breaks in respite units or family homes, and through day services in adult social care. A few staff in two services mentioned that direct payments could be used to pay for a personal assistant to support a young person's independence. In one of these services, adult social care staff reported that independent living skills were a central focus when drawing up support plans with disabled young people and their families.

However in two services, transition workers and social workers supporting young people in transition said they did provide some direct support to young people with regard to independent living skills, although they did not prioritise this aspect of their work. In one of these services, the transition nurse (when in post) took responsibility for providing this support.

### 4.10.10 Short breaks

Transition workers reported providing young people and their families with information about short break facilities and covering this issue within the assessment and review process.

Across all services, the range of short break provision was reportedly more diverse in children's services than in adult services. Children's services had in-house units, privately run schemes including hostel accommodation for young people with disabilities and special needs, and family link or foster carer schemes. Adult short break services, on the other hand, were largely provided in residential homes. One service did report an adult placement scheme where short residential breaks were provided by carers in their own homes. However, this scheme was only available to young people with learning disabilities and not to those with physical impairments requiring more intensive support.

In two services, some staff also reported that eligibility criteria were tougher for young people seeking respite provision in adult services than in children's services. This meant that young people who qualified for respite support in children's services may find they are not eligible for support in adult services.

The disparity between the amount of short break provision in children's and adult social care services was highlighted by staff across all services, with much greater provision available in children's services than in adult services. For example, the transition manager in one service reported that some young people received 120 overnight breaks a year in children's services, yet their entitlement in adult services was for a maximum of 28 nights. There was an expectation that this gap in provision would increase as additional short break funding was made available through *Aiming High for Disabled Children* to enhance current provision and develop new opportunities. Interviewees acknowledged the huge impact this reduction in short break provision had on the lives of young people and their families and were mindful that families needed to be prepared early for this big change.

Staff in all services also remarked upon the fact that adult respite facilities typically covered people aged 18 to 60 and were not designed to meet the specific needs of young adults. This meant that young disabled people could find themselves isolated amongst older people when placed in short break accommodation. In one service, the staff felt that short break provision for young people with physical impairments was inadequate. The core unit for young people with profound and multiple disabilities contained ten beds and only one of these was situated on the ground floor.

In all but one service, direct payments were specified by staff as a means of purchasing short breaks options different from traditional residential provision. Examples given included paying for a personal assistant to accompany the young person on holiday with their family, or for a holiday in a specialist activity centre for disabled people that was also a registered care home. However, staff in one transition service also noted that the only way for social services to fund direct payments was to reduce spending on residential provision and this was made problematic by the council's block contracts with respite providers. Transition workers had to demonstrate that a young person's needs could not be met by these providers in order to secure funding for short break accommodation elsewhere.

Nevertheless in two services, some staff hoped that direct payments would facilitate continuity during transition in relation to short break provision, with direct payments purchasing similar services in adult to those in children's services. In one of these services, continuity was also provided by placing young people for short breaks in supported living accommodation for adults. As well as giving them a short break from their families and carers, it also gave them a taster of this type of living as a possible future housing option. This practice proved so successful that the accommodation had become recognised as a transition team unit. Also in this service, the transition manager reported that within social care there was an agreement between children's and adult services to allow young people to continue receiving short break facilities in children's services beyond 18 and up until aged 19, so that support plans could be drawn up in adult services and put in place.

### 4.10.11 Adult sexuality and relationships

Several staff noted the importance of providing guidance to young people about sex and relationships in order to reduce their vulnerability to harm or abuse. Some staff also noted the sensitivity with which discussions about adult sexuality and relationships needed to be managed, not just with young people themselves but with their parents who were sometimes protective about their child's sexuality. In one area, transition workers felt that cultural differences could make this more problematic.

In most services, support with sexuality and relationship issues was seen largely as the responsibility of schools and a subject that should be covered within PSHE lessons. In services that included transition nurses, transition workers would refer young people to them for advice and support about sexual matters. In other services, transition workers and those supporting young people in transition reported signposting young people to a variety of sources for this support, as appropriate, including:

- Connexions personal advisers, sexual health advisers or workshops
- voluntary organisations in the local community, such as an advocacy service, a women's centre or an organisation supporting adults with a learning disability or mental health problem
- child and adolescent mental health services
- practitioners on the learning disability team for adults, such as community nurses or psychologists
- school nurses
- Teenage Pregnancy Unit
- Sex and Relationship Education practitioner
- community health services.

However, one service did sometimes provide direct support to young people in relation to adult sexuality and relationships. The transition manager and a social worker reported working jointly to support a young woman make an informed choice about, and obtain, contraception. One explained:

> ‘But we’d always take advice and we’d always, obviously, look to parents to support it and get advice from......the health professionals before we jumped in and made a decision, and obviously work with the young person around .... what they wanted’.

Additionally, in one service, it was reported that transition workers received training on adult sexuality and relationships, especially with regard to young people with learning disabilities.

### 4.10.12 Healthy living and emotional changes

Staff reported that schools would cover healthy living and emotional changes within the PSHE curriculum. Transition workers said any unmet needs in this regard would be identified when transition planning or carrying out health assessments and drawing up health action plans. Where there were concerns that could not be dealt with within the transition team, workers would signpost young people to other practitioners or services. These included:

- the community nurse or the psychologist within the multi disciplinary team for young people with learning disabilities
- child and adolescent mental health services
- community support workers within social services
- community health services such as GPs or dieticians
- voluntary organisations or local carers centres.

However, in three services, some staff reported that specialist support around these areas was a gap in provision that needed to be addressed.

### 4.10.13 Planning future goals

Transition workers across all services reported that planning future goals was paramount to their work and central to the process of assessment, planning and reviews. In particular, they highlighted the tools and approaches of person-centred planning as a way of helping young people think about what is important in their lives and what they would like to do in the future:

> ‘And then planning for future goals. Yeah, again I think we’re getting there especially with the person centred planning. If we can start implementing that more... I think that will give ... the young people we work with ...more of ...an idea that they can have access to, you know, what their goals are’.

However, in order to support young people in planning their future goals in this way, transition workers also reported that they needed to be properly resourced. As another transition worker in the same service put it: ‘*We know what we want to do, we just know we can’t do it*’.

In another service, a transition worker said it was planning future goals that their service did well:

> ‘Planning future goals....I think we’re pretty good at and I think families appreciate that, ....from kind of sixteen and a half I’m already talking to them about this is available and...post-eighteen and, you know, we could be flagging Johnny for this’.

## 4.11 Advantages and disadvantages of the transition services

All interviewees were asked what they perceived to be the advantages and disadvantages of their transition service for young people and their families, transition workers and other practitioners.

### 4.11.1 Advantages of the transition services

There was broad consensus among practitioners from all five services about the advantages of the transition services. Across all services, interviewees agreed that a multi-agency transition service model with a designated team or worker specialising in transition was crucial to improving the transition experience and outcomes for young people and their families. All agreed that individual practitioners from any agency working in isolation were not best placed to support a young person’s transition from child to adult services, since a variety of agencies were often involved in providing services or support for an individual young person. The existence of systems, processes and procedures for transition meant that transition planning was no longer dependent on key personalities with a strong interest in transition which meant greater consistency, quality and stability of the services.

***Advantages for young people and their families***

Interviewees identified a number of advantages for young people and their families of having a designated transition service. First, they identified a reduction in the number of assessments and/or the repetition of information as the transition worker could liaise with other agencies and share basic information about the young person and their situation. Secondly, a designated service offered the opportunity for a young person and their family to build a relationship with an individual transition worker or small team of transition workers who could support them through the process of transition from child to adult services, work to build trust and confidence and reduce anxieties about the future. The designated transition team or worker could act as a resource for information and advice and could build a more holistic picture of each young person’s condition, needs and aspirations, which in turn could inform the transition planning to make it more tailored to the individual young person. Thirdly, a designated transition worker or team could offer continuity to a young person at a time when many other people and places around the young person were changing. Fourthly, the emphasis on person-centred planning in transition, along with the greater use of direct payments and personal budgets, was leading to a shift from young people entering day services or receiving home care to young people spending their time in activities they enjoyed, such as sporting or leisure activities. Fifthly, the coordinated approach to transition tended to mean that young people and their families were given one clear message about their possible move to adult services rather than being told different things at different times by different practitioners which had previously caused confusion and upset.

#### ***Advantages for transition workers***

Interviewees employed as designated transition workers perceived many advantages to the designated role as this enabled them to develop an expert knowledge and understanding of the issues facing young people and their families in transition; develop knowledge of what services, support and opportunities were available locally for young people; establish close working links with partner agencies; and focus their time and attention on transition cases. By comparison, social workers who worked on transition as an ‘add-on’ to their other work reported feeling frustrated and concerned about not providing the young person and their family with adequate support, as they could not develop such a specialism in working with young people in transition and identifying the relevant information and networks that would support a smooth transition process.

#### ***Advantages for practitioners outside the transition team***

The majority of practitioners outside the transition teams spoke about the benefits of having a named transition worker or at least one central team to contact with any queries about transition cases, whether this was to determine whether a particular review had been carried out, if a particular agency was involved with a case or what stage a case was at. Practitioners also reported improved communication between agencies, improved understanding of the roles and responsibilities of different agencies and practitioners, and thus an ability to work more effectively and deal with issues more constructively than before. Steering group members in particular argued that the depth of knowledge and expertise developed within the transition team meant that transition workers, and through them senior management, could develop a strategic overview of the needs of young people who would be moving through to adult services, which in turn informed service development and budget-planning in adult services. School staff in most sites commented that the existence of a transition team had reduced the amount of calls for help that the school received from parents, especially after the young person had left the school, which was beneficial to the schools as it freed up resources and staff time for dealing with current students.

### ***Service-specific advantages***

In addition to the generic advantages of the transition services, interviewees also highlighted perceived advantages of their particular transition service model.

In one service, interviewees from a range of agencies maintained that it was advantageous to have the transition workers based in adult services rather than children's services as a smooth transition into adult services necessitated the transition workers knowing, understanding and working within the established systems and processes in adult services, knowing what is and is not available locally for young people, knowing about funding arrangements and opportunities, and having knowledge of the preferred provider scheme. In addition, despite being based in adult social care, the transition workers in this service were employed by Connexions. Some of the transition workers felt that this carried additional benefits in that the workers had good links with Connexions, they often heard about new opportunities for young people through Connexions, and as some families did not see the transition workers as representing social services they were, in some cases, more willing to engage with the transition workers or to speak more candidly than if they had been social workers.

In the service where the transition manager was based half-time in children's services and half-time in adult services, this was perceived to be advantageous in that it raised the profile of transition within each service. Interviewees from education, Connexions and social care maintained that the transition manager role was invaluable as practitioners knew to go straight to the manager rather than spend time trying to work out who to contact about different aspects of a case. Further, it was felt that the transition manager facilitated dialogue between agencies and effectively gave workers links or 'passports' into other agencies or services. This local authority was relatively small and there was stability in the workforce which meant that practitioners had a thorough understanding of their role, links with other agencies and the systems and processes they were required to work within. Having a joint commissioner for health and social care meant that there were no disputes between health and social care as to which agency would fund which parts of a transition package.

In the service where the transition team was based in an integrated children's centre, an interviewee said that this location made the team very accessible to families who would already be familiar with some of the other clinics and services that were run from the centre, families would feel more comfortable within the centre, and would be more aware of 'something called transition' through posters and information leaflets on display in the centre. Furthermore the transition team had access to the other services and practitioners that were housed in the same building thus increasing opportunities for networking and information and idea-sharing, and making multi-agency meetings logistically simpler and time-saving.

Another transition service spanned child and adult social care with the transition social workers in children's social care referring cases to the transition senior practitioner in adult social care. This had led to more joint working between transition workers in children's social care and adult social workers in relation to complex cases and thus led to a smoother transition. The transition workers and managers within children's social care spoke positively of the transition manager's enthusiasm, commitment and understanding of transition issues. It was felt that transition had been prioritised within the local authority and this had had a positive impact on both the resourcing and the profile of the service. A steering group member from adult services reported a better working relationship with children's social care.

In the fifth service, it was reported that despite adult services and children's services becoming more specialised and moving further apart with different targets and performance indicators, the transition team had been very successful in bridging that gap, keeping practitioners from each service aware of developments in the other, and helping parents and young people understand what to expect from adult services. A senior manager within children's social care argued that this greater 'joined-upness' between children's and adult services was critical 'because if we don't get it right now we have missed it, our experience is that once a young person moves into adult services the limited involvement …means that their life chances and life opportunities just fall off the agenda'. The designated service model with its clarity of role, policy and procedure was felt to be the only way of getting the different agencies together to discuss cases. Further, the transition team in this service had benefited from an increased knowledge and understanding of the work of other agencies through having representatives from outside agencies attend their practitioners' meetings to talk about their work. A further perceived advantage of this service was that it had been developed with a lot of consultation with young disabled people and their families, and had reportedly given young people a voice in shaping the services available to them and in raising the profile of transition within the local authority.

### 4.11.2 Disadvantages of the transition services

There was also broad consensus among practitioners from all five services about some of the disadvantages that still existed for young people and their families, for transition workers, and other generic disadvantages.

***Disadvantages for young people and their families***

Issues around the funding of care packages were a significant concern raised by a range of practitioners across all five services. In those services where adult practitioners were not involved in transition planning, practitioners and managers from adult services complained that transition workers and/or social workers from children's services raised the hopes and expectations of young people and their families about what they could expect from adult services and these had to be dashed by adult services if, for example, a placement was deemed to be too expensive or inappropriate. Similarly, practitioners from children's services maintained that they invested a lot of time and energy working with the young people and their families, and undertaking person-centred transition planning, only for the plan or proposed package to be blocked by adult services if the funding was unavailable. This left many transition workers feeling frustrated and questioning why they bothered to work in a person-centred way if this led to the hopes of young people and their families being raised and then dashed. Indeed some claimed that such limitations on funding meant that young people were taken out of good placements and placed in, for example, inappropriate local day centres. Linked to this was a feeling amongst some practitioners that the establishment of a transition team dedicated to working with young people in transition could make young people feel that they were extra special and would get special treatment in adult services, irrespective of the fact that adult services worked with all adults and had many competing targets and priorities such that some young people entering adult services would not receive special treatment or be prioritised.

An adult social worker in one service raised a point that could resonate in other services. This was a concern that a focus on the needs and desires of the young person may not meet the needs of the family or carer(s) and could lead to other difficulties. For example, a shift away from day services towards personal assistants taking young people swimming or bowling could mean that the young person is only out of the house for two hours per day instead of eight and thus other family members may be unable to work (or could only work part-time). This could lead to financial problems, and possibly even family breakdown. Although this was an argument about personalisation and self-directed support, rather than transition *per se*, it could clearly affect families at transition.

### ***Disadvantages for transition workers***

Some transition workers claimed that their workload was increasing as other practitioners expected the transition workers to undertake all transition related tasks and thus relieve them of certain tasks. It was suggested that this led to delays and less time spent on each case, and reduced the involvement of partner agencies. However, other transition workers felt it important that they work on all aspects of transition and free up other practitioners to work on other issues, for example child protection cases.

### ***Other generic disadvantages of transition services***

A common complaint across services was the lack of funding to employ more transition workers, and thus offer a more comprehensive service to the young people they already worked with or possibly amend their eligibility criteria to enable the transition team to work with a broader range of young people. Another common issue was that although the transition team could bridge the gap between children's and adult services and thus ease the transition process, there was still an element of transition when the young person exited the transition team and was handed over to adult services or generic social workers within adult social care.

***Service-specific disadvantages***

In addition to the generic disadvantages of transition services discussed above, interviewees also highlighted particular disadvantages of their transition service model.

Some interviewees raised concerns that the transition workers in one service (who were Connexions workers) were not qualified social workers and this could be seen as a cost-saving exercise, as the transition workers were typically on a lower pay scale than qualified social workers. There were concerns that this could cause ill-feeling among the transition workers, and indeed this was expressed by some of the transition workers themselves who reported that they were doing all of the 'leg work' but were not paid as much as and did not have the same status as social workers. There were also concerns that this could cause unease among social workers who may feel that their skills, qualifications and experience were undermined by the employment of less qualified staff. Some transition workers felt that the transition service would benefit from employing qualified social workers as they would have greater knowledge of the whole social care system. The transition workers also expressed particular concern that they did not know the social workers within children's teams and effectively did not belong to any adult social care team as the social work teams were area-specific while the transition workers worked county-wide. Some felt they didn't quite fit within Connexions or adult social care. Some transition workers reported feeling like isolated lone workers; some stated it was difficult to employ consistency in their own role across the county. Some transition workers thought that parents were confused as to why their son or daughter was now supported by somebody from Connexions rather than by a social worker, and some parents were concerned that their son or daughter would not have a social worker in adult services.

The biggest disadvantage of another transition service was reported to be the fact that there were no designated transition workers or team, only a transition manager. This meant that families could end up working with any generic social worker (or numerous agency workers) which could lead to a lack of consistency, the need for families to repeat information to different workers, and families not being supported by practitioners with in-depth knowledge of the processes involved in transition or the opportunities and support available for young people in the area. The fact that there was only one transition manager also meant that she had little time to work with individual social workers in children's or in adult services who were working on transition cases, which reduced opportunities for those social workers to build up expertise and knowledge around transition.

In the other coordinating service, the greatest disadvantage, reported by members of the transition team and practitioners from other agencies, was the lack of resource and under-staffing of the transition team. Interviewees also reported a lack of clarity over the role of the transition team: some interviewees from children's services noted that social workers, other practitioners and indeed young people and their families, were confused by the (temporary) involvement of a further set of practitioners (the transition team), with some children's social workers wondering if they really needed to involve the transition team or whether they could work directly with their counterparts in adult services. In this service, the current model within the service is being reviewed with consideration for a Team Around the Child care coordination model.

The transition workers in one service all agreed that there was a lot of enthusiasm and ideas within the transition team, but felt there was little opportunity to develop that creativity owing to constraints of funding, and the fact that a substantial amount of the team's time was spent on more generic social work issues, in particular child protection cases. An interviewee from adult services reported some duplication of work between the transition workers in children's social care and social workers in adult social care as, for example, both could end up assessing a young person at the same point in time. This interviewee also felt that there had been a lot of change happening simultaneously within adult services with the introduction of a transition team and the piloting of self-assessment processes and support planning. It was argued that the combination of these changes could be overwhelming for practitioners and for parents and young people alike. A manager and a practitioner from adult services also noted that the number of complaints received from families had increased following the introduction of the transition service in general, and person-centred planning in particular, and this inevitably resulted in the local authority using some of its scarce resources on dealing with such complaints. However, the majority of such complaints centred around self-directed support rather than transition planning *per se*, for example, difficulties in recruiting personal assistants, delays in getting the support package in place, the inability to gain a placement at the specialist college of their choice, and concerns over promoting independence, losing control and managing risk.

In the final service, the key disadvantage was reportedly the fact that the transition team had not been staffed to full capacity for some time: the transition nurse post had been vacant for ten months at the time of the interviews and the family support practitioner was on maternity leave and had not been replaced. In addition, the transition senior practitioner had just resigned from the service. Another reported disadvantage of the system was the fact that social workers in adult services worked on a six month rotation. Interviewees complained that this system meant that there was a lack of consistency with young people, families and transition workers sometimes having to work with different adult social workers which had led to confusion, delays and duplication. While managers from adult services argued that the rotation system would eventually allow all social workers to undertake some transition work, there was recognition that the lack of a consistent adult social worker was not ideal. Some staff argued that the transition team (who were from children's services) were doing more work (compared to a typical children's social work role) to set up the young person's care package and funding for adult services and to understand the different systems and processes within adult services. Whilst it could be argued that this is a central part of a transition role, the complaint was that despite undertaking such work, the transition team received no funding from adult services. Concerns were also raised that some of the progress with transition was based upon the strength of interpersonal relationships and could be lost if one of those parties were to leave.

## 4.12 Areas for improvement

Interviewees across all agencies in all services acknowledged that the local transition service could be improved and many gave recommendations as to how the service could be developed. These often related to the disadvantages noted above. Many recommendations were common across most services.

### 4.12.1 Staffing issues

All services reported some degree of under-staffing, lack of capacity and/or backlog of cases. Many of these issues are noted under disadvantages of the transition services, but are summarised here, as they underpin a number of other areas for improvement.

- One service had only one part time transition worker to work with young people with physical disabilities across the whole county so there was some lack of capacity in that particular field.

- Two services had been short-staffed for a considerable time. At the time of the interviews, the team in one service had recently grown from one to three people but they had a large backlog of cases. In the other, staff who had left or were on maternity leave had not been replaced at the time of the interviews.

- Another service did not have a designated transition team, transition work was carried out by social workers who felt that they did not have in-depth knowledge of transition as it was only a part of their jobs. In addition, the one transition manager did not have time to work closely with all the individual social workers who were involved in transition.

- In the service where transition social workers worked with all young people with disabilities aged 14-18, they spent a lot of time on generic social work tasks and felt that they lacked the capacity to get as involved with transition planning as they would like, and also had a backlog of cases.

Interviewees from all services argued for the recruitment of more transition workers (including transition nurses) so that all young people in transition may receive a fuller and more individually tailored service.

#### 4.12.2 Ages/stages of young people the services supported

Although transition planning in schools begins at age 14 and a member of the transition team would usually attend the Year 9 school review, the transition services typically did not get closely involved with the young people until they were approximately 16-17 years of age. This was primarily due to staff shortages. Interviewees in four services recommended that the transition team work more closely with the young people from an earlier age. This would support more preventative work with young people; provide more time for detailed transition planning and support a person-centred approach to transition planning; reduce some of the young peoples' and parents' anxieties surrounding the transition to adult services; and capture those young people who leave school at age 16 and do not have contact with a transition worker.

Interviewees also recommended that the transition team work with young people for longer, either until they have settled into their new package of support or until the young person is in their mid-twenties, as it was argued that the key transition in a young person's life was their transition from college to adult services when many more aspects of a young person's life were open to change, for example, employment, day services, housing, and thus when most support was necessary.

Interviewees in all services stated that the transition process would be smoother if the gap in provision between child and adult health services was eliminated such that a young person could transfer from child to adult health services without a possible gap in service which could prove detrimental to their physical and/or mental health.

### 4.12.3 Types and severity of disabilities the services supported

Interviewees across all five services maintained that more services and support were needed for those young people whose disabilities were not severe or complex enough for them to be eligible for adult services but who still required support. Typically such concerns were raised in relation to young people with autistic spectrum conditions (ASC) and those with mental health problems. Some interviewees recommended the introduction of designated transition workers for young people with ASC or mental health problems to advocate for more services for these groups of young people, provide information to families about any local services or provisions, provide more support and information around benefit checks and entitlements, and to make any links with relevant personnel in adult mental health services.

### 4.12.4 Roles of transition teams

Interviewees in three services suggested that there needed to be greater clarity on the role and responsibilities of the transition workers/team amongst staff from other agencies/services so that best use could be made of the transition service. Interviewees from one of these services also suggested that communication needed to be improved between different practitioners and agencies to increase understanding of each other’s roles and responsibilities, to reduce misunderstandings and duplication of effort, and to minimise any gaps in service.

In all services, referrals to adult mental health services were made directly by child mental health services and did not go through the transition team. Some interviewees felt that such referrals should go through the transition team to provide opportunities for holistic planning around education, employment, housing and social care.

Some interviewees in one service argued that the transition team could take on more of a coordination role, facilitating access to all the other agencies (health, education, and so on), and undertake less of the direct work with young people and families. However, interviewees in the two services which operated more of a coordination role argued strongly in favour of a designated transition team which undertook much of the direct work around transition.

### 4.12.5 Resources and care packages

Interviewees across all five services argued that transition for young people would be improved if there were more resources, facilities and activities available to disabled young people. Interviewees in two services maintained that transition could be improved if packages of support could be developed which combined employment with education and leisure to make up a five day-a-week package of care. The ideal was that this could be funded by one central transition budget as opposed to individuals having to apply to different agencies for monies from different funding streams.

### 4.12.6 Service specific recommendations

- Some interviewees in one service suggested that transition workers should attend some of the meetings in schools where leavers are discussed and provide regular updates on what is happening with the transition service. Other suggestions for improving this transition service included more information and support for young people around, for example, sexuality and relationships, employment, and benefits; and strong leadership in driving the transitions agenda and being accountable for the transition service.

- As noted above, interviewees in one of the coordinating services suggested that the service would be improved if there was a designated transition team which could work to set up the young person’s support package, get services in place, and make sure everything was going smoothly prior to transfer to adult services. However, while the current coordination model was still in operation, a health practitioner argued that young people could benefit from a ‘health’ transition coordinator that could coordinate health action plans and facilitate access to adult health services.

- Some interviewees in a service where all transition team members were social workers maintained that the transition team needed to be much more multi-agency, perhaps including staff from Connexions, education, health, and voluntary organisations, as well as social workers. It was suggested that such integration could save time and avoid some duplication of effort for both the families and the practitioners if the number of systems and processes were reduced.

- Transition workers whose roles included generic social work argued that the transition service would be improved if they were able to work solely on transition. They also suggested that the transition service would be improved if a worker from adult services could be based in the children’s team to guide colleagues through the adults’ system and processes, advise on whether support plans would be supported by adult services, advise on sources of funding and support joint working more generally. However, this was expected to be problematic due to (a) the different eligibility criteria between children’s services and adult services, and (b) issues around adult services funding an adult worker to work within children's services.

## 4.13 Summary

Interviews with transition workers, service managers, practitioners from various fields (including health, education and Connexions) and members of steering groups in the five case study sites showed that the services were similar in relation to the basic aims of the service, referral arrangements, having multi-agency representation in setting up and overseeing the service, and drawing up multi-agency transition plans. All services were supported and overseen by a multi-agency steering group and a range of multi-agency transition sub-groups. There was limited representation of parents and young people on the steering groups in some of the services: only one service had both parents and young people on the steering group. However, there were also considerable differences between the five service models:

- *Service A* consisted of a team of Connexions workers based in adult services who were able to develop an understanding of the systems, processes and funding within adult services. Transition workers in this service supported young people into adult services by negotiating their support package and funding during the transition process.

- In *Service B*, the fact that the transition manager was based 50/50 in children's and adult services meant that transition had a high profile in each service. However, this was a coordinating service with expertise on transition provided by the transition manager. The lack of a team of designated transition workers meant that transition was an 'add-on' to the caseload of generic social workers who did not necessarily have specific expertise in transition.

- *Service C* was also a coordinating service and had adopted a lead professional model. Based in an integrated children's centre the service was potentially more accessible to young people and their families, and more conducive to information sharing and multi-agency working with partner services. However, this service suffered from a lack of clarity about the role of the transition team, and a low profile among both families and other practitioners, possibly due to a prolonged period of under-staffing.

- In *Service D,* young people were supported by the multi-agency transition team in children's services, which included a transition nurse, and referred directly to designated transition workers in adult services (if eligible). This service provided joint working between children's and adult services and had a high profile within the area. However, as the transition team was also the generic social work team for young people aged 14-18 the transition workers appeared to spend a lot of time working on non-transition issues, such as child protection cases.

- *Service E* was based within children's services; however the multi-agency transition team negotiated the support package and funding in adult services to facilitate the young person's move from children's to adult services. Training around transition and the role of other agencies appeared strongest in this service. However, the service suffered from staff shortages and posts remaining vacant, including the post of transition nurse on the team. The recent reorganisation of adult social care from specialist to generic teams had also proved challenging for the transition team.

Key advantages of the transition services for managers and practitioners were reported to be: better multi-agency working; increased communication between different agencies; increased understanding of the role of other agencies; having a central point of contact for transition issues; continuity for the young person, their family and practitioners; and less duplication and repetition of assessments and visits. In the two coordinating services, the transition manager or transition workers typically did not hold cases and thus were in a position to oversee transition cases, support good communication between agencies, and ensure that referrals and meetings were taking place as planned.

Key difficulties reported by the services were: under-staffing and vacant posts; lack of options, facilities and services for young people to transition to in adult services; difficulties with information sharing; time spent on generic social work limiting the amount of time that could be devoted to transition in those services where transition workers did not work solely on transition cases; varying degrees of communication with other agencies and some lack of clarity among other agencies of the role of the transition team; a lack of transition specific training; and the different ages at which different services become involved and cease to be involved with young people at transition.

Factors that differed between services and appeared to be important to how the services operated included: whether transition workers simply led young people to adult services or supported their move into adult services by negotiating support packages and funding in adult services prior to transition; having clarity about the role of the transition worker/team; having designated or non-designated transition workers; transition workers having training for the role; whether the transition manager was involved at a strategic level; the extent to which transition planning incorporated person centred planning; and whether parents and/or young people were involved in overseeing the service.

In the next chapter, we report the results of the family survey and look at how differences in the service models related to outcomes of the services for families.

# Chapter 5 Results of the Family Survey

In this chapter we report the results of the survey of parents and young people. The results for pre- and post-transition samples are reported separately, and initial analyses of any differences between sites and differences between those who did and did not have a written transition plans or one transition worker to support them are reported. In addition (at the request of Department of Health) differences between families with young people with ASC and the rest of the sample are investigated. The parent samples are then combined for the purposes of multivariate analyses of factors related to better or worse outcomes. The young people's samples are too small for multivariate analysis.

## 5.1. Pre-transition parents

### 5.1.1 Characteristics of the sample

There were a total of 110 respondents. Respondents were predominantly mothers (85.5 per cent, n=94), 14 respondents (12.7 per cent) were fathers, one was a grandmother and one a carer. Seventy-eight respondents (70.9 per cent) were married or living as married, 15 (13.6 per cent were separated or divorced, 12 (10.9 per cent) were single, three (2.7 per cent) were widowed, and two did not provide data.

Fifty-two respondents were employed outside the home (47.3 per cent); 23 full-time and 29 part-time. Seven did not provide data. Fifty-nine partners were employed (78.7 per cent); 53 full-time and six part-time. Sixteen partners were not in employment. Table 5.1 gives details of the socio-economic status of respondents and partners, based on present or previous employment (if not currently employed), using the five-category system of the National Statistics Socio-Economic Classification (NS-SEC). There were no significant differences between the samples from the five services in terms of socio-economic status.

**Table 5.1 Socio-economic classification of respondents and partners (National Statistics Socio-Economic Classification (NS-SEC))**

| *Class* | *Label* | *Percentage of people aged 16-74 in employment (England and Wales)* [1] | *Percentage of respondents (N=47)* | *Percentage of partners of respondents (N=54)* |
|---|---|---|---|---|
| 1 | Managerial and professional occupations | 38 | 57 | 41 |
| 2 | Intermediate occupations | 13 | 21 | 2 |
| 3 | Small employers and own account workers | 10 | 2 | 24 |
| 4 | Lower supervisory and technical occupations | 10 | 0 | 11 |
| 5 | Semi-routine and routine occupations | 29 | 19 | 22 |

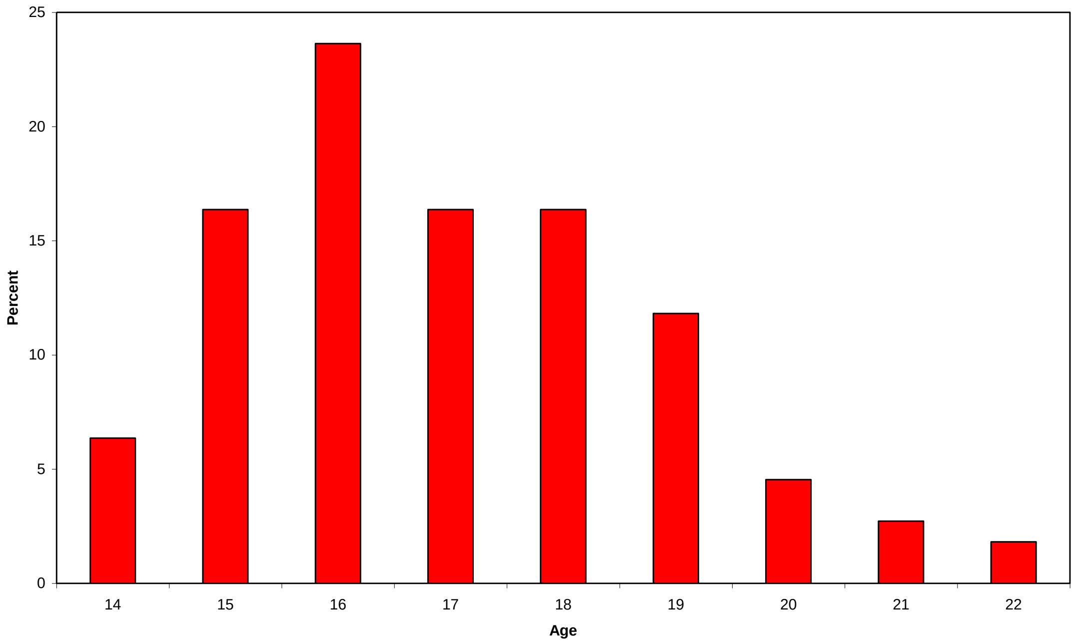
[1] National Statistics Socio-economic Classification Census 2001

Parents were asked if their main source of family income was from paid employment or social security benefits: 67 respondents (60.9 per cent) specified that their main source of family income was paid employment, whilst 26 (23.6 per cent) stated it was social security benefits. Four respondents did not know and 13 did not provide data.

### 5.1.2 Characteristics of young people

The ages of the disabled young people in these families ranged from 14 to 22, with a mean age of 16.98 years (SD=1.85, median=17.00) (see figure 5.1). Seventy were male and 40 female. One young person was adopted.

## Figure 5.1 Age of young people in sample



Seventy-six young people were white (69.1 per cent), six were Indian (5.4 per cent), five were Black-African (4.5 per cent), three were Black-Caribbean (2.7 per cent), one was Pakistani, one was Chinese, six (5.4 per cent) were mixed race, and seven (6.4 per cent) were from other backgrounds (including Iranian, Sri Lankan, Kurdish, Colombian, Black British). Three did not provide data.

The young people had a range of diagnoses, with most having more than one condition. The most common diagnoses are given in Table 5.2.

## Table 5.2 Most common conditions

| *Diagnosis* | *Number of young people* |
|---|---|
| Autistic spectrum | 43 |
| Cerebral palsy | 17 |
| Epilepsy | 16 |
| Down's syndrome | 12 |
| Other chromosomal abnormalities | 10 |

### *Types and levels of disability*

Parents were asked to rate from 0 (not at all) to 2 (very much so) whether their son or daughter experienced difficulty in a number of fields such as communication, behaviour, learning and mobility. The percentage of young people who experienced difficulty in these areas is shown in Table 5.3.

**Table 5.3 Types and level of difficulties**

| | *Not at all* | *Some difficulties* | *A lot of difficulties* |
|---|---|---|---|
| Communication (n=108) | 1.9% (2) | 35.2% (38) | 63.0% (68) |
| Behaviour (n=105) | 15.2% (16) | 48.6% (51) | 36.2% (38) |
| Learning (n=108) | 0.9% (1) | 25.0% (27) | 74.1% (80) |
| Mobility (n=99) | 36.4% (36) | 31.3% (31) | 32.3% (32) |
| Health (n=101) | 39.6% (40) | 42.6% (43) | 17.8% (18) |
| Vision (100) | 50.0% (50) | 32.0% (32) | 18.0% (18) |
| Hearing (n=102) | 72.5% (74) | 21.6% (22) | 5.9% (6) |
| Continence (n=102) | 47.1% (48) | 19.6% (20) | 33.3% (34) |

Results showed that, consistent with the eligibility criteria for the transition services (see Chapter 4), only one young person did not have learning difficulties, and most (74.1 per cent) had high levels of learning difficulties. High levels of communication difficulties were also common (63.0 per cent with many difficulties), and over 80 per cent had some or many behaviour difficulties. In contrast, mobility, continence and health difficulties were more evenly spread across the sample, with around a third of young people having no, some or many mobility problems, and only a minority (18.0 per cent) having many health difficulties.

A difficulties scale score on difficulty items was also computed (by summing scores for individuals with no missing data). The overall mean score was 8.02 (SD=3.11, range=2 - 15, median =9.00, n=97). There were no significant differences between the five services.

***School/college***

Nearly all young people (N=105) had a statement of special educational needs, two did not, and three didn't know or data were missing.

Parents were asked what type of school the young person currently attended or had attended if they had now left. Eighty-five young people (77.3 per cent) attended special schools, five attended special units in mainstream schools, five attended residential schools, seven attended mainstream schools. Five parents only supplied details of colleges currently attended (see below) and data were missing for three.

Thirty-seven young people were currently attending FE or sixth form colleges, with 15 of these attending residential colleges.

***Other activities***

Parents of young people who were no longer in full-time education were asked to indicate what they did during a typical week. Only 14 young people fit into this category, and their activities are summarised in Table 5.4.

**Table 5.4 Other activities amongst those not in full-time education**

| | *Number of young people involved each day* | | | | | *Any day* |
|---|---|---|---|---|---|---|
| | *Monday* | *Tuesday* | *Wednesday* | *Thursday* | *Friday* | |
| PT education | 3 | 4 | 4 | 5 | 3 | 7 |
| Stay at home | 3 | 2 | 3 | 1 | 3 | 3 |
| Day services | 4 | 4 | 2 | 3 | 3 | 4 |
| Paid work (supported) | 0 | 0 | 0 | 0 | 0 | 0 |
| Paid work | 0 | 0 | 0 | 0 | 0 | 0 |
| Voluntary work | 0 | 0 | 0 | 0 | 0 | 0 |
| Other | 3 | 3 | 3 | 4 | 4 | 4 |

It can be seen half of the young people (not in full-time education) were involved in some form of part-time education on at least one day a week. Four took part in day services, and four were involved in other activities, which included independent/daily living skills courses and attendance at an Enterprise Centre. Only three of the young people were reported to stay at home, and only one of these stayed at home five days a week. None of the young people were involved in any paid or voluntary work.

### 5.1.3 Influence of the young person's disability on employment

Parents were asked whether their caring responsibilities had affected their employment: 23 (23.7 per cent) said that they had not, 35 (36.1 per cent) stated that they had had to give up work to care for their child, 13 (13.4 per cent) felt that they had not progressed as far in their job, and 26 (26.8 per cent) felt they could not work as many hours as they would like.

Parents were also asked, if they had been employed in the previous three months, how many days they had had to miss work because of their caring responsibilities. Only 23 parents provided a response to this question. The mean number of days of work missed was four (SD=3, range=0 – 12, N=23).

### 5.1.4 Transition planning and information

***Planning for transition***

Parents were asked if their son/daughter had a written transition plan, and 35 parents (31.8 per cent) were aware of such a plan, with 43 not having a written plan and the remainder unsure of whether they had a written transition plan or not. Combining the 'no' and 'don't know' responses, the responses for each site can be seen in Table 5.5 the proportion of young people who had a written transition plan varies from 46.3 per cent in site A to 7.1 per cent in site C. The differences are statistically significant (unlikely to have occurred by chance), chi-square = 13.23, df = 4, p=0.01.

**Table 5.5 Presence of written transition plans by site**

| | *Has written transition plan* | |
|---|---|---|
| *Site* | *No/don't know* | *Yes* |
| A (N=41) | 53.7% (22) | 46.3% (19) |
| B (N=11) | 54.5% (6) | 45.5% (5) |
| C (N=28) | 92.9% (26) | 7.1% (2) |
| D (N=16) | 75.0% (12) | 25.0% (4) |
| E (N=14) | 64.3% (9) | 35.7% (5) |
| *Total (N=110)* | *68.2% (75)* | *31.8% (35)* |

Only 21 parents reported that their son/daughter had a copy of their transition plan. This represents 60 per cent of those young people whose parents reported that they had a written transition plan, but only a fifth (19.1 per cent) of all the young people.

The age at which services were reported to have started planning for transition ranged from 13 to 22, although the majority (86.3 per cent) of the young people had been between 14 and 17 years old (mean age=15.36, SD=1.71, N=80). A quarter of parents did not respond to this question, although some of those who reported that they did not have a written transition plan did answer this question.

Parents were asked how often transition planning for their son/daughter was reviewed, although only half of parents (55) responded to this question, including some who reported that they did not have a written transition plan. The majority (N=32) of plans were reviewed annually, with some reviewed more regularly than that. Nine young people had never had their transition plan reviewed. Parents were then asked if they felt their transition plan was reviewed regularly enough, and 88 parents answered this question (including some who did not have a written transition plan). Thirty-four of these parents (38.6 per cent) felt that review took place regularly enough, whilst 30 (34.1 per cent) felt that it did not. A quarter of parents reported that their plan had not been reviewed.

### 5.1.5 Contact with services

***Co-ordinated approach to transition***

Parents were asked if they had one person to support them and their son/daughter through transition. Seventy-one parents did have such a person, whilst 27 did not, nine parents didn't know, and three did not provide data. The responses by site are shown in Table 5.6 the proportion of parents who stated that they had a transition worker ranged from 42.9 per cent (Site E) to 82.9 per cent (Site A). The differences between sites were found to be statistically significant (chi-square = 9.69, df =4, p = 0.046), although the low frequencies may make this result unreliable. As staff had indicated that they did not become actively involved with young people until they were 17 (see section 4.3.2), a chi-square test was run comparing responses of parents of young people above and below 17 years of age. There was no significant difference on whether they had one person to support them through transition.

**Table 5.6 Presence of transition workers by site**

| | *Has one transition worker* | |
|---|---|---|
| *Site* | *No/don't know* | *Yes* |
| A (N=41) | 17.1% (7) | 82.9% (34) |
| B (N=11) | 36.4% (4) | 63.6% (7) |
| C (N=26) | 42.3% (11) | 57.7% (15) |
| D (N=15) | 40.0% (6) | 60.0% (9) |
| E (N=14) | 57.1% (8) | 42.9% (6) |
| *Total (N=107[a])* | *33.6% (36)* | *66.4% (71)* |

[a] Three parents did not answer this question

Of the parents who provided the job title of this support person (N=72), the majority were Connexions workers (33.3 per cent), social workers (30.6 per cent) or Transitions workers (26.4 per cent). Parents stated that they had had this support for between one and 73 months, with a mean of 23.31 (SD=19.61, N=62). Whether the young person had an Autistic Spectrum diagnosis or not did not seem to influence whether they had a single transition support person to support them.

Forty-seven per cent of families who had a transition worker reported that they had a written transition plan compared with six per cent of those who did not have a transition worker (chi-square = 18.17, df=1, p<0.001, n=107).

***Personal contacts with transition services***

In a period of three months, the mean number of times families saw their transition support person was 1.85 (SD=2.11, range=1 – 12, N=40), although a large number of parents did not provide this information. Mean number of times per site ranged from 1.18 in Site A (SD=0.39, N = 17) to 3.3 in Site B (SD=4.27, N = 6). The differences among services in the number of times families saw their transition support person were not significant.

The mean duration of visits from the transition support person was 64 minutes (SD=43, range=10 – 300, N=62). Services varied in the mean duration of their visits with a transition support person from 39 minutes in Site D (SD=18, N=8) to 82 minutes in Site C (SD=88, N=9). The differences among services were not significant.

Respondents were asked if they wanted to see their transition support person more often, the same, or less often: 32.8 per cent of families wanted to see their transition support worker more often, 65.7 per cent wanted to see them the same, and 1.5 per cent (just one family) wanted to see them less often. The percentage of respondents who wanted more contact ranged across services between zero per cent (site E) and 64.3 per cent (site C), although frequencies are too small to determine whether the differences between sites are statistically significant.

### ***Telephone contact with transition services***

Parents were asked how often they spoke to their transition support person on the telephone in an average three-month period. The mean number of telephone calls was 2.05 (SD=1.69, range=0 – 10, N=43). Mean number of calls per service ranged from 1.50 in Site C (SD=0.93, N=8) to 2.67 in Site D (SD=3.78, N=6), although the differences between services were not significant.

The mean duration of telephone calls was 13.3 minutes (SD=10.55, range=0 – 60, N=42). Mean duration per service ranged from 7.83 in Site C (SD=6.49, N=6) to 19.17 in Site B (SD=6.65, N=6). The differences between services were not significant.

Respondents were asked if they wanted to talk to their transition support worker more often, the same or less often: 25.0 per cent of families wanted to talk to their transition support person more often, 73.4 per cent wanted to talk to them the same, and 1.6 per cent (one respondent) wanted to talk to their transition support person less often. The percentage of respondents wanting more telephone contact ranged across services from 14.3 per cent (Site B) to 44.4 per cent (Site D), although again frequencies are too low to determine if the differences between sites are statistically significant.

### ***Pattern of contact with transition services***

Parents were asked if their transition support person contacted them regularly: 48.5 per cent of respondents (32) said that they did, with 43.9 per cent (29) saying that they did not, and 7.6 per cent (5) being unsure. Eight parents did not answer this question. The percentage of parents reporting that their transition support person contacted them regularly ranged across services from 30.8 per cent (Site C) to 85.7

per cent (Site B). The frequencies were too small to determine if the differences between sites were statistically significant.

Parents were also asked if the transition support person left it up to them to make contact: around half of parents (50.8 per cent) suggested that their transition support person was proactive in making contact, whilst 37.7 per cent were left to make contact themselves and 11.5 per cent were unsure. Thirteen parents did not answer this question. The percentage of parents reporting that their transition support worker left it up to them to make contact ranged from zero per cent (Site B) to 51.7 per cent (Site A). Again, frequencies were too small to determine if differences between sites were statistically significant.

### *Satisfaction with transition services*

Parents rated their level of satisfaction with the transition service they received. Responses ranged from one (very satisfied) to four (not at all satisfied). The mean score for satisfaction was 2.60 (SD=0.97, range=1 – 4, N=95). Mean satisfaction varied across the services from 2.12 in Site B (SD=0.99, N = 8) to 3.19 in Site C (SD=0.98, N=21). One way analysis of variance was significant (F=3.43, df=4, 90, p=0.012) and post-hoc tests showed that families in Service C had lower satisfaction with the service than families in Service A (mean difference 0.84, SE0.25, p=0.01) and Service B (mean difference 1.07, SE 0.38, p=0.007).

Table 5.7 shows the pattern of satisfaction across the whole sample, indicating that the around half (51.6 per cent) of respondents were satisfied or very satisfied with the transition services they received.

**Table 5.7 Satisfaction with transition services**

| *Very satisfied* | *Satisfied* | *Not satisfied* | *Not at all satisfied* |
|---|---|---|---|
| 11.6 (11)[a] | 40.0 (38) | 25.3 (24) | 23.2 (22) |

[a] ( ) = n

If we create a binary variable to represent very satisfied/satisfied and not satisfied/not at all satisfied, and look at differences in satisfaction across sites we see that the percentage of parents who were satisfied with the service ranged from 28.6 per cent (Site C) to 75.0 per cent (Site B). Having a child with a diagnosis of ASC did not significantly affect parents' satisfaction. Parents who stated that their child had a written transition plan were far more likely to be satisfied with the transition service (81.8 per cent) than those who did not (35.5 per cent), and this difference was statistically significant (chi-square = 18.51, df = 1, p <0.001). Similarly, those who had a transition support worker were more likely to be satisfied (68.2 per cent) than those who did not (14.3 per cent), and the difference was significant (chi-square = 22.88, df = 1, p<0.001).

### *Stress and transition services*

Parents were asked whether their contacts with the transition service had affected the amount of stress they experienced in caring for their son/daughter in the previous six months. Table 5.8 shows the pattern of the impact of the contact with transition services on stress levels across the sample. It can be seen that for over a third of parents (31), their contacts with the transition service were reported to have increased their stress over the previous six months.

**Table 5.8 The impact of contact with transition service on stress**

| *Considerably reduced my stress* | *Somewhat reduced my stress* | *Not had any effect on my stress* | *Somewhat increased my stress* | *Considerably increased my stress* |
|---|---|---|---|---|
| 9.5 (8) [a] | 14.3 (12) | 39.3 (33) | 21.4 (18) | 15.5 (13) |

[a] ( ) = n

A 3-point stress variable was created (reduced stress/no effect/increased stress). Frequencies were too small to determine if there was any difference in stress between sites, and there were no significant differences between those whose child did or did not have an ASC diagnosis.

### *Contact with other services*

Respondents were asked to report how many professionals their son/daughter had seen in the last three months. Frequencies and percentages are shown in Table 5.9.

**Table 5.9 Number of professionals seen in the last three months**

| *Number of professionals seen* | *Number of families* | *Percentage (%)* |
|---|---|---|
| 0 | 7 | 6.8 |
| 1 | 12 | 11.7 |
| 2 | 21 | 20.4 |
| 3 | 15 | 14.6 |
| 4 | 16 | 15.5 |
| 5 | 13 | 12.6 |
| 6 | 8 | 7.8 |
| 7 | 5 | 4.9 |
| 8 | 2 | 1.9 |
| 9 | 4 | 3.9 |
| *Total* | *103* | *100.0* |

The mean number of professionals families had seen was 3.52 (SD=2.25, range=0 – 9, N= 103). The five services varied in terms of the mean number of professionals seen between 2.45 (SD=1.69) and 4.44 (SD=2.39). One-way analysis of variance showed that there were significant differences among services (F=4.16, df=4, 98, p=0.004), and post-hoc tests showed that families in Service A saw a lower mean number of professionals than those in Services C (mean difference=1.89, SE=0.55, p=0.001), D (mean difference=1.99, SE=0.63, p=0.002), and E (mean difference=1.41, SE=0.66, p=0.036).

Parents were asked how many times their son/daughter had visited accident and emergency (A+E) in the previous three months: 94 young people (90.4 per cent) had not visited A+E at all, eight had visited once, and two had visited twice. Six parents did not answer this question.

Parents were also asked about inpatient stays: again, the vast majority of young people (92.8 per cent) had not been a hospital inpatient, four had had one inpatient stay, and three had had two stays. Thirteen parents did not answer this question.

The majority of young people (71.4 per cent) did not receive a short breaks service. Of those who did (N=30), 27 parents provided information about the number of days break they had per month/year. The mean number of days per year was 33 (SD=24, range=1 – 111, N=27). The mean number of short break days did vary across services, but the frequencies are too low to report any differences.

### 5.1.6 Unmet needs

***Information needs***

Parents were asked whether their needs relating to information about transition had been met, and the results are shown in Table 5.10. The first three columns indicate the proportion of respondents who did not need help in that area, who felt they were getting enough help, and needed more help. The final column indicates the proportion that had needs in that area which were not being met. Around two-thirds of parents had unmet needs relating to information to help plan for their son/ daughter’s future (68.7 per cent) someone to show them which services were available in the future (69.7 per cent), and someone to explain the transition process to them (59.6 per cent).

### Table 5.10 Parent information needs

| | *Help not needed (yet)* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Information to help you plan for your son/daughter's future | 6.6% (7) | 29.2% (31) | 64.2% (68) | 68.7% |
| Someone to show you which services are available as your son/daughter grows up | 3.9% (4) | 29.1% (30) | 67.0% (69) | 69.7% |
| Someone to explain the transition process to you | 2.9% (3) | 39.2% (40) | 57.8% (59) | 59.6% |

The mean number of unmet parent information needs was 1.87 (SD=1.32, range=0 – 3, N=102). Parent unmet information needs ranged among services between 1.51 in Site A (SD=1.35, N=39) and 2.40 in Site C (SD=1.15, N=25). Differences between services were not significant.

A T-test revealed that the mean number of unmet parent information needs was higher for those who did not have a transition worker (mean = 2.64, SD = 0.82, N=33) than for those who did (mean =1.46, SD=1.36, N=67), t = 5.34 (equal variances not assumed), df= 94, p<0.001. Similarly, the mean number of unmet parent information needs was higher for those who did not have a written transition plan (mean = 2.25, SD = 1.19, N = 69) than for those who did (mean = 1.09, SD = 1.26, N = 33), t = 4.49 (equal variances assumed), df = 100, p<0.001.

There was no significant difference between the mean number of unmet parent information needs for those whose child did or did not have an ASC diagnosis (t = -0.59 (equal variances assumed), df = 96, p = 0.553).

Parents were also asked whether their son/daughter's information needs relating to transition had been met, and the results are shown in Table 5.11.

### Table 5.11 Young people's information needs as reported by parents

| | *Help not needed yet* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Information for your son/daughter about future options | 6.9% (7) | 20.6% (21) | 72.5% (74) | 77.9% |
| Someone for your son/daughter to talk/communicate with about transition | 6.2% (6) | 29.9% (29) | 63.9% (62) | 68.1% |
| Someone to explain the transition process to you son/daughter | 6.2% (6) | 29.9% (29) | 63.9% (62) | 68.2% |

Around three-quarters (77.9 per cent) of parents felt their son/daughter had unmet needs in relation to information about their future options, and two-thirds felt their need for someone to talk to about transition (68.1 per cent) and to explain the transition process to them (68.2 per cent) was not being met.

The mean number of unmet young people's information needs was 1.98 (SD=1.33, range=0 – 3, N=96), slightly higher than the mean number of unmet parent information needs. Young people's unmet information needs ranged among services between 1.17 in Site E (SD=1.27, N=12) and 2.64 in Site C (SD=0.99, N=25). One way analysis of variance was significant (F=4.76, df=4, 91, p=0.002) and post-hoc tests showed that families in service C had higher unmet young people's information needs than those in Service A (mean difference 0.95, SE 0.31, p=0.029) and Service E (mean difference 1.47, SE 0.42, p=0.024).

The mean number of unmet young people's information needs was higher for those who did not have a transition worker (mean = 2.39, SD = 1.05, N=31) than for those who did (mean =1.77, SD=1.41, N=67), t = 2.40 (equal variances not assumed), df= 77, p=0.019. Again the mean number of unmet young people's information needs was higher for those who did not have a written transition plan (mean = 2.37, SD = 1.12, N = 6) than for those who did (mean = 1.19, SD = 1.38, N = 32), t = 4.23 (equal variances not assumed), df = 52, p<0.001.

There was no significant difference between the mean number of unmet young people's information needs for those whose child did or did not have an ASC diagnosis (t = -1.57 (equal variances not assumed), df = 91, p = 0.120).

### *Parents' unmet transition needs*

Table 5.12 shows the pattern of unmet need across the whole sample. The highest levels of unmet needs were for someone to provide emotional and practical support to the parents and someone to help them find suitable services.

**Table 5.12 Parent unmet transition needs**

| | *Help not needed (yet)* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Someone to talk to about your son/daughter's transition | 4.0% (4) | 32.7% (33) | 63.4% (64) | 66.0% |
| Someone speaking on behalf of the family when dealing with transition issues | 16.2% (16) | 34.3% (34) | 49.5% (49) | 59.0% |
| Someone looking at your needs | 5.2 (5) | 34.4 (33) | 60.4 (58) | 63.7% |
| Someone providing individual support for you (e.g. emotional and practical support) | 8.2% (8) | 29.6% (29) | 62.2% (61) | 67.8% |
| Someone co-ordinating your son/daughter's transition | 4.0% (4) | 37.4% (37) | 58.6% (58) | 61.1% |
| Someone helping you to find suitable services | 5.1 (5) | 29.3 (29) | 65.7 (65) | 69.1% |

The number of parent unmet needs per family was summed in order to obtain a total score of unmet parent needs relating to transition. Mean number of parent unmet needs was 3.62 (SD=2.55, range=0 – 6, N=95). Unmet needs ranged among services between 2.62 in Site A (SD=2.30, N=35) and 5.13 in Site C (SD=1.77, N=23), and one-way analysis of variance showed a significant difference between services (F=4.166, df=4, 90, p=0.004). Post-hoc tests showed that Service C had a significantly higher mean number of unmet parent needs than Service A (mean difference=2.50, SE=0.54, p<0.001).

The mean number of unmet parent transition needs was higher for those who did not have a transition worker (mean = 5.58, SD = 1.15, N=31) than for those who did (mean =2.62, SD=2.49, N=63), t = 7.89 (equal variances not assumed), df= 92, p<0.001. Similarly, the mean number of unmet parent transition needs was higher for those who did not have a written transition plan (mean = 4.54, SD = 2.18, N = 63) than for those who did (mean = 1.81, SD = 2.28, N = 32), t = 5.68 (equal variances assumed), df = 93, p<0.001.

There was no significant difference between the mean number of unmet parent transition needs for those whose child did or did not have an ASC diagnosis (t = -1.42 (equal variances not assumed), df = 87, p = 0.159).

***Young people's unmet transition needs as reported by parents***

Similarly the number of unmet young people's needs was summed to comprise a total score of unmet needs. Table 5.13 shows the pattern of unmet needs across the whole sample. The highest unmet need related to career/employment opportunities with 83.6 per cent of parents indicating that their child needed more help with this, and there were a number of categories where over three-quarters of young people had unmet needs for help: housing, leisure/social life, benefits/finance, achieving future goals/aspirations.

**Table 5.13 Young people's unmet transition needs as reported by parents**

| | *Help not needed (yet)* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Communication needs | 5.7% (6) | 29.2% (31) | 65.1% (69) | 69.0% |
| Mobility needs | 37.8% (37) | 32.7% (32 | 29.6% (29) | 47.5% |
| Other equipment needs | 47.9% (45) | 28.7% (27) | 23.4% (22) | 44.9% |
| Behavioural difficulties | 20.2% (20) | 37.4% (37) | 42.4% (42) | 53.2% |
| Self-care needs | 13.0% (13 | 25.0% (25) | 62.0% (62 | 71.3% |
| Further education/training | 9.0% (9) | 28.0% (28) | 63.0% (63) | 69.2% |
| Housing needs | 38.5% (37) | 14.6% (14) | 46.9% (45) | 76.3% |
| Social care needs | 19.8% (20) | 22.8% (23) | 57.4% (58) | 71.6% |
| Career/employment opportunities | 28.0% (26) | 11.8% (11) | 60.2% (56) | 83.6% |
| Leisure/social life | 8.0% (8) | 20.0% (20) | 72.0% (72) | 78.3% |
| Independent living skills | 17.0% (17) | 21.0% (21) | 62.0% (62) | 74.7% |
| Benefits/finances | 15.6% (15) | 18.8% (18) | 65.6% (63) | 77.8% |
| Transfer to adult health services | 14.7% (15) | 22.5% (23) | 62.7% (64) | 73.6% |
| Transport/getting around | 19.2% (19) | 31.3% (31) | 49.5% (49) | 61.2% |
| Short breaks/respite | 20.8% (21) | 22.8% (23) | 56.4% (57) | 71.2% |
| Adult relationships/sex education | 30.6% (30) | 26.5% (26) | 42.9% (42) | 61.8% |
| Emotional changes as your son/daughter grows up | 13.1% (13) | 31.3% (31) | 55.6% (55 | 64.0% |
| Support to prepare your son/daughter for the changes ahead | 6.2% (6) | 24.7% (24) | 69.1% (67) | 73.6% |
| Someone speaking on behalf of your son/daughter when dealing with transition issues | 8.1% (8) | 33.3% (33) | 58.6% (58) | 63.7% |
| Opportunities for your son/daughter to express their views about what they want for their future | 12.6% (12) | 28.4% (27) | 58.9% (56) | 67.5% |
| Identifying future goals/aspirations | 13.4% (13) | 23.7% (23) | 62.9% (61) | 72.6% |
| Achieving future goals/aspirations | 17.0% (16) | 19.1% (18) | 63.8% (60) | 76.9% |

The mean number of young people’s unmet needs was 11.96 (SD=7.24, range=0 – 21, N=71). Mean unmet needs ranged among services between 9.00 in Site B (SD=8.37, N=3.16) and 15.00 in Site C (SD=6.21, N=18). Differences between sites were not significant (F=1.59, df=4, 66, p=0.186).

The mean number of young people’s unmet transition needs was higher for those who did not have a transition worker (mean = 15.81, SD = 4.17, N=21) than for those who did (mean =10.12, SD=7.75, N=48), t = 3.94 (equal variances not assumed), df= 64, p<0.001. In addition, the mean number of young people's unmet needs was higher for those who did not have a written transition plan (mean = 13.33, SD = 6.68, N = 49) than for those who did (mean = 8.91, SD = 7.65, N = 22), t = 2.46 (equal variances assumed), df = 69, p = 0.16.

There was no significant difference between the mean number of unmet parent transition needs for those whose child did or did not have an ASC diagnosis (t = -1.87 (equal variances assumed), df = 68, p = 0.066).

### 5.1.7 Service process (MPOC)

The Measures of Process of Care (MPOC) measures respondents' perceptions of whether they feel that they received coordinated, enabling and responsive services (see Chapter 2). Whilst it clearly includes transition services, it is a general measure of the pattern of all the services received.

Families rated from one (not at all) to seven (to a very great extent) the quality of care they had received over the past year, from a range of professionals (individuals and organisations) working with their child. The mean MPOC score was 4.14 (SD=1.63, range=1 – 7, N=98). Differences between services were not significant (F=0.284, df = 4, 93, p = 0.888).

The mean MPOC score was slightly higher for those who had a transition worker (mean = 4.39, SD = 1.51, N=68) than for those who did not (mean =3.65, SD=1.74, N=29), t = -2.13 (equal variances assumed), df= 95, p=0.036. There was no significant difference between those who did and did not have a written transition plan.

There was no significant difference between the mean MPOC scores for those whose child did or did not have an ASC diagnosis (t = 1.05 (equal variances assumed), df = 93, p = 0.295).

## 5.2 Post-transition parents

### 5.2.1 Characteristics of the sample

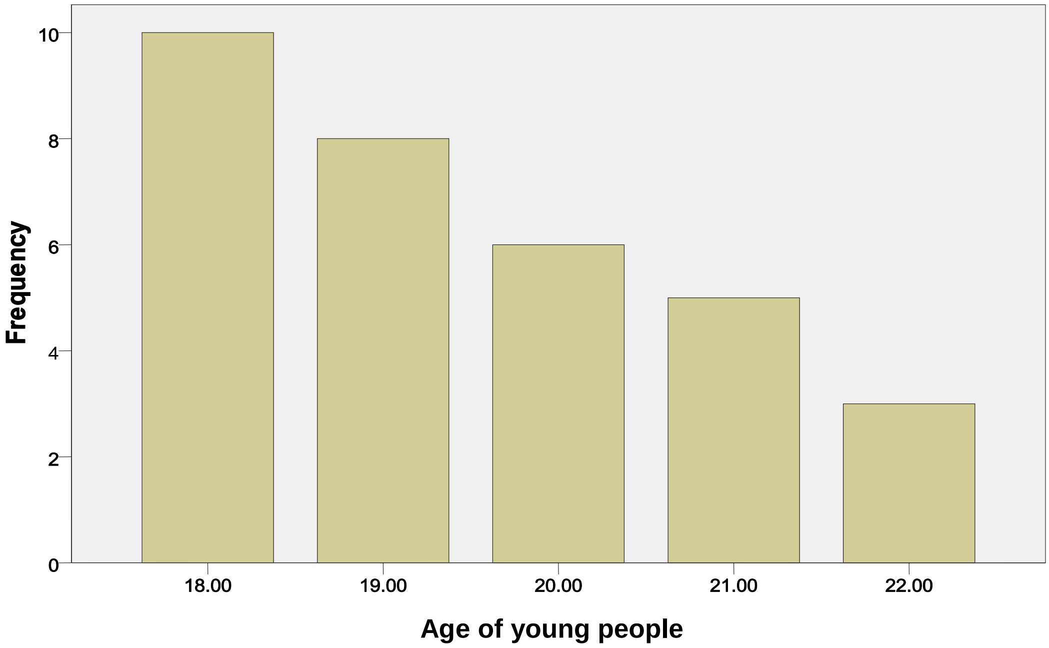
There were a total of 33 respondents. In many cases, frequencies are too low to consider differences between sites or by characteristics of the young people. Respondents were predominantly mothers (81.8 per cent, n=27), five respondents were fathers and one was a foster father. Twenty-five respondents (75.8 per cent) were married or living as married, three were separated or divorced, four were single and one was widowed.

Twenty-two respondents were employed outside the home (66.6 per cent); 11 full-time and 11 part-time. Four did not provide data. Seventeen partners were employed (68 per cent); 12 full-time and five part-time. Frequencies were too small to investigate socio-economic status of respondents.

### 5.2.2 Characteristics of young people

The ages of the disabled young people in these families ranged from 18 to 22 years, with a mean age of 19.47 (SD=1.34, median=19, N=32); 21 were male and 12 female. Two young people were adopted and one was fostered.

**Figure 5.2 Age of young people**



Twenty-two young people were white (66.6 per cent), four were Black-Caribbean (12.1 per cent), three were Black-African (9.1 per cent), one was Indian, one was Pakistani, and two were mixed race.

The young people had a range of diagnoses, with most having more than one condition. The most common diagnoses are given in Table 5.14.

### Table 5.14 Most common conditions

| *Diagnosis* | *Number of young people* |
|---|---|
| Autistic spectrum | 10 |
| Epilepsy | 6 |
| Down's syndrome | 4 |
| Other chromosomal abnormalities | 5 |

***Types and levels of disability***

Parents were asked to rate from zero (not at all) to two (very much so) whether their son or daughter experienced difficulty in a number of fields such as communication, behaviour, learning and mobility. The percentage of young people who experienced difficulty in these areas is shown in Table 5.15.

### Table 5.15 Types and level of difficulties

| | *Not at all* | *Some difficulties* | *A lot of difficulties* |
|---|---|---|---|
| Communication (n=33) | 3% (1) | 36.4% (12) | 60.6% (20) |
| Behaviour (n=33) | 27.3% (9) | 60.6% (20) | 12.1% (4) |
| Learning (n=33) | 3% (1) | 24.2% (8) | 72.7% (24) |
| Mobility (n=30) | 33.3% (10) | 40.0% (12) | 26.7% (8) |
| Health (n=31) | 32.3% (10) | 58.1% (18) | 9.7% (3) |
| Vision (n=27) | 70.4% (19) | 25.9 (7) | 3.7% (1) |
| Hearing (n=30) | 96.7% (29) | 3.3% (1) | 0 |
| Continence (n=30) | 46.7% (14) | 23.3% (7) | 30% (9) |

Results showed that, consistent with the eligibility criteria for the transition services (see Chapter 4) and as with pre-transition young people, only one young person did not have learning difficulties, and most (73 per cent) had high levels of learning difficulties. High levels of communication difficulties were also common (61 per cent with many difficulties), and over 70 per cent had some or many behaviour difficulties. In contrast, mobility and continence difficulties were more evenly spread across the sample, and only a few young people had many health or sensory difficulties.

A mean score on difficulty items was also computed (difficulties scale score). The overall mean score was 7.00 (SD=2.65, range=2 - 11, median=7.00, n=25).

***School/college***

All but one of the young people had a statement of special educational needs. Parents were asked what type of school the young person currently or had attended. Thirty young people (90.9 per cent) attended special schools, one attended a residential school, and two attended mainstream schools.

Eighteen young people were still in full-time education. Of these, seven young people were still in school, nine were attending FE colleges, and two were attending a residential college.

***Other activities***

Parents of young people who were no longer in full-time education were asked to indicate what they did during a typical week, and information was provided for 14 young people. Their activities are summarised in Table 5.16.

**Table 5.16 Other activities amongst those not in full-time education**

| | *Number of young people involved each day* | | | | | |
|---|---|---|---|---|---|---|
| | *Monday* | *Tuesday* | *Wednesday* | *Thursday* | *Friday* | *Any day* |
| PT education | 2 | 3 | 0 | 3 | 2 | 3 |
| Stay at home | 3 | 4 | 3 | 3 | 3 | 6 |
| Day services | 4 | 5 | 4 | 4 | 5 | 5 |
| Paid work (supported) | | | | | | 0 |
| Paid work (unsupported) | | | 1 | 1 | | 1 |
| Voluntary work | 3 | 1 | 2 | 2 | 2 | 3 |
| *Other* | *3* | *2* | *3* | *2* | *3* | *3* |

It can be seen that three young people were involved in some form of part-time education on at least one day a week. Five took part in day services, and three were involved in other activities, which included residential homes. One young person undertook two days unsupported paid work, and three were involved in voluntary work, with one of them doing this five days a week. A total of six young people stayed at home one day a week, with two doing so every day.

### 5.2.3 Influence of the young persons' disability on employment

Parents were asked whether their caring responsibilities had affected their employment: seven (25.9 per cent) said that they had not, eight (29.6 per cent) stated that they had had to give up work to care for their child, six (22.2 per cent) felt that they had not progressed as far in their job, and six (22.2 per cent) felt they could not work as many hours as they would like.

Parents were also asked, if they had been employed in the previous three months, how many days they had had to miss work because of their caring responsibilities. Six parents stated that they had missed between two and six days.

### 5.2.4 Transition planning and information

***Planning for transition***

Parents were asked if their son/daughter had had a written transition plan, and 22 parents (66.7 per cent) were aware of such a plan, with five not having a written plan and the remainder (6) unsure of whether they had had a written transition plan or not. Only 13 parents reported that their son/daughter had a copy of their transition plan, representing 59.1 per cent of those with a written transition plan, but only 39.4 per cent of the whole sample.

The age at which services were reported to have started planning for transition ranged from 13 to 19 (mean age=15.83, SD=1.69, N=29).

Parents were asked how often transition planning for their son/daughter had been reviewed, although only around half of parents responded to this question including some of those who reported that they did not have a written transition plan. Four young people had had their transition plan reviewed at six-monthly intervals, and seven on an annual basis. Six young people had never had their transition plan reviewed. Parents were then asked if they felt the transition plan had been reviewed regularly enough, and 29 parents answered this question (including some whose child did not have a written transition plan). Around half of these parents (N=15) felt the transition plans had been reviewed regularly enough, with eight (27.6 per cent) stating they were not reviewed regularly enough, and the remainder not having had their plan reviewed.

### 5.2.5 Contact with services

***Co-ordinated approach to transition***

Parents were asked if they had had one person to support them and their son/daughter through transition. The majority of parents (n=28, 84.8 per cent) stated that they had, with most of them being Transition Workers, Social Workers or Connexions Workers. Parents stated that they had had this support for between one and 60 months, with a mean of 26.15 (SD=20.75, N=20). Seventy-five per cent of families (n=21) who had a transition support worker reported that they had had a written transition plan compared with only one of the five families who had not a transition support worker. The difference was significant (chi-square = 5.77, df=1, p=0.016, n=33) although low numbers may make this unreliable.

### *Contact with transition services*

A third of parents (9) would have liked more regular personal contact with their transition support person, with a similar number (10) having wanted more regular telephone contact. Three parents did not answer these questions.

The majority of parents (16) felt that their transition support person had contacted them regularly, with ten disagreeing, and one being unsure. One parent did not provide data. Parents were also asked if the transition support person had left it up to them to make contact: 15 parents suggested that their transition support person had been proactive in making contact, whilst six were left to make contact themselves and two were unsure. Five parents did not answer this question.

### *Satisfaction with transition services*

Parents rated their level of satisfaction with the transition service they had received. Responses ranged from one (very satisfied) to four (not at all satisfied). The mean score for satisfaction was 2.23 (SD=0.97, range = 1-4, N = 30). Table 5.17 shows the pattern of satisfaction across the whole sample, indicating that the around two thirds (66.6 per cent) of respondents were satisfied or very satisfied with the transition services they had received.

**Table 5.17 Satisfaction with transition services**

| *Very satisfied* | *Satisfied* | *Not satisfied* | *Not at all satisfied* |
|---|---|---|---|
| 23.3 (7)[a] | 43.3 (13) | 20.0 (6) | 13.3 (4) |

[a] ( ) = n

### *Stress and transition services*

Parents were asked whether their contacts with the transition service affected the amount of stress they experienced in caring for their son/daughter during the transition process. Table 5.18 shows the pattern of the impact of the contact with transition services on stress levels across the sample. It can be seen that for over a third of parents (12), their contacts with the transition service increased their stress, although a similar number (11) reported that the amount of stress they experienced had been reduced by contact with transition services.

**Table 5.18 The impact of contact with transition service on stress**

| *Considerably reduced my stress* | *Somewhat reduced my stress* | *Not had any effect on my stress* | *Somewhat increased my stress* | *Considerably increased my stress* |
|---|---|---|---|---|
| 23.3 (7) [a] | 16.7 (5) | 20.0 (6) | 23.3 (7) | 16.7 (5) |

[a] ( ) = n

***Management of the transfer process***

Parents were asked overall how well the process of transfer was managed for a number of transitions.

**Table 5.19 Management of the transfer process**

| | *Managed well* | *Managed OK* | *Poorly managed* |
|---|---|---|---|
| Children’s and adult social care (N=26) | 19.2% (5) | 42.3% (11) | 38.5% (10) |
| Children’s and adult health services (N=23) | 13.0% (3) | 47.8% (11) | 39.1% (9) |
| School to FE (N=24) | 33.3% (8) | 41.7% (10) | 25.0% (6) |
| School to day services (N=12) | 33.3% (4) | 25.0% (3) | 41.7% (5) |
| School to paid work (N=2) | | | 100.0% (2) |
| School to voluntary work (N=3) | | 33.3% (1) | 66.7% (2) |
| College to day services (N=5) | 20.0% (1) | 20.0% (1) | 60.0% (3) |
| College to paid work (N=3) | | | 100.0% (3) |
| College to voluntary work (N=5) | 20.0% (1) | | 80.0% (4) |

Although frequencies for some types of transitions are small, it would appear that many of these transfers were felt to be poorly managed.

***Contact with other services***

Where their son/daughter was still living at home (N=22), parents were asked how many professionals they had seen in the last three months. The mean number of professionals seen was 2.91 (SD=1.60, range=0 – 6, N=22).

Reported contacts with other services were limited. One young person had visited accident and emergency once, and one had visited three times. One young person had had seven inpatient stays. Four young people had received a short breaks service.

### 5.2.6 Unmet needs

Respondents were asked about both parent and young person unmet needs relating to information, and transition. They were also asked about their son/daughter's current unmet needs now they had transferred to adult services.

***Information needs***

Parents were asked whether their needs relating to information about transition had been met, and the results are shown in Table 5.20. Around two-thirds of parents (67.7 per cent) had not had their needs met in relation to having someone to show them which services were available in the future, and over half (56.2 per cent) had needed more information to help them plan for their son/daughter’s future. A lower proportion of parents (43.8 per cent) stated unmet need in relation to having someone to explain the transition process to them.

**Table 5.20 Parent information needs**

| | *Help not needed yet* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Information to help you plan for your son/daughter's future (N=32) | | 43.8% (14) | 56.2% (18) | 56.2% |
| Someone to show you which services are available as your son/daughter grows up (N=32) | 3.1% (1) | 31.2% (10) | 65.6% (21) | 67.7% |
| Someone to explain the transition process to you (N=32) | | 56.2% (18) | 43.8% (14) | 43.8% |

The mean number of unmet parent information needs was 1.66 (SD=1.33, range=0 – 3, N=32).

Parents were also asked whether son/daughter's information needs relating to transition had been met, and the results are shown in Table 5.21.

**Table 5.21 Young people's information needs as reported by parents**

| | *Help not needed yet* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Information for your son/daughter about future options (N=32) | 3.1% (1) | 40.6% (13) | 56.2% (18) | 58.1% |
| Someone for your son/daughter to talk/communicate with about transition (N=29) | 6.9% (2) | 48.3% (14) | 44.8% (13) | 48.1% |
| Someone to explain the transition process to you son/daughter (N=30) | 6.7% (2) | 50.0% (15) | 43.3% (13) | 46.4% |

The greatest unmet need was for information about future options (58.1 per cent). Less than half of parents felt their son/daughter's need for someone to talk to about transition (48.1 per cent) and to explain the transition process to them (46.4 per cent) had not been met.

The mean number of young people's unmet information needs was 1.38 (SD=1.42, range=0 – 3, N=29).

On the whole, the numbers of unmet parent and young people's information needs were lower amongst this group of post-transition parents than those pre-transition, which suggests that needs were, to some extent, being met during the transition process.

***Parent transition unmet needs***

The number of parent unmet transition needs per family was summed in order to obtain a total score of unmet parent needs relating to transition. The mean number of unmet needs was 3.31 (SD=2.95, range= 0-7, N=26). Table 5.22 shows the pattern of unmet needs across the sample. The highest level of unmet need was for someone to help in finding suitable services (64.3 per cent). Interestingly, having someone to talk to about their son/daughter's transition, which was rated as an unmet need by two-thirds of parents in the pre-transition sample, was felt to be an unmet need by just less than a third (31.0 per cent) of the post-transition parent sample.

**Table 5.22 Parent transition unmet needs**

| | *Help not needed* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Someone to talk to about your son/daughter's transition (N=29) | | 69.0% (20) | 31.0% (9) | 31.0% |
| Someone speaking on behalf of the family when dealing with transition issues (N=27) | 3.7% (1) | 55.6% (15) | 40.7% (11) | 40.7% |
| Someone looking at the needs of your son/daughter (N=30) | | 53.3% (16) | 46.7% (14) | 46.7% |
| Someone looking at your needs (N=28) | 7.1% (2) | 42.9% (12) | 50.0% (14) | 53.8% |
| Someone providing individual support for you (e.g. emotional and practical support) (N=29) | 6.9% (2) | 41.4% (12) | 51.7% (15) | 55.6% |
| Someone co-ordinating your son/daughter's transition (N=28) | 3.6% (1) | 50.0% (14) | 46.4% (13) | 48.1% |
| Someone helping you to find suitable services (N=29) | 3.4% (1) | 34.5% (10) | 62.1% (18) | 64.3% |

***Young people's unmet transition needs as reported by parents***

Similarly the number of unmet young people's needs relating to transition was summed to comprise a total score of unmet child needs. The mean number of unmet child needs was 8.38 (SD=6.51, range=1 – 20, N=16) although there was a large degree of missing data. The highest unmet needs related to career/employment opportunities, short breaks/respite, and leisure/social life.

### Table 5.23 Young people's transition unmet needs as reported by parents

| | *Help not needed* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Communication needs (N=31) | 3.2% (1) | 45.2% (14) | 51.6% (16) | 53.3% |
| Mobility needs (N=30) | 23.3% (7) | 40.0% (12) | 36.7% (11) | 47.8% |
| Other equipment needs (N=26) | 42.3% (11) | 42.3% (11) | 15.4% (4) | 26.7% |
| Behavioural difficulties (N=31) | 25.8% (8) | 48.4% (15) | 25.8% (8) | 34.8% |
| Self-care needs (N=28) | 17.9% (5) | 46.4% (13) | 35.7% (10) | 43.5% |
| Further education/training (N=29) | 3.4% (1) | 37.9% (11) | 58.6% (17) | 60.7% |
| Housing needs (N=29) | 48.3% (14) | 20.7% (6) | 31.0% (9) | 60.0% |
| Social care needs (N=29) | 10.3% (3) | 37.9% (11) | 51.7% (15) | 57.7% |
| Career/employment opportunities (N=27) | 37.0% (10) | 14.8% (4) | 48.1% (13) | 76.5% |
| Leisure/social life (N=29) | 6.9% (2) | 27.6% (8) | 65.5% (19) | 70.4% |
| Independent living skills (e.g. managing money, safety, risk, etc.) (N=29) | 17.2% (5) | 41.4% (12) | 41.4% (12) | 50.0% |
| Benefits/finances (N=28) | 7.1% (2) | 42.9% (12) | 50.0% (14) | 53.8% |
| Transfer to adult health services (N=28) | 7.1% (2) | 46.4 (13) | 46.4% (13) | 50.0% |
| Transport/getting around (N=27) | 11.1% (3) | 48.1% (13) | 40.7% (11) | 45.8% |
| Short breaks/respite (N=27) | 29.6% (8) | 18.5% (5) | 51.9% (14) | 73.7% |
| Adult relationships/sex education (N=26) | 50.0% (13) | 23.1% (6) | 26.9% (7) | 53.8% |
| Emotional changes as your son/daughter grows up (N=27) | 25.9% (7) | 29.6% (8) | 44.4% (12) | 60.0% |
| Support to prepare your son/daughter for the changes ahead (N=28) | 14.3% (4) | 35.7% (10) | 50.0% (14) | 58.3% |
| Someone speaking on behalf of your son/daughter when dealing with transition issues (N=28) | 21.4% (6) | 32.1% (9) | 46.4% (13) | 59.1% |
| Opportunities for your son/daughter to express their views about what they want for their future (N=28) | 21.4% (6) | 39.3% (11) | 39.3% (11) | 50.0% |
| Future goals/aspirations (N=25) | 16.0% (4) | 36.0% (9) | 48.0% (12) | 57.1% |

#### *Young people's current unmet needs as reported by parents*

Respondents were asked about their son/daughter’s current unmet needs now they had transferred to adult services. The mean number of unmet needs post-transition was 10.05 (SD=7.38, range=0 – 21, N=20). The highest unmet needs related to short breaks/respite, support to prepare the young person for the changes ahead, independent living skills, and future goals/aspirations. Career/employment opportunities and leisure/social life, which had high levels of unmet need at transition, continued to show high levels of need at 68 per cent and 69 per cent respectively.

**Table 5.24 Young people's current (post-transition) unmet needs as reported by parents**

| | *Help not needed* | *Getting enough help* | *Need more help* | *% with need not being met* |
|---|---|---|---|---|
| Communication needs (N=31) | 9.7% (3) | 41.9% (13) | 48.4% (15) | 53.6% |
| Mobility needs (N=29) | 27.6% (8) | 34.5% (10) | 37.9% (11) | 52.4% |
| Other equipment needs (N=28) | 64.3% (18) | 21.4% (6) | 14.3% (4) | 40.0% |
| Behavioural difficulties (N=30) | 33.3% (10) | 43.3% (13) | 23.3% (7) | 35.0% |
| Self-care needs (N= 28) | 14.3% (4) | 50.0% (14) | 35.7% (10) | 41.6% |
| Further education/training (N=29) | 3.4% (1) | 34.5% (10) | 62.1% (18) | 64.3% |
| Housing needs (N=28) | 35.7% (10) | 25.0% (7) | 39.3% (11) | 61.1% |
| Social care needs (N=29) | 13.8% (4) | 41.4% (12) | 44.8% (13) | 52.9% |
| Career/employment opportunities (N=27) | 29.6% (8) | 22.2% (6) | 48.1% (13) | 68.4% |
| Leisure/social life (N=30) | 13.3% (4) | 26.7% (8) | 60.0% (18) | 69.2% |
| Independent living skills (e.g. managing money, safety, risk, etc.) (N=27) | 25.9% (7) | 18.5% (5) | 55.6% (15) | 75.0% |
| Benefits/finances (N=27) | 7.4% (2) | 44.4% (12) | 48.1% (13) | 52.0% |
| Transfer to adult health services (N=26) | 15.4% (4) | 30.8% (8) | 53.8% (14) | 63.6% |
| Transport/getting around (N=28) | 3.6% (1) | 46.4% (13) | 50.0% (14) | 51.9% |
| Short breaks/respite (N=28) | 25.0% (7) | 17.9% (5) | 57.1% (16) | 76.2% |
| Adult relationships/sex education (N=25) | 44.0% (11) | 20.0% (5) | 36.0% (9) | 64.3% |
| Emotional changes as your son/daughter grows up (N=26) | 26.9% (7) | 26.9% (7) | 46.2% (12) | 63.2% |
| Support to prepare your son/daughter for the changes ahead (N=28) | 14.3% (4) | 21.4% (6) | 64.3% (18) | 75.0% |
| Someone speaking on behalf of your son/daughter when dealing with transition issues (N=27) | 14.8% (4) | 29.6% (8) | 55.6% (15) | 65.2% |
| Opportunities for your son/daughter to express their views about what they want for their future (N=27) | 14.8% (4) | 33.3% (9) | 51.9% (14) | 60.8% |
| Future goals/aspirations (N=25) | 24.0% (6) | 20.0% (5) | 56.0% (14) | 73.7% |

## 5.3 Multivariate analyses of relationships between transition experience, service context and outcome variables

Identification of factors related to better or worse outcomes of service provision for families can help inform the development of transition services which produce the best outcomes. Four outcomes were examined in this section of multivariate analysis: parental satisfaction with the transition service, level of young person's unmet needs during the transition process, level of parents' unmet transition needs, and the impact of the transition service on parents' stress levels.

A number of possible predictor variables were used in the analysis. These were selected on the basis of being indicated as potentially important in previous research and/or in interviews with staff: whether families had a written transition plan, whether they had one transition worker, the level of the young person's difficulties, the type of school attended (currently or pre-transition), MPOC scores (in bivariate analysis only, see below), and the age at which transition planning started. In addition, a number of variables relating to the services (having designated transition workers; transition workers having specific training for the role; clarity on the transition worker role; transition workers setting up and negotiating funding for the adult care package; transition manager having strategic involvement; person-centred planning for all young people; parent involvement in steering group; young people's involvement in steering group - see section 2.4.4) were used in the analysis. Analyses were carried out on the combined pre- and post- transition samples, as no significant differences were found between the four outcome variables in the two samples.

The first step was to look at the correlations between the service-level variables (Table 5.25). It can be seen that 'clarity on role of transition workers' and 'parental involvement' are perfectly correlated (singularity), and that several pairs of variables have high correlations. Multicollinearity is a problem in regression analysis, and highly correlated independent variables should not be used in the same regression model.

### 5.3.1 Measure of Process of Care

MPOC scores were only available for those in the pre-transition sample so were not routinely used in the multiple regressions. Bivariate relationships between MPOC and the other independent variables were investigated. Higher MPOC scores indicate that parents felt that received a more coordinated, enabling and responsive service:

- MPOC was not significantly correlated with young people's level of difficulties or with the age at which transition planning started.

- There was no significant difference in MPOC scores for those with and without a written transition plan.
- Those with one transition worker had higher mean MPOC scores (mean=4.393, SD=1.508, N=68) than those without (mean=3.646, SD=1.742, N=29) (t=-2.132 (equal variances assumed), df=95, p=0.036).
- There were no significant differences in MPOC by the type of school a young person attended.
- None of the service-level variables had a significant relationship with MPOC.

## Table 5.25 Spearman's Rho correlations between service-level variables

| | *Specific training on transition for transition worker* | *Service manager involved at strategic level* | *Designated transition workers* | *Did the transition workers set up the adult package and negotiate funding for it?* | *Person centred planning* | *Clarity on role of transition worker* | *Parent involvement* | *Involvement of young people* |
|---|---|---|---|---|---|---|---|---|
| Specific training on transition for transition worker | 1.000 | -.192$^{*}$ | .490$^{**}$ | -.020 | -.505$^{**}$ | .361$^{**}$ | .361$^{**}$ | .327$^{**}$ |
| Service manager involved at strategic level | -.192$^{*}$ | 1.000 | .376$^{**}$ | .784$^{**}$ | .562$^{**}$ | .661$^{**}$ | .661$^{**}$ | .485$^{**}$ |
| Designated transition workers | .490$^{**}$ | .376$^{**}$ | 1.000 | .705$^{**}$ | .505$^{**}$ | .736$^{**}$ | .736$^{**}$ | -.128 |
| Did the transition workers set up the adult package and negotiate funding for it? | -.020 | .784$^{**}$ | .705$^{**}$ | 1.000 | .717$^{**}$ | .519$^{**}$ | .519$^{**}$ | .089 |
| Person centred planning used for all | -.505$^{**}$ | .562$^{**}$ | .505$^{**}$ | .717$^{**}$ | 1.000 | .372$^{**}$ | .372$^{**}$ | -.450$^{**}$ |
| Clarity on role of transition worker | .361$^{**}$ | .661$^{**}$ | .736$^{**}$ | .519$^{**}$ | .372$^{**}$ | 1.000 | 1.000$^{**}$ | .321$^{**}$ |
| Parent involvement | .361$^{**}$ | .661$^{**}$ | .736$^{**}$ | .519$^{**}$ | .372$^{**}$ | 1.000$^{**}$ | 1.000 | .321$^{**}$ |
| Involvement of young people | .327$^{**}$ | .485$^{**}$ | -.128 | .089 | -.450$^{**}$ | .321$^{**}$ | .321$^{**}$ | 1.000 |

* sig at 0.05 level
** sig at 0.01 level
*** sig at 0.001 level

### 5.3.2 Satisfaction with transition service

The first stage of the analysis was to identify variables which had a significant bivariate association with parents' satisfaction with the transition service, where a lower score (on a scale of 1 – 4) indicates a higher level of satisfaction.

Correlations were run between continuous independent variables and level of satisfaction with the transition service:

- Satisfaction was significantly correlated with MPOC scores (r=-0.475, p<0.001, N=88), so that as MPOC scores increased (indicating a higher level of coordination of services) satisfaction with the transition service increased.

T-tests were run between binary independent variables and level of satisfaction:

- Parents whose child had a written transition plan had higher levels of satisfaction (a lower score) (mean=1.98, SD=0.772, N=53) than those without a written plan (mean=2.90, SD=0.938, N=72) (t=6.02 (equal variances not assumed), df=121, P<0.001).
- Parents whose child had one transition worker had higher levels of satisfaction (mean=2.23, SD=0.87, N=91) than those without (mean=3.24, SD=0.867, N=33) (t=5.73 (equal variances assumed), df=122, P<0.001).

A one-way analysis of variance (ANOVA) was run with type of school, but there were no statistically significant differences in level of parental satisfaction with transition by the type of school a young person (had) attended.

T-tests were then run between each of the service-level variables and satisfaction with the transition service:

- Parents whose service had a manager involved at a strategic level were more likely to be satisfied (mean = 2.29, SD = 0.896, N = 82) than those whose service did not (mean = 2.93, SD = 1.009, N=43) (t=3.618 (equal variances assumed), df=123, p<0.001).
- Parents whose service had designated transition workers had higher satisfaction (mean=2.38, SD=0.919, N=90) than those who did not (mean=2.86, SD=1.061, N=35), (t=-2.352 (equal variances not assumed), df=55, p=0.022).
- Parents who had access to a service where the transition workers set up the adult package and negotiated funding for it had higher levels of satisfaction (mean=2.28, SD=0.873, N=69) than those who did not (mean=2.80, SD=1.034, N=69), (t=-3.043 (equal variances not assumed), df=108, p=0.003).
- Parents whose service operated a system of Person Centred Planning for all young people in transition were more satisfied (mean = 2.23, SD=0.831, N=48) than those whose service did not (mean=2.69, SD=1.029, N=77), (t=-2.736 (equal variances not assumed), df=115, p=0.007).

- Parents in services which had clarity on the role of transition workers were more satisfied (mean=2.38, SD=0.930, N=103) than those who did not (mean=3.14, SD=3.14, N=22), (t=-3.430 (equal variances assumed), df=123, p=0.001).
- Parents in services with parental involvement in the steering group had higher levels of satisfaction (mean=2.38, SD=0.930, N=103) than those who with no parental involvement (mean = 3.14, SD=0.990, N=22), (t=-3.430 (equal variances assumed), df=123, p=0.001).

These results are summarised in Table 5.26, which identifies the variables selected for inclusion in multiple regression analysis.

**Table 5.26 Predictors of satisfaction scores: bivariate analyses**

| *Individual-level* | *Service-level* |
|---|---|
| (Measure of Processes of Care ***) | Service manager involved at strategic level*** |
| Had written transition plan*** | Designated transition workers* |
| One transition worker*** | (Service set up adult package**) |
| | Person centred planning** |
| | (Clarity on role of transition workers**) |
| | Parental involvement in steering group** |

*p<0.05, **p<0.01, ***p<0.001

Variables which had a significant bivariate relationship with level of satisfaction (excluding MPOC as this was only available in the pre-transition sample, and clarity of the transition worker role due to multicollinearity with parent involvement, and negotiation of the adult package due to multicollinearity with service manager involvement at strategic level) were then entered into a forwards stepwise multiple linear regression (Table 5.27). The final model contained three variables and explained 32 per cent of the variance in satisfaction scores (Adjusted $R^2$=0.322, F=20.483, df=3, 120, p<0.001).

**Table 5.27 Stepwise multiple linear regression: level of satisfaction with transition service**

| | | *Unstandardized Coefficients* | | *Standardized Coefficients* |
|---|---|---|---|---|
| *Model* | | *B* | *Std. Error* | *Beta* |
| 3 | (Constant) | 2.715*** | .265 | |
| | Has written transition plan | -.528** | .166 | -.269 |
| | Has one transition worker | -.739*** | .179 | -.336 |
| | Service manager involved at strategic level | .412* | .159 | .201 |

*p<0.05, **p<0.01, ***p<0.001

The unstandardized coefficients (and their associated standard errors) show the change in satisfaction score given a unit change in the variable of interest. Thus in the final model, having a written transition plan reduced the satisfaction score (that is, increased satisfaction) by 0.528. The standardized coefficients show that in the final model having one transition worker is a stronger predictor of satisfaction than having a written transition plan and there being a service manager involved at strategic level, although all three had a significant predictive effect.

### 5.3.3 Young people's unmet needs as reported by parents

Firstly we identified those independent variables which had a significant bivariate relationship with young people's unmet needs scores, defined by a scale on which scores ranged from 0-21 where a higher score indicates greater unmet need.

Correlations were run between the continuous independent variables and level of young people's unmet needs:

- Level of young people's unmet need was significantly correlated with MPOC scores (r=-0.507, p<0.001, N=65), so that as MPOC scores increased, level of unmet need decreased.

T-tests were run between binary independent variables and level of young people's unmet need:

- Those who had a written transition plan were reported to have lower levels of unmet needs (a lower score) (mean=8.861, SD=7.560, N=36) than those without a written plan (mean=13.291, SD=6.573, N=55) (t=2.876 (equal variances not assumed), df=67, P=0.005).
- Those who had one transition worker were reported to have lower levels of unmet needs (mean=9.985, SD=7.715, N=65) than those without (mean=15.417, SD=4.180, N=24) (t=4.237 (equal variances not assumed), df=75, P<0.001).

A one-way analysis of variance (ANOVA) was run with type of school, but there were no statistically significant differences in level of young people's unmet needs by the type of school a young person (had) attended.

T-tests were then run between each of the service-level variables and level of young people's unmet needs:

- Those whose service had a manager involved at a strategic level had lower levels of unmet needs (mean = 10.190, SD = 7.369, N = 58) than those whose service did not (mean = 13.909, SD = 6.554, N=33) (t=2.486 (equal variances not assumed), df=73, p=0.015).
- Those who had access to a service where the transition workers set up the adult package and negotiated funding for it had lower levels of unmet need

(mean=10.062, SD=7.396, N=48) than those who did not (mean=13.186, SD=6.846, N=43), (t=-2.083 (equal variances not assumed), df=89, p=0.040).

- Those with access to a service which offered clarity on the role of transition workers had lower levels of unmet needs (mean=10.583, SD=7.298, N=72) than those who did not (mean=15.158, SD=6.076, N=19), (t=-2.793 (equal variances not assumed), df=33, p=0.009).
- Those in services which had parental involvement in the steering group had lower levels of unmet need (mean=10.583, SD=7.298, N=72) than those whose services had no parental involvement (mean = 15.158, SD=6.076, N=19), (t=-2.793 (equal variances not assumed), df=33, p=0.009).

These results are summarised in Table 5.28 which identifies the variables selected for inclusion in multiple regression analysis.

**Table 5.28 Predictors of young people's unmet needs scores: bivariate analyses**

| *Individual-level* | *Service-level* |
|---|---|
| (Measure of Processes of Care ***) | Service manager involved at strategic level* |
| Had written transition plan** | (Service set up adult package*) |
| One transition worker*** | (Clarity on role of transition workers**) |
| | Parental involvement in steering group** |

*p<0.05, **p<0.01, ***p<0.001

Variables which had a significant bivariate relationship with level of young people's unmet need (excluding MPOC as this was only available in the pre-transition sample, and clarity of the transition worker role and negotiation of the adult package due to multicollinearity) were then entered into a forwards stepwise multiple linear regression (Table 5.29). Only one variable (having one transition worker) entered the model which explained ten per cent of the variance in the level of young people's unmet needs (Adjusted $R^2$=0.099, F=10.686, df=1, 87, p=0.002).

**Table 5.29 Stepwise multiple linear regression: level of young people's unmet needs**

| | | *Unstandardized Coefficients* | | *Standardized Coefficients* |
|---|---|---|---|---|
| *Model* | | *B* | *Std. Error* | *Beta* |
| 1 | (Constant) | 15.417*** | 1.420 | |
| | Has one transition worker | -5.432** | 1.662 | -.331 |

*p<0.05, **p<0.01, ***p<0.001

The unstandardized coefficients (and their associated standard errors) show the change in young people's unmet needs scores given a unit change in the variable of interest. Thus in the final model, having one transition worker reduced the baseline young people's unmet needs score of 15.5 by just over five points.

### 5.3.4 Parents' unmet transition needs

Firstly we identified those independent variables which had a significant bivariate relationship with parent unmet transition needs, defined by a scale on which scores ranged from 0-7 where a higher score indicates greater unmet need.

Correlations were run between the continuous independent variables and level of parent unmet transition needs:

- level of parent unmet transition needs was significantly correlated with MPOC scores ($r=-0.415$, $p<0.001$, $N=87$), so that as MPOC scores increased, level of unmet need decreased.

T-tests were run between binary independent variables and level of parent unmet transition needs:

- Those who had a written transition plan reported lower levels of parent unmet transition needs (a lower score) (mean=2.163, SD=2.494, N=49) than those without a written plan (mean=4.500, SD=2.295, N=72) (t=5.307 (equal variances assumed), df=119, $P<0.001$).
- Those who had one transition worker reported lower levels of parent unmet transition needs (mean=2.682, SD=2.592, N=85) than those without (mean=5.600, SD=1.217, N=35) (t=8.374 (equal variances not assumed), df=116, $P<0.001$).

A one-way analysis of variance (ANOVA) was run with type of school, but there were no statistically significant differences in level of parent unmet transition needs by the type of school a young person (had) attended.

T-tests were then run between each of the service-level variables and level of parent unmet transition needs:

- Those whose service had a manager involved at a strategic level had lower levels of parent unmet transition needs (mean = 2.818, SD = 2.569, N = 72) than those whose service did not (mean = 4.841, SD = 2.241, N=44) (t=4.359 (equal variances assumed), df=119, $p<0.001$).
- Those with access to a service with designated transition workers had lower levels of parent unmet transition needs (mean=3.107, SD=2.598, N=84) than those who did not (t=-2.896 (equal variances assumed), df= 119, p = 0.004).

- Those who had access to a service where the transition workers set up the adult package and negotiated funding for it had lower levels of parent unmet transition needs (mean=2.687, SD=2.429, N=64) than those who did not (mean=4.526, SD=2.529, N=57), (t= -4.077 (equal variances assumed), df = 119, p<0.001).
- Those whose service operated a system of Person Centred Planning for all young people in transition had lower levels of parent unmet transition need (mean = 2.286, SD=2.277, N=42) than those whose service did not (mean=4.228, SD=2.572, N=79), (t=-4.110 (equal variances assumed), df=119, p<0.001).
- Those with access to a service which had clarity on the role of transition workers had lower levels of parent unmet transition needs (mean=3.155, SD=2.671, N=97) than those who did not (mean=5.167, SD=1.736 N=24), (t=-4.509 (equal variances not assumed), df = 53, p<0.001).
- Those in services which had parental involvement in the steering group had lower levels of parent unmet transition needs (mean=3.155, SD=2.671, N=97) than those in services with no parental involvement (mean=5.167, SD=1.736 N=24), (t=-4.509 (equal variances not assumed), df = 53, p<0.001).

These results are summarised in Table 5.30, which identifies the variables selected for inclusion in multiple regression analysis.

**Table 5.30 Predictors of parent unmet need: bivariate analyses**

| *Individual-level* | *Service-level* |
|---|---|
| (Measure of Processes of Care ***) | Service manager involved at strategic level*** |
| Had written transition plan*** | Designated transition workers** |
| One transition worker*** | (Service set up adult package***) |
| | Person centred planning*** |
| | (Clarity on role of transition workers***) |
| | Parental involvement in steering group*** |

*p<0.05, **p<0.01, ***p<0.001

Variables which had a significant bivariate relationship with level of parent unmet transition need (excluding MPOC as this was only available in the pre-transition sample, and clarity of the transition worker role and negotiation of the adult package due to multicollinearity) were then entered into a forwards stepwise multiple linear regression (Table 5.31). Three variables were included in the final the model which explained 35 per cent of the variance in the level of parent unmet needs (Adjusted $R^2$=0.347, F=22.070, df=3, 166, p<0.001).

**Table 5.31 Stepwise multiple linear regression: level of parent unmet need**

| *Model* | | *Unstandardized Coefficients* | | *Standardized Coefficients* |
|---|---|---|---|---|
| | | *B* | *Std. Error* | *Beta* |
| 3 | (Constant) | 3.785*** | .745 | |
| | Has one transition worker | -2.219*** | .472 | -.384 |
| | Service manager involved at strategic level | 1.281** | .431 | .234 |
| | Has written transition plan | -1.029* | .457 | -.193 |

*p<0.05, **p<0.01, ***p<0.001

The unstandardized coefficients (and their associated standard errors) show the level of parent unmet transition needs given a unit change in the variable of interest. Thus in the final model, having one transition worker reduced the baseline value of parent unmet transition need scores of 3.785 by just over two points. The standardized coefficients show that in the final model having one transition worker is a stronger predictor of parent unmet transition need than there being a service manager involved at strategic level and having a written transition plan, although all three had a significant predictive effect.

### 5.3.5 Impact of the transition service on parental stress

The fourth and final outcome considered was whether parents reported increased stress levels as a result of their contact with the transition service (this binary variable was created from a categorical variable with the categories increased/ neither/decreased). Overall around a third of respondents (37.7 per cent) felt their contact with the transition service had increased their stress level (N=114).

As this was a binary outcome variable logistic regressions were run, firstly without controlling for other factors, see Table 5.32. significant bivariate relationships are starred.

**Table 5.32 Odds of parents reporting increased stress as a result of contacts with the transition service**

| *Variable (N in brackets)* | *Not controlling for other factors* | *Variables entered stepwise* |
|---|---|---|
| Has written transition plan | | |
| Yes (53) | 1.00 | |
| No (61) | 2.98** | |
| Has one transition worker | | |
| Yes (89) | 1.00 | |
| No (25) | 6.58*** | 8.193*** |
| Level of difficulties | 1.17* | 1.188* |
| Type of school attended | | |
| Special school | 1.00 | |
| Mainstream school/special unit | 0.55 | |
| Residential school | 0.97 | |
| Other | 0.36 | |
| MPOC | 0.71* | |
| Age transition planning started | 0.85 | |
| Specific training on transition | | |
| Yes (38) | 1.00 | |
| No (76) | 0.76 | |
| Service manager involved at strategic level | | |
| Yes (79) | 1.00 | |
| No (35) | 1.37 | |
| Designated transition workers | | |
| Yes (82) | 1.00 | |
| No (32) | 1.70 | |
| Did the transition workers set up the adult package and negotiate funding for it? | | |
| Yes (65) | 1.00 | |
| No (49) | 1.71 | |
| Person centred planning | | |
| All (44) | 1.00 | |
| Some (70) | 2.12 | |
| Clarity on role of transition worker | | |
| Yes (96) | 1.00 | |
| No (18) | 1.39 | |
| Parent Involvement | | |
| Yes (96) | 1.00 | |
| No (18) | 1.39 | |
| Involvement of young people | | |
| Yes (35) | 1.00 | |
| No (79) | 0.62 | |
| | | Constant = 0.084** |
| | | % correctly predicted = 73.0% |
| | | Nagelkerke $R^2$ = 0.258 |
| | | N=100 |

Four independent variables showed a significant bivariate relationship with increased stress: those whose child did not have a written transition plan were three times as likely to report increased stress, and for those without one transition worker the factor was over six times. As a young person's level of difficulties increased, so did the likelihood that their parent reported increased stress as a result of contact with the transition service, and as MPOC scores increased the odds of increased stress reduced.

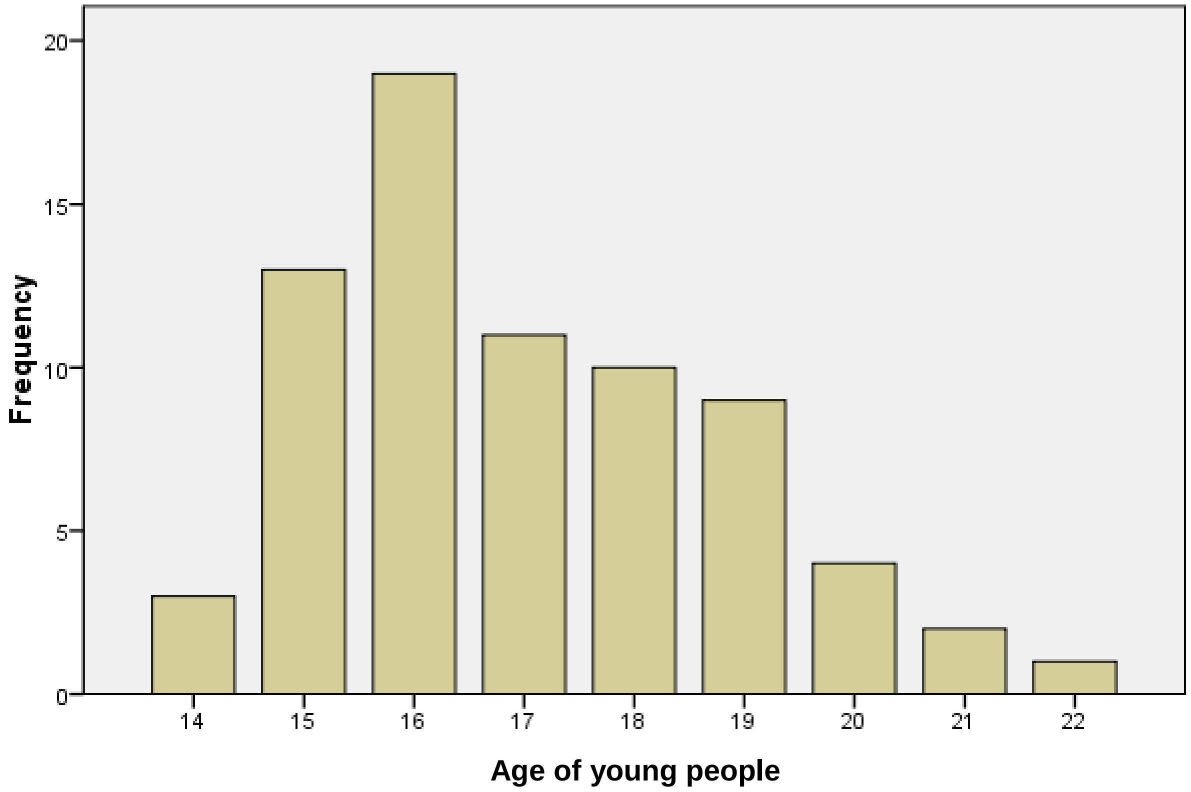
Those variables which had a significant bivariate relationship with increased stress were entered into a stepwise multivariate logistic regression (excluding MPOC as this was only available in the pre-transition sample). Only two variables were included in the final model, which explained 26 per cent of the variance in increased stress. Not having a single transition worker increased the odds of contact with the transition service increasing stress by over eight times. In addition, those whose child had higher levels of difficulties had slightly higher odds of their contacts with the transition service increasing their stress.

## 5.4 Pre-transition young people

### 5.4.1 Characteristics of the sample

Seventy-three young people completed at least part of the pre-transition questionnaire, with 19 of these completing only the symbol questionnaire, which did not include questions on met and unmet needs. The ages of respondents ranged from 14 to 22 years, with a mean age of 17 years (SD=1.82, median=17) (see Figure 5.3).

**Figure 5.3 Ages of young people (pre-transition group)**



### 5.4.2 Support provided by transition workers

In answer to the question 'Do you have one main person from services to support you in planning for transition?' 45 indicated that they did have (one of these had two people carrying out the role), 16 that they did not have, and 12 didn't know. For those who had such a person, 27 were able to give job titles for these: ten identified specific transition workers (for example, transition key worker, transition coordinator, transition advisor, personal advisor transition), eight identified social workers, five Connexions workers, and four teachers/school or college staff. For ease, we will call these people 'transition workers'. There was no significant difference between those under and over 16 years of age on whether they had a transition worker.

Table 5.33 shows responses to questions on how transition workers helped the young people. The responses provide a broadly positive picture of how transition workers supported the young people. The majority of transition workers provided young people with a range of support and information, and importantly young people felt that they were listened to and asked for their ideas. Nearly half the young people (n=21) would have liked to see their transition worker more often, nine did not want this and 14 didn't know.

**Table 5.33 Help given by transition workers**

| | *Yes* | *No* |
|---|---|---|
| Help to think about what I want to do next (n=44) | 88.6% (39) | 11.4% (5) |
| Gives me information and advice (n=46) | 84.8% (39) | 15.2% (7) |
| Asks for my ideas (n=46) | 84.8% (39) | 15.2% (7) |
| Listens to me (n=45) | 91.1% (41) | 8.9% (4) |
| Finds things out for me (n=44) | 88.6% (39) | 11.4% (5) |
| Visits me in school or college (n=44) | 84.1% (37) | 15.9% (7) |
| Talks to me about how I feel (n=42) | 88.1% (37) | 11.9% (5) |

### 5.4.3 Unmet needs

Young people completing the written questionnaire were asked about their needs in 19 areas of life: whether they were getting enough help, help was not needed, or more help was needed (unmet need). The number of unmet needs per young person was summed in order to obtain a total score of unmet needs for help from services. Mean number of unmet needs was 10.13 (SD=6.16, range=0 – 19, N=46). There was no significant difference between those who did and did not have one transition worker to support them in planning for transition (transition worker: mean=9.73, SD=6.28, n=30; no transition worker or don't know: mean=10.87, SD=6.05, n=16). Neither was there any significant relationship between unmet need and age of the young person (r=-0.14, n=46). Numbers were too small for analysis of differences between sites.

There was no significant difference in number of unmet needs between young people with ASC and others (ASC: mean=10.14, SD=6.71, n=14; other disabilities: mean=10.79, SD=6.04, n=28; information on diagnosis was missing for four young people).

Table 5.34 shows the pattern of unmet need across the whole sample. Only three variables showed unmet needs for help for less than 50 per cent of the sample. These were help with mobility, equipment, self care, and adult relationships or sex education. It should be noted, however, that these variables all had quite high levels of help not needed (around a third of responses). The final column in the table shows unmet need as a proportion of those who needed help in each category. For all variables, the levels of unmet need were higher than levels of met need, and considerably so in most cases. The highest levels of needs that were not met (75 per cent or more) were for help with housing, job or career opportunities, leisure or social life, benefits and finances, short breaks/respite, support to prepare for the changes ahead, opportunities for the young person to say what s/he wants for the future, and help with thinking about future goals. These are all key aspects of young people's transition to adulthood which require attention in transition planning.

**Table 5.34 Young people's met and unmet needs**

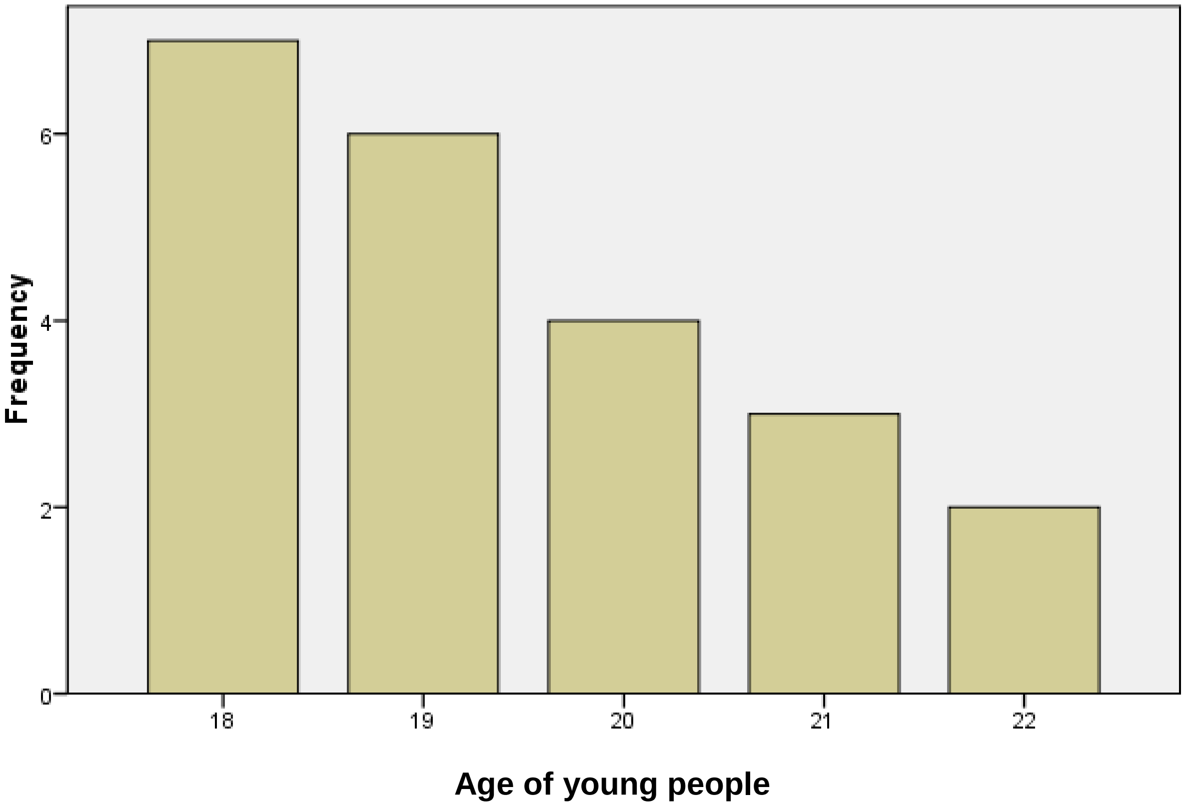
| | *Help not needed* | *Getting enough help* | *Need more help* | *Proportion of those having a need who need more help* |
|---|---|---|---|---|
| Help with communication needs (n=53) | 7.5% (4) | 28.3% (15) | 64.2% (34) | 69.4% |
| Help with mobility needs (n=49) | 36.7% (18) | 28.6% (14) | 34.7% (17) | 54.8% |
| Help with other equipment needs (n=49) | 32.7% (16) | 28.6% (14) | 38.8% (19) | 57.6% |
| Help with self care (n=50) | 36% (18) | 30% (15) | 34% (17) | 53.1% |
| Help with further education/training (n=52) | 7.7% (4) | 26.9% (14) | 65.4% (34) | 70.8% |
| Help with housing needs (n=48) | 35.4% (17) | 12.5% (6) | 52.1% (25) | 80.6% |
| Help with job or career opportunities (n=51) | 25.5% (13) | 13.7% (7) | 60.8% (31) | 81.6% |
| Help with leisure or social life (n=52) | 13.5% (7) | 15.4% (8) | 71.2% (37) | 82.2% |
| Help with independent living skills (e.g. shopping, cooking) (n=51) | 23.5% (12) | 23.5% (12) | 52.9% (27) | 69.2% |
| Help with benefits or finances (n=50) | 24% (12) | 16% (8) | 60% (30) | 78.9% |
| Help with transfer to adult health services (n=52) | 13.5% (7) | 26.9% (14) | 59.6% (31) | 68.9% |
| Help with transport or getting around (n=50) | 24% (12) | 24% (12) | 52% (26) | 68.4% |
| Help with short breaks or respite care (n=50) | 28% (14) | 18% (9) | 54% (27) | 75% |
| Help with adult relationships or sex education (n=46) | 37% (17) | 26.2% (12) | 37% (17) | 58.6% |
| Help with emotional changes as you grow up (e.g. feeling sad or angry) (n=50) | 24% (12) | 22% (11) | 54% (27) | 71.1% |
| Support to prepare you for the changes ahead (n=50) | 8% (4) | 22% (11) | 70% (35) | 76.1% |
| Opportunities to say what you want for the future (n=53) | 9.4% (5) | 18.9% (10) | 71.7% (38) | 79.2% |
| Help with thinking about your future goals (n=50) | 6% (3) | 20% (10) | 74% (37) | 78.7% |
| Help with achieving your future goals (n=50) | 4% (2) | 26% (13) | 70% (35) | 72.9% |

## 5.5 Post-transition young people

### 5.5.1 Characteristics of the sample

Twenty-four young people responded to the questionnaire, with eight of these completing only the symbol questionnaire. The ages of respondents ranged from 18 to 22 years, with a mean age 19.41 years (SD=1.33, median=19).

**Figure 5.4 Ages of young people (post-transition group)**



### 5.5.2 Support provided by transition workers in planning for transition

In answer to the question 'Did you have one main person from services to help support you in planning for transition?' 18 young people indicated that they did have this, four did not and three didn't know. For those who had such a person, 15 were able to give the job title of the person: four identified specific transition workers (for example, transition worker, transition nurse), six identified social workers (and one of these was also supported by a teacher), four identified Connexions, and one said 'manager for Children in Need'. Again, for ease, we will call these 'transition workers' in the following text.

Table 5.35 shows responses to questions on how transition workers had helped the young people. The responses again provide a very positive picture of how transition workers had supported the young people in planning for transition. The majority of transition workers provided young people with a range of support and information, and importantly all young people except one felt that they had been listened to and asked for their ideas. Ten young people would have liked to see their transition worker more often, two did not want this, four didn't know, and two did not answer.

**Table 5.35 Help given by transition workers**

| | *Yes* | *No* |
|---|---|---|
| Helped to think about what I want to do next (n=17) | 17 | 0 |
| Gave me information and advice (n=17) | 17 | 0 |
| Asked for my ideas (n=15) | 14 | 1 |
| Listened to me (n=16) | 16 | 0 |
| Found things out for me (n=16) | 16 | 0 |
| Visited me in school or college (n=17) | 14 | 3 |
| Talked to me about how I felt (n=14) | 12 | 2 |

### 5.5.3 Unmet needs

Young people who completed the written questionnaire (n=16) were asked about their met and unmet needs in the past, that is when making the transition to adult services, and currently. For each, the number of unmet needs per young person was summed in order to obtain a total score of unmet needs for help from services.

#### *Past unmet needs*

Mean number of unmet needs was 10.38 (SD=6.43, range=0-17, N=13). Numbers were too small for reliable analysis of differences between sites or between those who had and had not had a transition worker.

Table 5.36 shows the pattern of unmet need across the sample. Numbers are small, and the question was about past needs and could be affected by potential recall problems, so it is difficult to draw conclusions. In general, there were high levels of unmet need, with more than half of those who needed help indicating unmet need in all areas except communication, mobility, equipment and self care. The highest levels of unmet need (three quarters or more of those needing help) were for help with career and employment opportunities, leisure or social life, independent living skills, transfer to adult health services, and achieving future goals. This is likely to reflect the key priorities of the young people in this age group and suggests that they do not feel that they were supported in these areas before and during their transition to adult services.

**Table 5.36 Young people's met and unmet needs at time of transition**

| | *Help not needed* | *Getting enough help* | *Need more help* |
|---|---|---|---|
| Help with communication needs (n=16) | 3 | 6 | 7 |
| Help with mobility needs (n=14) | 4 | 6 | 4 |
| Help with other equipment needs (n=14) | 8 | 4 | 2 |
| Help with self care (n=15) | 5 | 5 | 5 |
| Help with further education/training (n=16) | 1 | 6 | 9 |
| Help with housing needs (n=15) | 5 | 4 | 6 |
| Help with job or career opportunities (n=15) | 2 | 2 | 11 |
| Help with leisure or social life (n=15) | 2 | 2 | 11 |
| Help with independent living skills (e.g. shopping, cooking) (n=15) | 4 | 0 | 11 |
| Help with benefits or finances (n=14) | 1 | 6 | 7 |
| Help with transfer to adult health services (n=14) | 4 | 2 | 8 |
| Help with transport or getting around (n=14) | 2 | 4 | 8 |
| Help with short breaks or respite care (n=14) | 3 | 3 | 8 |
| Help with adult relationships or sex education (n=14) | 4 | 4 | 6 |
| Help with emotional changes as you grow up (e.g. feeling sad or angry) (n=14) | 3 | 3 | 8 |
| Support to prepare you for the changes ahead (n=14) | 2 | 4 | 8 |
| Opportunities to say what you wanted for the future (n=14) | 2 | 5 | 7 |
| Help with thinking about your future goals (n=14) | 2 | 4 | 8 |
| Help with achieving your future goals (n=14) | 2 | 2 | 10 |

### *Current unmet needs*

The same questions were asked in relation to young people's current needs. Mean number of unmet needs was 9.86, (SD=7.41, range 0-19, n=14).

The pattern of current unmet need was similar to that for past unmet need, with more than half of those needing help indicating unmet needs in all areas except equipment and housing. The highest levels of unmet need (three-quarters or more of those needing help) were for help with leisure and social life, transfer to adult health services, and achieving future goals.

### Table 5.37 Young people's current met and unmet needs

| | *Help not needed* | *Getting enough help* | *Need more help* |
|---|---|---|---|
| Help with communication needs (n=16) | 2 | 5 | 9 |
| Help with mobility needs (n=16) | 5 | 5 | 6 |
| Help with other equipment needs (n=15) | 7 | 4 | 4 |
| Help with self care (n=15) | 3 | 5 | 7 |
| Help with further education/training (n=16) | 2 | 4 | 10 |
| Help with housing needs (n=16) | 2 | 7 | 7 |
| Help with job or career opportunities (n=16) | 2 | 4 | 10 |
| Help with leisure or social life (n=15) | 3 | 3 | 9 |
| Help with independent living skills (e.g. shopping, cooking) (n=16) | 2 | 4 | 10 |
| Help with benefits or finances (n=16) | 2 | 5 | 8 |
| Help with transfer to adult health services (n=15) | 5 | 2 | 9 |
| Help with transport or getting around (n=16) | 0 | 6 | 10 |
| Help with short breaks or respite care (n=14) | 2 | 3 | 9 |
| Help with adult relationships or sex education (n=15) | 5 | 3 | 7 |
| Help with emotional changes as you grow up (e.g. feeling sad or angry) (n=15) | 2 | 5 | 8 |
| Support to prepare you for the changes ahead (n=15) | 2 | 5 | 8 |
| Opportunities to say what you want for the future (n=15) | 2 | 5 | 8 |
| Help with thinking about your future goals (n=15) | 3 | 4 | 8 |
| Help with achieving your future goals (n=15) | 2 | 3 | 10 |

## 5.6 Summary

The results of the family survey showed a range of scores on outcome variables of satisfaction with the service, impact of the service on parental stress, parents' unmet transition needs, and young people's unmet needs, and considerable variation both between and within services on key factors in transition, such as whether families had a written transition plan and whether they had a transition worker to support them through transition. Only a few differences between services were significant, but low numbers of respondents per service meant that the analysis of differences between sites had insufficient power and so would be subject to Type II error. However, the aim of the study was to investigate which characteristics of service models were related to better outcomes for families, rather than to look for differences between individual services. This was possible for outcomes explored in parent questionnaires (which included parents' perceptions of the young person's unmet needs) but not for young people’s questionnaires where the sample was too small for reliable further analysis.

The descriptive data for both parents’ and young people’s questionnaires showed high levels of unmet need for pre and post-transition young people in many areas of their lives, especially employment opportunities, and social and leisure opportunities. There appeared to be slightly less unmet need in some areas, such as support for independent living skills and goals and aspirations, among the post-transition group than in the pre-transition group on parent responses, with unmet need post-transition being around the 50 per cent level, but there were no significant differences in total scores. Post-transition young people themselves still identified these areas as high unmet need, although the sample was small. Around two-thirds of the parent pre-transition sample identified unmet needs for information about transition for themselves and their sons and daughters. This was slightly lower for the post-transition sample.

There was considerable consistency between the analyses for the four outcome measures, indicating that key factors in services relating to better outcome were families having one transition worker to support them and a written transition plan, and the service having the transition manager involved at a strategic level. At the bivariate level, other variables were important: the service having designated transition workers, the transition workers setting up the adult care package and negotiating funding for it, the service using person-centred planning for all young people in transition, having clarity about the role of the transition workers, and having parents on the service’s steering group. These lost significance in the multivariate analyses, but there was a high degree of multicollinearity with other variables, so they should not be completely discounted. The analyses explained over 30 per cent of the variance in outcome measures relating to parents’ satisfaction and unmet transition needs, and 26 per cent for impact of the service on parental stress, but only 10 per cent of the variance in young people’s unmet needs. This is not surprising as many of the items in the young people’s unmet needs scale are partly dependent on other factors outside the transition services themselves, such as the provision of accessible leisure services in the local area.

The results of the young people’s questionnaires highlight the importance of transition workers. They indicated that where young people had one transition worker to support them the workers provided a range of support and information and the vast majority of young people were positive about their relationship with the worker, for example, feeling that they were listened to and asked for their ideas, and that the worker would help them to think about what they wanted and find things out for them. In addition, the significant relationship between families having one transition worker and MPOC scores suggests that these workers contributed to the provision of more coordinated and responsive services. As MPOC scores were only available for the pre-transition sample, they were not used in the multivariate analyses but their significant bivariate relationships with outcome measures indicate the importance of this aspect of services in general to outcomes for young people and parents.

# Chapter 6 The Experiences of Parents and Young People

This chapter reports on the interviews we conducted with a sample of parents and disabled young people who had experience of the transition services in the case study sites and the qualitative data from parents' and young people's responses on the survey questionnaires.

The chapter begins with a basic description of the characteristics of the interviewees. This section is purposely brief to protect the anonymity of those who took part. The next section (6.2) contains case studies of each of the six families represented in the interviews. The case studies paint a picture of how the young people spend a typical week; which agencies were involved in supporting the young people to undertake those activities; the parents' perceptions of the support they had received from their transition worker; how successful or otherwise they felt their child's transition into adult services had been in relation to health, education, employment or training, social care, and housing; and the challenges they had faced during the transition period. Following the case studies, section 6.3 looks at factors that helped and factors that hindered a good transition experience for the families we interviewed and families' suggestions for how services and support could be improved. Finally, we report data from analysis of parents' and young people's open comments on the survey questionnaires.

## 6.1 Characteristics of the interviewees

Interviews were conducted with six sets of parents across three different sites (three in one site, two in another site, and one in a further site). Of these six sets, two interviews were conducted with married couples, two were conducted with married mothers, and two were conducted with divorced or separated mothers. We also interviewed the disabled son or daughter of three of these sets of parents in two of the sites (two in one site and one in another site). The three young people we interviewed either had very limited communication, or were unable to share with the researcher in any depth what they thought about their transition, who had helped them during their transition, or whether they were currently following what was on their transition plan and/or what they really wanted to do. If the researchers had had the resources to visit the young people on numerous occasions to build a relationship and gain a deeper understanding of each young person's communication skills, it may have been possible to gain more information. Each of the young people wanted their parent(s) to be in the room with them during the interview, indeed two of the interviews with young people took place during the course of the interview with the parents as this was how the young people felt most comfortable. All the families were from the 'post-transition' group - the young people had completed the transition for children's to adult services. Chapter 2 (p.17) gives more details of sampling and procedures.

## 6.2 Case Studies

### 6.2.1 Case Study 1

This young person lived with her foster parents and attended a social services day centre for three days a week, through which she had two jobs. From September she was enrolled on a day centre course that the parents had identified to further develop their daughter’s independent living skills. Previously she had attended college three days per week and the resource centre for two days per week. As a looked after child in children’s services, this young person had been supported by social workers and a specialist nurse for looked after children. Despite attending a special needs school until age 16, the young person had only been classed as ‘special needs’ by social services just before she turned 18, and thus she was only eligible for support from the transition service from this point. Accordingly, the parents reported that it was her school that had provided most support in terms of identifying and securing a place at the local college when she was 16 and signposting the family to other services and support. The local transition worker, based in adult social care services, took over responsibility for their daughter just before she turned 18, and shortly before she was transferred to a social worker from the adult learning disability team. The parents reported that the transfer to the transition worker was made more ‘comfortable’ for their child by the fact that the transition worker was a familiar face from school and college. The parents believed there was a transition plan but they did not recall ever seeing it. They displayed little knowledge or understanding of the transition worker role, possibly because of the limited time their daughter was supported by the transition worker. They did, however, report how supportive the transition worker had been in discussions about their child’s needs, and that how the transition worker had been able to advise the adult social worker about paperwork that needed to be completed. The young person had reportedly not required a transfer from child to adult health services as she did not have any chronic or complex health needs.

The majority of this young person’s social and leisure activities were arranged by, and undertaken with, her family as opposed to any statutory, voluntary or private provider. The parents’ main concerns were over their daughter’s future housing and employment. However, the parents had as yet received no support or guidance in terms of finding alternative accommodation or employment for their daughter. The parents reported that they were happy with the service they had received from the transition worker and the social workers and made no recommendations for changing the system. The young person reported that she enjoyed her work at the resource centre, liked the staff she worked with, and had made some new friends. She clearly enjoyed spending time with her foster family and wanted to remain living with them in the family home.

### 6.2.2 Case Study 2

This young person lived with his mother. He was in receipt of direct payments (administered by his mother) which were used to pay an agency to supply personal assistants to support the young person on his college course and to undertake various activities for three and a half days and one evening per week. These activities included college courses in computing and photography, hydrotherapy swimming, gardening and cooking, and trips to the local shops. The transition worker had produced a transition plan for the young person and, in conjunction with the mother, had worked out how many hours of personal assistance the direct payments could fund.

The mother reported that the main problems she had experienced in relation to her son’s transfer from children’s to adult services were the loss of a five-day per week provision for her son and the poor transition from paediatric to adult health services. She reported that her son had a paediatrician until the age of 16 when all his health services (primarily his physiotherapy) had been withdrawn. The mother had had to personally provide physiotherapy for her son daily since the age of 16 to help him be more comfortable and so that his health would not deteriorate. The mother had fought for her son to access physiotherapy services and, after a four year gap in service, this was currently being provided. She reported that the GP had provided her with most support but that nobody had advised her that this was the route to take to access adult health practitioners. On the other hand, there had been a seamless transition from children's to adult occupational therapy services. The mother reported that during the transition period, she and her son had received a lot of support from the transition worker. The transition worker had spent a lot of time with the young person during the transition planning stages, yet the young person’s options were limited as the transition worker could only work within the confines of what little resources, activities and opportunities were available. However, the transition worker did not get involved in the practicalities of finding a care agency that was both affordable and could meet the young person's needs; this was left to the mother to arrange. Despite it taking up a lot of her time and energy, the mother reported satisfaction with the team of workers she had put together to provide care for her son. Her son too, expressed his pleasure at leaving college, where his mother reported he was frequently bored and consequently disruptive, to take part in an array of activities with different support workers. The mother explained that he was now able to choose now what he wanted to do most days and this had given him a degree of independence he did not have as a ‘child’.

The family was now reliant upon social workers in adult services for guidance. The mother was concerned that she would not be able to afford her son's support package in the future. She reported feeling pressure from adult services to employ personal assistants herself rather than use an agency. However she was unwilling to do this as she had concerns over what would happen if the PA was off sick or on holiday, her own time and ability to manage the paperwork and pay employer's tax and national insurance contributions, and the fact that her son enjoyed spending time with different PAs and undertaking a range of activities.  Housing options had not been addressed as the mother expected the young person to continue to live at home with her and the house had been adapted accordingly.

### 6.2.3 Case Study 3

This young person had moved at the age of 17 to a 52-week out of area residential placement, which specialised in his condition. In this case the transition worker had first secured agreement that adult services would fund a placement once the young person turned 18, then identified three possible placements for the parent to consider, taken the parent to view these residences, and made arrangements for the young person to move to the preferred placement whilst he was still in children's services. The parent reported that she had been fully involved in the process and that the transition worker had kept her informed of progress every step of the way. As the young person had no specific health needs, there had been no need for a coordinated transition from child to adult health services. The young person was registered with a general practitioner in the host area and his medical records had been transferred without any problems. The young person had been excluded from his special needs school at age 17 (four months before he moved into his placement), and was not undertaking any further education or training at his placement. The parent had been introduced to the social worker in adult services on the young person's 18th birthday, that is, the day at which the young person was officially transferred to adult services.

The parent reported that the current placement was ideal for her son as it offered a good range of activities that he enjoyed. The parent was extremely happy with the service she had received from the transition worker, despite reporting that the transition team were under-staffed and under a great deal of pressure. The parent had been involved in the transition planning, was invited to all the meetings relating to her son, was always sent copies of the meeting minutes and any reports that had been produced, and she reported that everything in the transition plan was either in place or was in the process of being set up. Her only concern for the future was whether adult services would continue to fund the placement. She feared that any attempt to bring her son back into the area would be detrimental to his well-being as he needed open space and was happy in the placement. Any future issues would need to be taken up with a social worker in adult services as the transition worker's role in the case had come to an end. The mother had thus far had little contact with adult services but the two contacts she had had were with a different social worker each time.

### 6.2.4 Case Study 4

This young person lived at home with her parents, attended college four days per week and attended a range of other activities (including sports) on the fifth day. The transition team had been involved with the young person between the ages of 16 and 18. The mother reported that the transition team had been particularly helpful when the young person transitioned from school to college at the age of 16. The transition worker had visited the family on several occasions to explore what the young person and her family wanted to do; helped the young person find a college course and supported her to get a place on the course; found the young person a packing job one morning per week during the college holidays; and found some social and leisure activities for the young person to get involved with while she was still in children’s services. The young person did not have any specific health needs. and thus there had been no need for a coordinated transition from child to adult health services. However, the mother reported that the transition nurse had played an important role in providing the young person with six weekly sessions exploring issues around menstruation, sex and relationships.

This family had, however, also experienced difficulties with transition. The mother reported that her daughter’s school placement had been taken away at age 16 (owing to her abilities and shortage of places at the school); the young person had not been offered any alternative to college but was only told a month before starting the course that she actually had a place; and all input from the transition team stopped when her daughter turned 18: 'as soon as she turns eighteen that’s it, you’re on your own, useless.' The mother reported that the transition worker had not introduced her to adult services; instead the transition worker had simply provided the mother with contact details for adult services. The mother stated that her daughter did not have a named social worker in adult services and so had to repeat her story each time contact was made with a social worker; that no plans had been made for her daughter in adult services; and that nobody had spoken to the young person or family about future options around housing or employment. The young person herself told the researcher that she wanted to move out and live with friends in shared accommodation, but the mother had discovered that her daughter could only be considered a priority for local authority housing if she was in crisis, for example if she had been made to leave the family home or if the parents were separating or were terminally ill. The young person also had ambitions to work and was quite specific about the work she would like to undertake, but her mother did not where to turn to for help, advice and support in seeking employment opportunities for her daughter. The mother was also particularly concerned that nobody was providing information about social and leisure activities for her daughter now that she was in adult services. The mother was investing a lot of time and effort in uncovering activities and received most of her information from other parents of young people with disabilities. Although such complaints are a criticism of adult services rather than the transition service, this was a service where the transition worker role including setting up a package of support and funding in adult services and this had arguably not happened in this case.

### 6.2.5 Case Study 5

This young person received support from care agency staff five days per week to take part in a number of social and leisure activities while his parents both worked. The parents reported that the young person had been well supported in children's services and they were very impressed by the hard work of the transition worker, however they felt that the support they were getting in adult services was poor. Adult services had been passively involved in the young person's case from the age of 17 but become actively involved when the young person was close to 19. The parents reported that the transition worker had been empathetic to the worries of the parents and extremely proactive in working to secure a package that suited the needs of the family. The transition worker had arranged and led some multi-agency meetings which included the parents, school, Connexions, child health, the transition nurse, the school nurse, adult social care services, community paediatrician, school physiotherapist, respite, care agency and the local resource centre staff. The parents reported that, as part of their transition support for leavers, the school had produced a DVD all about the young person: his likes, dislikes, needs, and how to read his body language and vocalisation. This had then been used as a training aid for the care agency support workers and the staff at the local resource centre.

The parents reported that although the transition nurse had been very helpful, the transition to adult health services had been problematic. The young person reportedly had no community nurse in adult health services, no named adult physiotherapist, and there was uncertainty over which hospital consultant the young person would be referred to. However, this was reportedly a result of adult health posts being vacant rather than a failing on the part of the transition team. The community paediatrician and general practitioner had been most supportive; however, there had not been a health-specific transition meeting. It was reported that while the respite service in children's services was excellent, this had ceased at age 16 and there were no appropriate adult respite services that could meet the needs of the young person. The parents had also had poor experiences with adult social care services who reportedly had no record of the young person post-transition and who eventually gave the young person a named social worker but then that worker left. The parents were particularly concerned that the future housing needs of their son should be addressed; however, as the young person was being cared for at home, he apparently was not a priority on the housing list. Housing was not discussed during any of the transition meetings the parent attended and they were unsure where to turn for advice or support.

The family's interaction with the transition service was largely positive: the transition worker was reported to be very supportive, very hard-working, enthusiastic, built a good relationship with the young person and the parents and was a good advocate for the young person. However, the parents had experienced some challenges: they commented that the transition team was new, their transition worker was the first transition worker in that team and the transition systems and processes were not yet established. This had resulted in delays, uncertainty and consequently a degree of anxiety over what support would be available for their son in adult services and whether both parents could continue to work full-time. The contrast between the transition service and adult services were summarised thus by this parent:

> 'During the actual transition bit we felt incredibly well supported and we felt we were listened to and we felt they understood [young person's] needs very well. But really, when you got to adult care services, we just felt they didn't know him, they didn't understand him and they don't understand us'.

The parents suggested that a mentoring programme be established whereby parents whose young people had been through transition could provide some support or guidance for those who were about to experience it. They also suggested that a flowchart would be useful whereby parents could trace the process that they and their child would go through on the transition journey.

### 6.2.6 Case Study 6

This young person attended a local college three days per week and was supported by a personal assistant during the two remaining weekdays, who was paid for from the young person's direct payments. The mother reported that her son had not had a social worker in children's services and she was not aware of the role of transition workers. The young person had reportedly not had a transition plan, only a plan for his transfer from school to college which had been supported by Connexions and the school. The mother felt that the local community should be made aware of the role of the transition team as she felt that the message 'was not out there'. However, during the interview it was clear that the family had had contact with those social workers responsible for transition in both children's and adults' services. The mother had requested assistance from adult services but reported that her case had been passed from social worker to social worker, had not been followed up, and subsequent social workers reported that there were no records of the young person or the contacts made by the mother on the social services database. The school nurse had produced a health action plan, and the transition from child to adult health services had been unproblematic.

The mother’s main concern was over the proper use of her son’s direct payments. She reported that she had received no guidance on how to use the direct payments, on what was and was not acceptable to purchase, and she had had a particularly challenging time in trying to find a care agency whose staff had Criminal Records Bureau checks, which was affordable from the amount of direct payment received, and who the mother felt she could trust. A direct payments support organisation had become involved to provide some support, but the mother stated she would prefer her son to attend a day centre rather than be given direct payments, which involved responsibility for the care package being passed to the family. The mother was particularly distressed that there were no activities or facilities for her son in the local community, nowhere for the paid support workers to take him, and no clear eligibility criteria for benefits options or housing options for her son. She reported that adult services and Connexions each blamed the other for the lack of support that had been given to this family.

## 6.3 Factors that helped, and factors that hindered, a good transition experience

It is clear from the case studies that no transition was totally smooth, even though families were selected from those indicating in the questionnaires that they were satisfied with the support from the transition service. However, some transition experiences appear to be better than others. It is possible to identify key factors that parents felt supported a good or better transition experience and factors that they found were barriers to a good transition experience.

### 6.3.1 Factors that aided a good transition experience

It was clear from the interviews that the parents valued certain aspects of the transition workers’ role and the service they received:

- The personal relationship they could build with a transition worker whom they felt to be supportive, enthusiastic, designated to their role and genuinely interested in securing the best possible package for the young person within the confines in which they had to operate.
- The transition worker spending time getting to know the young person, trying to fully understand what the young person wanted in their future, and advocating on behalf of the young person at meetings.

- The fact that they had a named transition worker whom they could direct all queries and concerns to, and with whom they did not need to keep repeating their story.
- Introducing the parents and young person to the adult social worker so that the family had a central contact once the case had been fully transferred to adult services.
- The transition worker setting up multi-agency meetings with the aim of ensuring that the young person's future was looked at holistically and all agencies and practitioners understood their own role and the role of others.
- The parent(s) attending planning and review meetings for their son/daughter, being sent copies of reports and minutes of meetings, and being informed of progress every step of the way. This helped parents to feel involved, respected and supported.
- Support from the transition nurse to work with the young person on issues around sexuality and relationships.
- In the service where the transition worker from children's services had negotiated a support package and secured funding from adult services, the parent reported a very smooth transition.

### 6.3.2 Factors that hindered a good transition experience

The parents we interviewed reported five key areas where they had experienced challenges in the transition from child to adult services:

- *Lack of options around housing, employment, and social and leisure activities for young people once they left children's services, and thus the lack of support offered by transition workers in identifying any such opportunities:* Four sets of parents made particular reference to the lack of housing options for their child. Two sets of parents also expressed concern over the lack of employment opportunities for their child. They believed that with adequate support and opportunity their young person could undertake some level of work which would provide more structure and purpose to their week. All parents expressed concern over the lack of local social and leisure activities for their son/daughter. With the exception of the mother whose son had moved to a residential placement, all the other parents we interviewed had spent considerable time and effort researching and identifying local facilities and activities and all reported that they had not been supported in this search by the transition workers. This point was articulated by one of the parents:

> 'We've got strong views on what we think should be good for [young person], but it's not available, and once they turn eighteen it gets worse, and once they get to finish college it gets dire, it gets suicidal.

> You stick your head in the sand and you have to pull it out at some stage because you could cry your heart out too much as to what should be but it isn't. Once they leave school that little, little safety net, life's bad.....'

- *Premature cessation of support from the transition service:* Two sets of parents reported that although they were happy with the support they had received from their young person's transition worker, they would have liked to continue to receive such support until their young person had made the transition from college into adult services proper.

- *Lack of a coordinated transition from child to adult health services:* Two sets of parents reported difficulties owing to the lack of a coordinated transition from child to adult heath services. These parents argued that health services should not simply cease at a certain age; and that young people should be transferred from a paediatrician to an adult consultant, this should not be left up to the parents who do not know what to do or who to contact. For example, one parent reported that once her child was discharged by the paediatrician she did not know where to go to access adult health services. Eventually she sought assistance from her GP.

- *Vacant posts:* Parents expressed their concern that their son or daughter had not been referred to particular services, primarily in health and social care, owing to posts being vacant. This led to a lack of consistency, uncertainty and gaps in treatment and support.

- *Lack of information about adult services:* Two parents reported their frustration at the lack of (accurate) information about what services were available for young disabled people in adult services. One parent suggested that the way to keep informed about possible options was to join the relevant committee (for example, college committee): 'If you're on the committee you find out what's happening'.

These points reflect the findings from the staff interviews (see Chapter 4) about the lack of local housing, employment and social/leisure opportunities for disabled young people, the early cessation of the transition service, problems in transfer from child to adult health services for those with complex health needs, staff shortages, and the lack of information about adult services.

### 6.3.3 Recommendations for improving the transition from child to adult services

The parents we interviewed made a number of suggestions as to how the transition services they had experienced could be improved:

- The transition service should continue to support the young person to a later age, until they had transitioned from college into adult services.
- Improve coordination of the transition from child to adult health services.
- Increase the number and range of local services and facilities (for example, leisure, employment and respite services) for young people with disabilities, so that there is something for young people to transition to.
- Increase the supply of suitable supported living places for young people with disabilities, as a lack of appropriate housing was identified as one of the key gaps.
- Have a named social worker in adult services to whom the transition worker can hand over, so that the young people and their families have a central point of contact.
- The provision of more information regarding what is available in adult services. One parent suggested such information could be provided through a dedicated local authority website on transition:

> ‘It would be good if they had a website that is eligible for the layman to understand how to get, right, my child is seventeen, what’s available socially, housing-wise, benefit-wise, all in one block, all on one website. When they’re eighteen what’s available? Who do I phone? That would be bliss’.

## 6.4 Qualitative data analysis from the family survey

All parents and young people who took part in the family survey were given the opportunity to add any further comments about their experience of the transition service via an open-ended question at the end of each questionnaire. This data was inputted into SPSS and analysed by a single researcher using content analysis.

### 6.4.1 Young people

The standard version of the pre- and post-transition questionnaires for young people included a section at the end where young people were encouraged to add any further thoughts or comments about the transition service. The symbol version of the young people’s questionnaires did not have this option; however there was enough space at the end of the questionnaire for comments to be added if the young person so wished.

Six of the 54 pre-transition young people's standard questionnaires and two of the 19 pre-transition symbol questionnaires included further comments. Four of the 16 post-transition young people's standard questionnaires and one of the eight post-transition symbol questionnaires included further comments. The comments received were very similar, irrespective of whether the young person was currently using the transition service (pre-transition) or had exited the transition service (post-transition). It was not always clear whether these were young people's own views or those of the parent or professional who had written them.

Of the 13 written comments received from young people, two reported on their positive experiences of transition (one pre-transition and one post-transition young person) while the majority, 11responses, reported on the challenges they had encountered or were continuing to encounter (seven pre-transition and four post-transition young people).

***Positive responses***

Of the two positive comments written in the young people's questionnaires, one had been written by the parent of the young person and the other had been written by a senior figure within the young person's residential placement as neither young person was reportedly able to complete the questionnaire themselves.

The mother of one young person (pre-transition) explained how the transition service had ensured she was fully involved with the transition process, kept informed of all developments, and subsequently her daughter had had a smooth and relatively happy transition:

> 'My daughter's transition period started one year before my daughters 18th. I was kept up-to-date, visited at home, given contact numbers if I had any queries. I was invited to attend all meetings. I felt I was involved in every aspect. It was all in place by her 18th birthday and the changing period was less stressful and went smoothly and my daughter remained happy throughout!'

The other positive comment was written by a senior figure at a residential placement on behalf of a young person (post-transition). It was stated that the young person's transition worker 'did absolutely everything she could to ensure that [young person] got a placement to meet her needs and which her parents were happy with'.

***Negative responses***

Eleven young people (seven pre-transition and four post-transition) reported (some) negative experiences of transition. These experiences were primarily due to staff shortages, a lack of services and facilities for young disabled people, a lack of information about what services and support were available for young disabled people, and a small number of ‘other’ issues.

*Staff shortages:* Two post-transition young people from the same service area reported difficulties resulting from staff leaving the transition service and not being replaced by the appropriate agency:

> ‘ALL the support workers, that is, Transition Nurse, Connexions Officer and Social Worker have left and not been replaced’.

The written comments from one of those young people’s questionnaires explained that staff shortages had resulted in fewer visits from the transition worker than the family would have liked, and the young person 'being held by team instead of an allocated worker' which was described as 'not satisfactory and impersonal'.

A young person pre-transition in the same site also reported that staff shortages had been problematic; however this was in relation to an advocate rather than a transition worker:

> ‘I did have a transition advocate from [name of advocacy organisation] for a while but funding was removed and she lost her post’.

*Lack of services and facilities:* Two post-transition young people from two different sites reported a lack of services and facilities for young disabled people. For one of these young people the problem was a lack of age-appropriate day care services. For the other, the problem was more all-encompassing:

> ‘I would like to see more disabled adult services, particularly for autistic young people after leaving school. More day care centres, holiday play schemes, permanent services, a special needs walk-in health centre, getting more assistance and help in getting some information, emergency support, sports schemes with guidance, special needs sport centre’.

*Lack of information:* In addition to the young person who reported a lack of help in getting information (quoted above), two pre-transition young people in another site reported a lack of information about what services and support would be available to them once they left school/college.

***Other:*** One pre-transition young person reported being 'let down big time!' as s/he was in a mainstream school and was supported by a regular Connexions worker instead of a special needs transition worker. The young person felt that s/he had missed out on the specialist support that was available to peers in special needs schools. Another pre-transition young person in the same service reported that although teachers asked for her/his ideas, those ideas were then blocked by the teachers.

A teacher of a pre-transition young person in one of the coordinating services reported that the young person had still not met her transition worker after many months of waiting. This was the site which had suffered from chronic under-staffing and a backlog of transition cases which could explain the lack of support from the transition service.

### 6.4.2 Parents

The pre and post-transition questionnaires for parents each included six open-ended questions located throughout the questionnaire where parents were encouraged to tell us about their and their child's experiences of the transition service. These six questions were:

1. Concerning your son/daughter's transition, what do/did you need most help with from services?
2. How can/could the transition service help/have helped you with this?
3. Concerning their transition, what do you feel your son/daughter needs/needed most help with from services?
4. How can/could the transition service help/have helped your son/daughter with this?
5. Concerning your son/daughter's transition what, if anything, causes or caused you the most concern?
6. Please note any specific comments on the transition service or any improvements you would like to see.

The latter two questions offered most space for parents to write comments. Responses to these two questions were analysed first. Upon reading through the responses from the remaining questions it was clear that the same comments and issues were being raised time and again, thus responses to the latter two questions have been analysed and are reported here.

#### 6.4.2.1 What caused parents most concern about their child's transition?

***Pre-transition parents***

Of the 110 parents who returned pre-transition questionnaires, 75 responded to the question about what was causing them the most concern about their son or daughter's transition. The responses were as follows (note these total more than 75 as some parents reported more than one concern):

- Lack of information and uncertainty about what was happening and what was available for their son/daughter (14 responses): 'Not knowing what will happen when he is 18-19, the worry is killing me.'

- Lack of adult services/provision, including lack of housing options (14 responses).
- General worries about whether the young person would be able to cope with changes (eight responses).
- Concerns over whether their child would be accepted at the college/placement/ service of their choice (five responses).
- The fact they had had no contact with the transition service (four responses).
- Everything to do with transition (three responses).
- Concerns about whether/how their child's health would be affected by the transition (three responses).
- Lack of support from their transition worker, including an instance where the transition worker had left the service and not been replaced (three responses).
- The transition process starting late and concerns that it may be rushed (two responses).
- Concerns over funding for their child's support package (two responses).
- Five parents reported that they had no concerns at the moment.
- In addition, the following concerns were each expressed by just one parent: language barriers, the young person's safety, the residential placement coming to an end, benefits, employment prospects for the young person, the young person missing the transition process as they were not in local authority education, funding, the parents not being involved in the transition process, lack of communication between agencies, lack of understanding about the transition process, concerns that the support received by their child in their placement may not be adequate, transition workers' lack of knowledge about the needs of families with disabled young people, and concerns about their son/daughter being offered what the parents perceived to be an unsuitable service.

Many of the concerns of parents whose son/daughter was currently going through transition were also reported by parents whose son/daughter had now exited the transition service, suggesting that many of these difficulties were not fully resolved during the transition process.

***Post-transition parents***

Of the 33 parents who returned post-transition questionnaires, 28 responded to the question about what had caused them the most concern about their child's transition. The responses were as follows (note these total more than 28 as some parents reported more than one concern):

- Worries about their son or daughter's ability to cope with changes (five responses).
- Lack of information and not knowing what was available for their child (four responses).

- Lack of support (two responses) or inconsistent support (two responses) from the transition workers.
- Lack of a named transition worker (one response) and changes in transition worker (one response).
- Lack of contact with the transition service (one response).
- Finding suitable services and/or accommodation for their son/daughter (two responses).
- Lack of services and facilities for their son/daughter in adult services (one response), lack of options for their son/daughter in the community (one response), lack of choice – in relation to day-care for disabled adults (one response) or in relation to college and transport (one response).
- Late negotiation of the adult care package (one response).
- Lack of clarity over who was providing what support (one response).
- Not knowing if any parental financial contribution to the young person's support package was needed when in adult services (one response).
- The young person currently only having access to support for one day a week (one response).
- The young person not being eligible for support from adult services (one response).
- Three parents responded that they had no concerns as they were happy with the transition support received.

#### 6.4.2.2 Further comments

At the end of the questionnaires, parents were given the opportunity to add any further comments about their/their child's experience of the transition service, and to note any improvements that they would like to see to the service.

***Pre-transition parents***

Forty-six of the 110 pre-transition parents provided further comments and/or suggestions for improvements to the transition service.

***Positive experiences of transition***

Four parents commented that the transition worker(s)/team had been helpful and informative. For example, one parent wrote:

> 'We feel that the transition service has been very helpful and supportive. We have worked with the same people all the way through and have found this very beneficial to [young person] and all our family'.

***Negative experiences of transition***

Negative experiences of transition related primarily to a lack of support/contact/knowledge of the transition service, the duration of the support received from the transition service, lack of information, premature withdrawal of service, lack of provision in adult services, staff shortages, and eligibility for support from adult services.

*Lack of support/contact/knowledge of the transition service:* Four parents reported being unaware of the transition service; a further five parents reported that they had had no contact with the transition service, one of whom reported that their son/daughter had been missed by the transition service as s/he was not in the state education system; one parent reported having had little contact with the transition service thus far; and another parent reported that the family had received little transition support as the young person was in an out of area placement.

In addition, two parents reported that no transition plan was in place, while a third stated they needed more help with transition planning; another parent whose child was in mainstream school reported feeling let down that her child had not had access to a special needs transition worker; and a further parent reported a poor experience with one transition worker, but a good experience with a replacement who seemed better informed and more helpful.

*Staff shortages:* Three parents reported that the high turnover of transition workers, and the fact that transition worker and transition nurse posts were left vacant, had led to a lack of further contact with the transition service, and a fourth parent reported a lack of continuity as the parent and young person had had to get used to yet another worker.

*Duration of support from the transition service:* Two parents complained that transition planning started too early as their child was only aged 14; one of them explained her fear that the services available now may not still be available when the young person transitioned to adult services in a few years' time and thus their hopes and expectations may be dashed. In contrast, three parents reported that transition planning started too late and in some cases appeared rushed. A further parent commented that their transition support had ended too soon (when the young person started college).

*Lack of information:* Six parents expressed concern over the lack of information about what services and support were available for young disabled people in adult services, and a further parent reported a lack of information regarding what benefits they and their child would be entitled to. In addition, three parents reported a lack of information about the transition service, and about the transition process and the role of the transition worker:

> ‘It has felt like having another social worker and at times we felt we were pulling the [transition] worker along with us instead of them pointing us in the right direction. We were supported at meetings but all not entirely sure what the role is’.

*Withdrawal of services:* Four parents reported that services – predominantly health services - had been withdrawn when, or sometimes before, the young person reached transition age. One of these noted that speech and language support 'stopped before he left school.' Another commented on the difficulties involved at 16 when child health services ceased:

> ‘It's hard to believe that someone can be born with a disability and from 16-18 years they are denied services like physiotherapy, speech therapy and others. Their illnesses do not go away at 16 and come back at 18 years old’.

*Lack of provision in adult services:* Six parents were concerned about the lack of services for young disabled people in adult services, and a further parent was concerned about the lack of appropriate housing for disabled young people in the area.

*Eligibility for support from adult services:* Two parents reported that their transition worker had been pessimistic about the likelihood of their young people receiving any services from adult services owing to the strict eligibility criteria and funding issues. This had caused the parents significant worry. A further family had already been told that their young person was not eligible for support from adult services.

*Multi-agency working:* Two parents reported a serious lack of communication between services.

***Suggested improvements to the services***

Pre-transition parents’ suggestions on how to improve the transition service focused on reversing the negatives discussed above. A broader range of improvements was suggested by post transition parents (see below).

#### 6.4.2.3 Post-transition parents

Nineteen of the 33 post-transition parents provided further comments and/or suggestions for improvements to the transition service.

***Positive experiences of transition***

Two parents reported a smooth transition from child to adult services. A further parent reported a very positive experience with the transition team:

> ‘Our transitions social worker made frequent contact and visited our son at home and at school, making a good relationship with him and his family. We felt very supported. Also their work integrated health and social services seamlessly’.

However, this was reportedly followed by a complete lack of support once the young person moved into adult services.

***Negative experiences of transition***

Negative experiences of transition reported by post transition parents primarily related to staff shortages, lack of provision in adult services, and lack of information.

*Staff shortages:* Four parents reported difficulties relating to staff shortages and posts not being filled when transition workers left. This had reportedly resulted in transition support falling apart for these families.

*Lack of provision and/or support in adult services:* Eleven parents in total reported a lack of services/support and provision in adult services, including the general lack of choice available to young people, and lack of appropriate housing for disabled young people. One was 'shocked' at the difference in services and support between children’s services and adult services. Another stated:

> ‘My son is now 19 and his clubs are now saying they have to drop him. Where do we go from here? Everything is a hardship, no-one seems to know what is going on or who is doing what and parents of special needs children do not need the added stress, the only way we can get things done is by causing a stink and being forceful. When we try to contact our social workers they are always 'out on business' or doing course and rarely do they bother phoning back’.

Three parents reported their frustration at their child not having a named/allocated social worker in adult services, one of these stated that the reorganisation of adult services in the area had negatively impacted upon the young person’s transition:

> ‘Social services re-organisation has resulted in a [name] team response with no named social worker. The staff who receive communications often do not understand disability issues. … We have had to make repeated emergency requests/contacts to adult care services … to expedite matters. It turned out that the persons charged with responding to the [information] request did not know even basic details of our son's current provision by adult services. This shows that there must have been a breakdown of communication between transition and adult services. The repetition of the problem indicates this is a systemic failure’.

*Lack of information:* One parent reported a lack of awareness among children’s services and colleges about what services were out in the community and what welfare benefits were available to young people and their families. A further parent commented on how hard it was to understand what benefits were available.

***Suggested improvements to the services***

Parents' suggestions on how the transition service could be improved were generally to put measures in place to counter the negatives discussed above, for example, to increase the number of transition workers/fill vacant posts, improve the information available to families, and increase the number and range of services and support available to young disabled people in adult services.

Additional suggestions for improving the service were:

- Include carers' assessments in the transition assessment.
- Develop an intermediary support service for those young people who are not eligible for support from adult services.
- Introduce joint visits between transition workers and adult social workers.
- Eliminate the gap between child and adult health services.
- Increase communication between services.
- Increase the involvement of parents and carers.
- Increase person centred planning and be more holistic.

On the whole, these comments and the suggested improvements to the transition services reflect those made by the transition workers, managers, other practitioners, and steering group members described in Chapter 4.

## 6.5 Summary

This chapter explored what disabled young people and their parents thought about the transition service that they had received or were currently receiving, through analysis of the responses to open-ended questions in the family survey and through qualitative interviews with a small sample of six parents and three young people.

Of the 13 young people who provided further comments in the family survey, two reported positive experiences of transition, marked by involvement of the family and good communication between the family and the transition team in one case, and securing an appropriate placement in the other. Eleven young people reported some negative experiences of transition. These experiences were primarily due to staff shortages, a lack of services and facilities for disabled young people, a lack of information about what services and support were available for young disabled people, and a small number of 'other' issues, including not being allocated a special needs transition worker.

When asked in the family survey what had caused them the most concern about their child’s transition, pre-transition parents who responded to the survey reported a range of factors, the most common of which were: lack of information and uncertainty about what was happening and what was available for their son/daughter; lack of adult services/provision, including lack of housing options; concerns over whether their child would be accepted at the college/ placement/service of their choice; the fact they had had no contact with the transition service; lack of support from their transition worker, including an instance where the transition worker had left the service and not been replaced; the transition process starting late and concerns that it may be rushed; and concerns over funding for their child’s support package. Negative experiences reported in parents’ further comments also highlighted concerns about premature withdrawal of services; staff shortages; eligibility for support from adult services; and difficulties with multi-agency working, for example lack of communication between services.  However, four parents reported positive experiences of the transition services and noted the information and help they had received from transition workers.

Many of the concerns of parents whose son/daughter was currently going through transition were also reported by parents whose son/daughter had now exited the transition service, suggesting that many of these difficulties were not fully resolved during the transition process. Post-transition parents’ concerns included the following areas: lack of information and not knowing what was available for their child; lack of support or inconsistent support from the transition workers, including the lack of a named transition worker, changes in transition worker, and a total lack of contact with the transition service; finding suitable services and/or accommodation for their son/daughter; lack of services, facilities or options for their son/daughter in adult services and/or in the community; and late negotiation of the adult care package. In addition, parents’ further comments highlighted concerns about staff shortages in the transition services. Two reported a smooth transition from child to adult services and a further parent reported a very positive experience with the transition team; however, this was followed by a complete lack of support once the young person moved into adult services.

Parents’ suggestions on how the transition services could be improved were generally to put measures in place to counter the negatives discussed above, for example, to increase the number of transition workers/fill vacant posts, improve the information available to families, and increase the number and range of services and support available to disabled young people in adult services. On the whole, these comments and the suggested improvements to the transition services reflect those made by the transition workers, managers, other practitioners, and steering group members described in Chapter 4.

Follow-up qualitative interviews conducted with a small sample of parents and young people who had indicated in the questionnaires that they were satisfied with the support from the transition service, identified the following as factors that aided a good transition experience: a good personal relationship between the parent and/or young person and the transition worker; having a named transition worker as a central point of contact; the transition worker introducing the parents and young person to the adult social worker so that the family have a central contact in adult services; multi-agency planning meetings at which the young person's life and needs are looked at holistically; and full engagement and inclusion of parents. However, challenges in the transition from child to adult services were reported in relation to the lack of options around housing, employment, and social and leisure activities for young people once they have left children's services; the cessation of support from the transition service before a young person made the transition from college to adult services; the lack of a coordinated transition from child to adult health services; staff shortages and posts remaining vacant; and lack of information about adult services. Each of these points reflects the findings from the staff interviews (see Chapter 4) and from parents' comments in the family survey. Parents' recommendations for how the transition service could be improved largely mirrored those reported in the family survey, and also included the transition service working with young people up to a later age, and improving the transition from child to adult health services.

# Chapter 7 The Costs of Transition Support

## 7.1 Introduction

As Chapter 1 described, there is considerable policy interest in the transition of children to adulthood. Improving this transition links closely to the five ‘global outcomes’ first enunciated in *Every Child Matters*, in particular the fifth that aims for all children to achieve economic well-being (Department of Health and Department for Education and Skills, 2003). Much of the policy emphasis is on the move from child to adult services, and transition should encompass a wide range of processes, such as taking up further education or finding employment. Thus supporting transition should be a multi-agency affair requiring skilled workers with liaison both horizontally between children’s services and vertically with adult services. While many policy documents recognise the importance of the transition period, many also recognise the problems in the provision of services to support transition and the lack of evidence on what works, for whom and in what circumstances (Department of Health and Department for Education and Skills, 2004; Cabinet Office, 2005; CSCI, 2006). A poor transition is likely to lead to reductions in support during older adolescence and adulthood (Morris, 2002; Ko and McEnery, 2004; Fiorentino, 1998). It may also mean a higher likelihood of Not Being in Employment, Education or Training (NEET) between the ages of 16 and 18 years - a costly experience (Godfrey *et al*., 2002).

To date there has been little by way of an evidence base on which to build effective transition services (see Chapter 1) although a recent review identified many of the essential components to success (Forbes *et al*., 2002). 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. It is on this last issue that this chapter focuses, complementing the findings in other parts of this report. One recent study found efforts to estimate the costs of transition for young people with complex communication needs was seriously hampered by the lack of research evidence (Knapp *et al*., 2008). There were few existing research data on how transition was supported or on the short- or longer-term outcomes of either good or poor transitions. While the estimate provided in that paper is probably the best available to date, it was built up from a less-than-ideal evidence base. This paucity of evidence does not so much reflect the status of transition work as the poor development of economic research in services for disabled young people (Beecham *et al*., 2007) and children’s services more generally (Beecham, 2006; Beecham and Sinclair, 2007 )

The overarching aim of this part – Stage 5 – of the study was to estimate the costs of current arrangements for multi-agency assessment, transfer planning and transfer from child to adult service in the English local authority areas. This work was closely linked to other parts of this transition study and, as described below we make use of data collected in the national survey (Stage 1), the interviews with staff in the five selected sites (Stage 2), and the data collected during Stage 3, the survey of parents and families.

## 7.2 The national survey: service level costs

### 7.2.1 Methods

One of the aims for the national survey (Stage 1) was to provide broad estimates of the costs of multi-agency transition teams across the country. The first phase of the survey was to contact the Directors of Children's Services in the 150 local authorities in England to ascertain the existence of a transition service, its location and contact details. The second phase, in autumn 2007, was to send out the survey questionnaire to the named contacts (see Chapter 3).

The Stage 1 survey questionnaire included questions on the type of team, links with other agencies, funding sources, management and supervision arrangements, training, eligibility criteria and other broad indicators of the types of clients (see Chapter 3). To facilitate cost estimation a series of 'nested' questions was included which, based on the previous study of key worker arrangements (Beecham *et al*., 2007), contained an implicit hierarchy of the information required to estimate costs. Ideally full and detailed information on the service's expenditure over the past year was required alongside workload data. Expenditure accounts, however, are often difficult to obtain so to improve response rates broader information was requested. This was structured around a set of standardised cost categories likely to fit with accounting practices: salaries and on-costs for transition workers, managers and clerical/domestic staff; service costs, such as staff or user travel, office expenses; building costs (for example, power, maintenance) and rent or capital charges; overhead costs or charges to the managing agency; charges made to the scheme for input from other services; and other costs.

In case expenditure data were not forthcoming, the whole-time-equivalent staffing profile for the transition service was sought. Staffing usually absorbs the major part of total costs for this type of service, possibly as high as 80 per cent (Curtis, 2007). From these profiles salary costs could be estimated and then the costs for the other categories added using data from teams that had provided financial information and a variety of other reliable sources. Thus the 'margin of error' for the total cost calculation would not be too wide.

Of course, without knowing the services' 'output' costs data are less useful. We cannot compare the costs of, say, a 20-person team with a 3-person team, unless the data on activity levels are also reported so that the costs for a similar ‘unit’ can be calculated. Again, ideal requirements (how much time have transition workers spent with each of the families using this service?) had to be matched against the likely availability of information for a postal survey. Questions asked about numbers of families supported, typical caseloads and proportion of worker time spent on transition activities; data that would be easier to access at this service level. More detail would be sought from the services taking part in the second phase of the research (see section 7.3).

### 7.2.2 Data availability

As Chapter 2 describes, 105 local authorities responded to the initial screen (after one reminder) of which 55 stated they had a multi-agency transition service. Fifty were willing to complete the questionnaire but it emerged that some of these services were not multi-agency or were only just being developed. After several reminders, 33 multi-agency transition services provided information. Despite employing tried and tested methods in the survey instrumentation, few teams provided sufficient information to allow us to estimate costs. The following is a summary of the completion rates for the various data used in estimation of costs. Table 7.1 summarises the findings for the nine teams that included some financial data in their survey.

On the finance data:

- The few teams that could provide staff salary costs were likely to provide data that referred to staff within their organisation but less likely to know staffing or salary details for staff employed in other organisations.
- Eight teams could provide information on salaries and on-costs. Of these, two did not provide the information on managers’ costs and three did not report the costs associated with clerical staff. One team provided only the manager’s salary costs.
- Six teams provided information on revenue costs associated with the team that were not linked to salaries (for example, expenses associated with the office, travel, telephones or services to clients). Often these data were partial because some support was provided from a central resource and the associated costs were not known. One team provided *only* this non-salary information.
- No teams could provide information on expenditure for building costs (cleaning, heating and the like), and just two could provide information on overheads payable for shared functions such as the payroll office or human resources department.
- No teams could provide information on the team’s share of capital costs (rent or capital charges, furniture, equipment).

On the teams' staff profile:

- Half of the 33 teams (16) could provide full information on the staff composition in whole-time-equivalent numbers. Where the data were missing it was most commonly because the team operated as a 'virtual team' or one that used a number of non-designated workers across several teams or agencies.
- Whole-time-equivalent staff numbers for transition workers were relatively easily available for staff within the organisation of the person completing the survey, but appeared less accurate for staff 'donated' from the other partnership organisations.

On the workload measures:

- Of the nine teams providing some finance data, two could not provide information on how many young people were currently supported so it was impossible to estimate a unit cost.
- In one team for which staffing data were available, allocated non-designated workers supported individual young people but also worked with other transition workers' cases. The team provided information on their caseload, but not how much time was spent working with others' cases. This partial workload measure would lead to a highly inflated unit cost.
- Overall, six teams did not report how many young people were currently supported by the transition team (range for responders, between 10 and 2528 young people).
- Sixteen teams could provide an answer to the questions 'how many young people have a transition/key worker?' Numbers ranged from one to 500, plus one team stating that all young people in SEN schools had a transition worker and one simply stating 'all young people'.
- Six teams could not say how many young people would come into the service each year (range for responders between seven and 300, plus one team reporting 'it varies').

### 7.2.3 Findings from teams that provided financial data

Table 7.1 summarises the data for the teams who provided some cost-related information. Poor data availability for cost-related research is common for two main reasons. The first reason is the ease with which data for specific teams can be abstracted from the central accounting or recording processes. The second is that despite the frequent calls for better evidence on costs and cost-effectiveness, many organisations are hesitant to provide finance data to help generate that evidence; commercial sensitivity and confidentiality are oft-heard pleas.

There are two points worth noting on data availability. First that where finance data could be provided it was most likely to be the staff salary costs. These commonly appear in devolved cost centre accounts held by team managers. Second, the major data gaps are for building costs and overheads. These are commonly (cross-charges) set by the providing organisation. Individual teams and services are often unaware of how these charges are estimated and responding to requests for this information can come quite low on the priority list of busy personnel in finance departments. It is also worth repeating that a third of teams in the Stage 1 survey were relatively new, only having been formed in 2007. Many managers, therefore, may not have had access to their first year’s expenditure data, only to the budgets prepared for the beginning of the financial year.

### Table 7.1 Summarised data for teams that provided finance data

| | *#16* | *#32* | *#34* | *#41* | *#74* | *#106* | *#112* | *#63* | *#68* |
|---|---|---|---|---|---|---|---|---|---|
| Started | Apr ‘06 | Sept ‘05 | July ‘07 | Nov ‘06 | Sept ’07 | Sept ‘05 | Sept ‘02 | June ‘02 | Jan ‘07 |
| Type of funding | M/S | M/S | Pilot | Pilot | M/S | M/S | M/S | M/S | M/S |
| Distinct team/part of wider team | Distinct | Wider | Distinct | Distinct | Wider | Distinct | Distinct | Distinct | Distinct |
| *Finance data* | | | *Estimated* | *Estimated* | *Estimated* | | | | |
| *Transition worker salary. costs* | *£47,900* | *£225,000* | *£120,000* | *£130,000* | *£100,000* | *£238,000* | *£125,600* | *No access to data; budget £15,000 excluding staff costs.* | *£97,600* |
| *Manager salary costs* | *£34,200* | *£25,000* | *?* | *£42,000* | *?* | *£55,00* | *?* | | *£45,000* |
| *Clerical/admin* | *£6,700* | *£20,000* | *£25,000* | *£12,000* | *?* | *?* | *?* | | *£18,500* |
| *Other services* | *£13,800* | *£30,000* | *£2,000* | *£15,000* | *?* | *£30,000* | *?* | | *£1,300* |
| *Building costs* | *?* | *?* | *£500* | *?* | *?* | *?* | *?* | | *?* |
| *(Charge for) overheads* | *£9,000* | *?* | | *?* | *?* | *?* | *£20,000* | | *?* |
| *Special grants* | *Yes* | *Yes: 3fte* | | *No* | *?* | *Yes* | *No* | | *?* |
| Staffing wte (workers + manager) | ? + ? | 11 + 0.15 | 4.5 + 0.5 | ? + ? | 3 + 0 | 10 + 1.0 | 5.0 + 0.5 | ? + 0.6 | 6 + 1.0 |
| Currently supported | 64 | 160 | *No data: too soon after set-up* | 2,528 | 32 | ? | 200 | 135 | 86 active |
| Supports one-to-one | ? | No | | No | Yes | ? | Yes | Yes | Yes |
| No. with transition worker | 64 | ? | | ? | ? | ? | 200 | 125 | 86 active |
| New cases per year | 72 | 40 | | 300 | 10 | ? | 30-40 | 20 | 110 |
| Cases per wte transition worker | 20 | ? | | ? | 10 | ? | 30-40 | 40 | 20 |

Notes: ? indicates that no data was provided in the survey or accompanying information

### 7.2.4 Cost estimates for less-than-ideal data

In previous service-level cost estimations it has been possible to use findings from teams or services that provided full data to estimate costs for those that provided only partial data; perhaps using the ratio of overheads to staffing costs, or absolute levels of non-staff costs per staff member (see, for example, Beecham *et al*., 2002; Beecham *et al*., 2007). However, from this survey we found that none of the teams provided all the data required for such extrapolations.

Broader estimates have therefore been made, drawing together information on whole-time-equivalent (wte) staffing levels from the survey, and average salary and on-costs for different groups of staff. These allow us to estimate the likely *staffing* costs for 16 multi-disciplinary transition teams.

Twelve of these teams also provided data on the current caseload allowing us to estimate a (partial) cost per case. On many service-level indicators, these 12 teams were similar to those for whom it was not possible to estimate a staffing cost per case. Of course, these are small numbers to test; moving just one team from one sub-group to another could make a considerable difference. Given this caveat, similar proportions were found for whether the team had transition protocols (all but two teams had these, see Chapter 3), whether the team had a service level agreement, whether young people had one person as a transition worker, whether the team had designated transition/key workers, whether there was a designated person in the adult services to take over, whether the team had a co-ordinator, the caseload per whole time equivalent worker, and the number of young people coming into the service. The number of young people currently supported was not significantly different between the ‘cost’ and ‘no cost’ samples (t-test), although the latter group had an average of 90 more cases, probably driven by one team recording a very high caseload.

There were some differences. Teams in the ‘cost sample’ were more likely to be distinct teams (58 per cent v. 33 per cent) and more likely to be a pilot scheme (25 per cent v. 14 per cent) and less likely to have transition workers who were part of a wider team (58 per cent v. 76 per cent). The 12 teams with costs were also more likely to have had an evaluation of the service (50 per cent v. 29 per cent) and slightly more likely to have a single lead agency (100 per cent v. 86 per cent) although all but three teams reported they had one.

Sixteen survey respondents provided sufficient data on the whole-time-equivalent composition of their teams, their professions and employing organisations (see Table 7.2). Among these teams, there were between two and 11 staff members, and just five had a full-time manager. Four teams did not separately identify the time the manager spent on the transition team, but we cannot tell whether this was because the post was already included in the staffing count, or whether the team did not have a manager. On average transition teams had 6.5 staff including the team manager.

Salary and on-costs were estimated by selecting the most likely profession of worker for each employing organisation and their average salary costs (see Table A7.1 in the Appendix to this chapter). Using these data, total annual staff costs for the 16 teams could be estimated. Total costs varied four-fold – from £83,000 to £365,000 around a mean of £219,000. The median is fairly close at £197,800 per annum.

The most commonly available workload measure for this sample was in answer to the question ‘How many young people are currently being supported by the transition service?’ Thirteen of the teams provided this service output measure. Caseloads vary considerably (Table 7.2); from 32 to 500 around a mean of 170 young people. Only four of these teams reported that they *did not* provide one-to-one work with the young people.

**Table 7.2 Staffing costs, by team and by current cases**

| *Team ID* | *WTE: staff + manager* | *Staff/manager cost pa, 2006-07* | *No. cases currently supported* | *Cost per case pa currently supported* |
|---|---:|---:|---:|---:|
| 14 | 8.0 + 1.0 | £304,510 | 190 | £1,600 |
| 15 | 3.3 + 0.4 | £123,530 | 100 | £1,240 |
| 32 | 11.0 + 0.15 | £358,440 | 160 | £2,240 |
| 34 | 4.5 + 0.5 | £165,460 | n/a | |
| 37 | 6.0 + 0.0 | £200,240 | 220 | £910 |
| 56 | 5.0 + 0.0 | £195,230 | 130 | £1,500 |
| 68 | 6.0 + 1.0 | £237,440 | 86 | £2,760 |
| 71 | 2.0 + 0.4 | £82,720 | 67 | £1,230 |
| 74 | 3.0 + 0.0 | £102,130 | 32 | £3,190 |
| 90 | 8.0 + 1.0 | £304,070 | n/a | |
| 91 | 10.0 + 0.0 | £326,560 | 500 | £650 |
| 99 | 10.0 + 0.05 | £301,940 | n/a | |
| 106 | 10.0 + 1.0 | £365,180 | n/a | |
| 107 | 2.0 + 1.0 | £108,330 | 220 | £490 |
| 112 | 5.0 + 0.5 | £178,270 | 200 | £890 |
| 126 | 4.0 + 0.5 | £151,380 | 140 | £1,080 |
| *Mean (sd)* | *6.6 (3.0)* | *£219,100 (95833)* | *170 (120)* | *£1,483 (841)* |

The final column in Table 7.2 shows the estimated cost per case (total staff costs divided by the current caseload). Again we see considerable variation; from £910 to just over £3,000. The mean cost per case is £1,480 (sd = 840). These are annual (staffing) costs of course, and contain an implicit assumption that the ‘case’ would remain with the team over a whole year.

It is important to remember that the costs shown in Table 7.2 are not the full costs of providing a transition support service. They cover only transition workers' and managers' salary costs. They exclude the costs of clerical and administrative support, office-related costs, other staff costs such as travel, client-related service costs, building costs, and overheads payable to the managing organisation for section- or department-wide functions. From the few finance data provided by the survey participants (Table 7.1) we found that clerical/ administration costs could add between nine per cent and 21 per cent of transition worker salary costs and 'other service costs' could amount to between one per cent and 28 per cent. Overheads payable to the managing agency are likely to be at least a further 15 per cent (Curtis, 2008) but probably far higher.

Data for child and adolescent mental health teams provide some comparison. Direct costs (travel, training, equipment) are equivalent to at least ten per cent of salary costs; managers and administrative staff add a further ten per cent; and capital overheads (land and building) account for an additional six per cent (Curtis, 2007). Using these figures for the transition teams, the mean staffing cost per case (£1,480) would rise to £1,865, again on the assumption that the young person was supported for the whole year.

## 7.3 The five transition services: service level costs

### 7.3.1 Introduction

In this section the costs of transition teams in the five study areas are estimated, providing additional and more detailed data than available through the national survey. Data from the staff interviews are used and also enabled us to assess unit costs per working hour and a 'weighted' cost per hour.

In section 7.4, these data are used to calculate the costs of transition support families have received in the three months prior to completing the questionnaire. What use do young people make of the transition services? What are the costs? Health, education and social care professionals respond to the varying and individual needs of their clients and therefore we should expect their support and the costs of that support to vary. A further task is to explore the costs data for associations with the young people's and families' characteristics, needs and outcomes.

In this section we also report the other services young people used – alongside transition support for those who had not moved to adult services, and the 'post-transition' service use and costs for those who were now supported by adult services. The costs are calculated for these support packages and findings described and the costs data subject to a similar cost variation analysis.

For the five teams that form the focus of this cost estimation work there were two main data sources; the returns from the national survey and the Stage 2 interviews (see Chapter 4). Importantly these data allow us to describe the make-up of the team in terms of staffing, including the reports from each member of staff about amount of time they spend on activities related to transition (percent of whole time equivalent). However, the challenges around releasing finance data that dogged the national survey also caused problems here; for only three of the teams could we obtain any site-specific expenditure information and this was, at best, partial. Those teams that provided data could commonly only supply salary-related information for the staff directly managed by the agency from which the respondent came. We have, therefore, been guided by these data but have used nationally applicable costs for staff members. This means that each member of staff in all the teams has been included using the same cost- or work-related assumptions. The costs include salary, salary on-costs, direct and indirect and overheads, and the annuitised cost of any buildings and equipment; that is, the costs of all items required to provide the service as described. All costs are reported in 2007-08 prices.

The staff interviews provided two further sets of data relating to unit costs. First some workers reported what proportion of their time was spent on each of eight activities likely to make up their workload; direct and telephone contact with young people and families, meetings with and about young people and families, assessment and report writing, liaising with other agencies, travel, other meetings, and other administration. These data allow us to derive a *weighted* unit cost, in particular a unit cost for face-to-face contact that would be required when considering the costs of providing transition support for young people (see section 7.4). Second, we were able to estimate costs for linked *events* such as the transition steering groups and some of the sub-groups that operate in each area to monitor the work of the transition teams, co-ordinate the multiple agencies involved and identify the young people to be supported (see section 4.6.1 and 4.6.2). The interviewees in each area were able to give a good picture of how often these meetings were held and how long they lasted and who attended them. Hourly unit costs could then be attached to these inputs. Details of the methods employed can be found in the Appendix to this chapter.

### 7.3.2 The costs of five transition teams

***Service A***

Service A was set up in 2002 as a response to Valuing People and given added momentum by adult services’ concerns that without information about the young people moving out of children’s services, they could not plan to support the young people in adulthood (see section 4.1.1). The service covers a large rural country and is based in the Connexions service. Service A is supported by a multi-agency Steering Group that meets four times a year.

**Table 7.3 Service A: costs per annum (2007-08 prices)**

| *Staff member* | *wte on transition* | *£ p.a* |
|---|---|---|
| Transition team manager | 0.4 wte | £22,300 |
| Transition co-ordinators | 4.3 wte | £158,800 |
| **Other supervision and support** | | |
| LA team managers | 90 hours pa | £3,150 |
| LA area managers | 205 hours pa | £8,830 |
| ***Total*** | | ***£193,080*** |
| *Additional costs for Transition Groups* | *Total hours p.a* | *£ p.a.* |
| **Steering Group (meets quarterly)** | | |
| Team managers | 94 | £3,380 |
| Service managers | 172 | £6,360 |
| Area managers | 46 | £1,980 |
| ***Total*** | | ***£1,1720*** |
| **TOTAL COST** | | **£204,800** |

The four transition workers reported a similar proportional split for how they spent their time on the eight categories of tasks identified for this research. On average, around 15 per cent of their time was spent on direct contact with young people and families, 22 per cent was spent in telephone contact with them and another 15 per cent in meetings at which the young people and families attended. Liaison (12 per cent) and report-writing or assessments (15 per cent) also absorbed considerable amounts of time. Despite the fact that this was a rural county, travel absorbed only eight per cent of their time on average, and other meetings (five per cent) and other administrative tasks (eight per cent) took similarly small proportions of their time.

Using these data from the staff interviews, the cost per working hour (total cost/ transition staff hours) can be calculated at £29.40 for the team and £31.20 if the cost of the Steering Group is included. The national survey return from Service A reports a caseload of 200 young people and families giving average costs per young person per annum of £965 and £1,025 with the Steering Group included.

### *Service B*

Service B is based in a small unitary authority in which the transition service was launched in June 2005 (see section 4.1.2). The co-ordinator works closely with other personnel in social services, health and education (including special schools) to ensure a smooth transition for disabled young people who have complex needs. A local voluntary sector organisation undertakes personal care planning and is in regular contact with the transition co-ordinator.

This transition service has a complex ‘cost picture’ involving many people and agencies. The cost estimates include only the co-ordinator and the interviewees reporting having close contact with her. We also report the costs of the Steering Group and the three main Transition Sub-groups (see section 4.6.2) as these were essential to ensuring all young people requiring additional transition support were identified and appropriately supported. Thus, although much of the work *planning* transition support has been included, the cost of transition *support* has probably not been included.

## Table 7.4 Service B: costs per annum (2007-08 prices)

| *Staff member* | *wte on transition* | *£ p.a* |
|---|---|---|
| Transition co-ordinator | 1.0 | £43,540 |
| Transition co-ordinator supervision | 0.02 | £980 |
| **Some of the 'Virtual' team members** | | |
| Social workers in children's team | 0.35 | £15,240 |
| Practice manager in children's team | 0.05 | £2,680 |
| Social workers in adult team | 0.28 | £12,190 |
| Connexions advisor | 0.03 | £1,670 |
| Adult operational director | 0.05 | £3,280 |
| Divisional manager | <0.01 | £570 |
| ***Total*** | | ***£80,150*** |
| *Additional costs for Transition Groups* | *Total hours p.a* | *£ p.a.* |
| **Strategic Management Group (meets monthly)** | | |
| Managers: Children's Services | 99 | £3,480 |
| Managers: Adult Services | 77 | £3,530 |
| Managers: Education/Training | 22[1] | £1,040 |
| Area managers: Connexions | 22[1] | £810 |
| Managers: Health | 88[2] | £3,940 |
| | | *£13,160* |
| **Transition sub-groups[3]**<br>**(2 meet monthly, 1 meets each term)** | | |
| Child services managers | 143.5 | £5,310 |
| Adult services managers | 116 | £4,290 |
| Health services managers | 215.5 | £7,975 |
| Education services managers | 235 | £915 |
| Connexions | 22 | £815 |
| Voluntary organisations' personnel | 44 | £1,055 |
| | | *£20,360* |
| ***Total*** | | ***£33,520*** |
| **TOTAL COST** | | **£113,670** |

Notes: 1. No information from staff interview
2. One of two interviewed
3. Sixteen of 26 members interviewed

The transition co-ordinator spent 40 per cent of her time on direct contact with young people and their families and ten per cent on assessments and reports. Her remaining time was spent on liaising with people from her own and other agencies (20 per cent), travel (ten per cent) and other meetings (20 per cent). Just one social worker, from adult services, reported time use: two-thirds was spent on contact with young people in face-to-face meetings, telephone conversations and meetings with the young people present.

These data from the staff interviews allowed us to calculate the cost per working hour (total cost/transition staff hours) at £21.70 for the team and £25.30 if the cost of the Strategic Management Group is included. The national survey return for Service B reports the team are supporting 203 young people of whom 79 have complex needs and 124 have moderate learning disabilities. The average annual costs per young person are £395 and £460 if the Strategic Management Group is included.

***Service C***

Re-launched in June 2007, the service was fully staffed for the first time just before the research interviews were undertaken (see section 4.1.3). As with Service B, it has no case-holding responsibilities or budget but works to co-ordinate transition for young people with very complex needs. The service manager reported total salaries (plus on-costs) for 2008-09 of between £159,087 and £168,304 per annum for the range payable for the grades of workers.

**Table 7.5 Service C: costs per annum (2007-08 prices)**

| *Staff member* | *wte on transition* | *£ p.a* |
|---|---:|---:|
| Team manager/business support[1] | 2.0 | £77,220 |
| Social worker/social work assistant | 1.5 | £74,580 |
| Other support and supervision (not included above) | <0.1 | £5,550 |
| ***Total*** | | ***£157,350*** |
| *Additional costs for Steering Group* | *Total hours p.a* | *£ p.a.* |
| **Steering Group** | | |
| Managers: Children's Services | 56 | £2,570 |
| Managers: Adult Services | 42 | £1,890 |
| Managers: Health | 32 | £1,740 |
| Managers: Education/Training | 60 | £2,760 |
| ***Total*** | | ***£8,960*** |
| **TOTAL COST** | | **£166,310** |

Notes: 1. Not interviewed

Much of the team's activities were still focused on the backlog of cases. On average, direct work with young people and families absorbed only seven per cent of their time, and telephone calls with the family only slightly more (ten per cent). Time spent in meetings with the family was around 12 per cent. Two social work staff worked quite intensively with eight or nine cases. Liaison with other agencies and meetings each took up nearly a quarter of their working time (22 per cent and 23 per cent).

Using these data from the staff interviews the cost per working hour (total cost/transition staff hours), assuming the team manager spent half her time managing the team, was calculated at £51.60 for the team and £54.50 if the cost of the Steering Group is included. The national survey return for Service C reports the team supports 184 young people, giving average costs per young person per annum of £855 and £904 respectively.

***Service D***

The transition team at Site D is located in the education department within an integrated disabled children's service (section 4.1.4). The team was set up in November 2007 and the research interviews were undertaken in October 2008. There had been problems getting staff in place and many interviewees were involved in statutory duties as well and felt they had only just got to the point where transition work could begin. As with all five services, the costs are based on the proportion of time each member of staff reported spending on transition, including the linked staff from the adult team.

**Table 7.6 Service D: costs per annum (2007-08 prices)**

| *Staff member* | | *wte on transition* | *£ p.a* |
|---|---|---|---|
| **Children's services** | | | |
| Manager transition team/administrator | | 0.50 | £20,810 |
| Social workers/key workers | | 0.75 | £31,460 |
| Nurse (cyp)/Trainee psychologist | | 0.70[1] | £32,070 |
| Connexions TPAs | | 1.00[2] | £36,930 |
| **Adult services** | | | |
| Manager adult team | | 0.60 | £32,190 |
| Social worker (adult) | | 0.80 | £34,830 |
| Senior practitioner (adult social work) | | 0.75 | £40,240 |
| Nurse (adult) | | 0.80 | £35,940 |
| Supervision (various managers, not included above) | | 0.08 | £4,870 |
| ***Total*** | | | ***£269,340*** |
| *Additional costs for Groups* | *Total no. meetings* | *Total hours p.a* | *£ p.a.* |
| **Steering Group and sub-groups** | | | |
| Managers: Children's Services | 6 | 33 | £1,550 |
| Managers: Adult Services | 4 | 14 | £660 |
| Managers: Education/Training | 6 | 12 | £520 |
| Services Managers: LA | 12 | 42 | £830 |
| Connexions | 9 | 22.5 | £1,550 |
| ***Total*** | | | ***£5110*** |
| **TOTAL COST** | | | **£274,450** |

Notes: 1. No information from staff interview.
2. One of two interviewed but no information on time spent

Eight team members provided information on the proportion of time undertaking specific tasks towards the young person's transition. On average they spent around 12 per cent of their time on face-to-face contact and 17 per cent on telephone contact with the young people and families. Assessments and writing reports absorbed more than a quarter of their time (28 per cent). Meetings with the young people and families or other staff took 11 per cent and liaison away from meetings took 12 per cent. Travel (12 per cent) and general administration (ten per cent) were the other activities listed.

Using this information from the staff interviews, the cost per working hour (total cost/ transition staff hours), assuming the team manager spent all her time managing the team, is £36.80 for the team and £37.50 if the cost of the Steering Group is included. The national survey return for Service B reports that the team were supporting 76 young people, giving average costs per young person per annum of £3,544 and £3,610 if the Steering group is included. Because inputs from the adult team have been included these costs are likely to include support for some young people post-transition to adult services.

***Service E***

The research focussed on the transition team serving the western area of the county (section 4.1.5). It comprises a core team (two vacant posts) and a wider team of people who worked on transition in addition to their usual roles.

Various multi-agency groups supported the transition service including a county-wide steering group, cohort meetings to identify young people, practitioner meetings to discuss individual cases and panel meetings that provide a link between children and adult services. Only the cost of the steering group (meeting three times a year during the research period) has been included as membership of the other groups varies depending on the cases being discussed.

The transition service supported around 60 open cases. The social worker had a transition caseload of 22 and spent 20 per cent of her time on direct contact with young people and families, five per cent on telephone contact, 18 per cent on meetings involving young people and their families, and a further 43 per cent of her time writing reports and assessments. Liaison (five per cent), other meetings (two per cent), other administration tasks (two per cent), travel (five per cent) and training (two per cent) absorbed the remainder of the three days per week she spends on transition. The senior practitioner spends less time in direct or telephone contact (15 per cent) and half of her time in writing reports/assessment (25 per cent) or liaison and meetings with young people and families (25 per cent). Other meetings (ten per cent) and administrative tasks (ten per cent) and travel (15 per cent) absorbed the remainder.

Using these data from the staff interviews, the cost per working hour (total cost/ transition staff hours), assuming the team manager spent all her time managing the team, was calculated at £41.70 for the team and £42.40 including the cost of the Steering Group. The national survey return from Service E reports that the team were supporting 57 young people, giving average costs per young person per annum of £3,410 and £3,460 if the Steering Group is included. Inclusion of the wider team means the costs include a wide range of supports, not just social care.

### Table 7.7 Service E: costs per annum (2007-08 prices)

| *Staff member* | *wte on transition* | *£ p.a* |
|---|---:|---:|
| **Core team** | | |
| Manager/business support | 1.50 | £51,450 |
| Senior practitioner/Social worker | 1.60 | £79,780 |
| **Wider team** | | |
| Head integrated services (total transition & supv.) | 0.25 | £16,410 |
| Connexions personal advisor | 1.00 | £36,930 |
| Leaving care worker, Adults' social worker, and special education needs officer | 0.20 | £8,380 |
| **Additional supervision** | | |
| Area manager | 28 hours | £1,320 |
| ***Total*** | | ***£194,270*** |
| *Additional costs for Groups* | *Total hours p.a* | *£ p.a.* |
| **Steering Group** (meets 3x year) | | |
| Connexions senior | 11 | £410 |
| CAMHS LD lead | 4 | £260 |
| Area manager adult social work | 11 | £470 |
| LA Lead professionals/coordinators/etc. | 49 | £1820 |
| ***Total*** | | ***£2960*** |
| **TOTAL COST** | | **£197,230** |

Table 7.8 summarises the cost estimations for each of the five services participating in Stage 3 of the study.

### Table 7.8 Summary of the costs for the five study transition services

| *Service* | *Mean cost per working hour* | | *Mean cost per case per year* | |
|---|---|---|---|---|
| | *For team* | *Incl. Steering Group* | *For team* | *Incl. Steering Group* |
| A | £29.40 | £31.20 | £965 | £1,025 |
| B | £21.70 | £25.30 | £395 | £460 |
| C | £51.60 | £54.50 | £855 | £905 |
| D | £36.80 | £37.50 | £3,545 | £3,610 |
| E | £41.70 | £42.40 | £3,410 | £3,460 |
| Average[1] | £36.20 | £38.20 | £1,830 | £1,890 |

Notes: 1. Unweighted average, calculated using the data in the rows above

## 7.4 Supporting young people and their families: user level costs

### 7.4.1 Methods

This section describes the level of support that the five transition services provided for the families participating in the Family Survey (Stage 3) and the costs associated with that support. The unit costs for the transition teams have been described in the previous section. Rather than estimating an average annual cost per family supported by the transition team, here our interest is in the different amounts of transition worker support the young people and families receive, and the costs associated with that level of contact. To assess the level of support and the associated costs, four specific questions were included in the family survey questionnaire:

- How often have you seen your transition worker in the past three months?
- Typically, how long do these visits last?
- How often have you spoken to your transition worker on the telephone in the past three months?
- Typically how long do these contacts last?

These questions were only asked for those young people who were still supported by the transition teams. The Family Survey data show how long the transition workers spent in contact (face-to-face or by telephone) with each young person and family, but obviously parents will not be aware of the time spent travelling to the family's house, writing reports and case notes afterwards, or liaising with other professionals on their behalf, etc. Thus we have 'weighted' the unit cost to include the activities that transition workers undertake using their descriptions of the proportion of time spent on them (see section 7.3). This gives a better estimate of the costs of *delivering* the transition service to families, rather than just solely the costs associated with the support the family reports *receiving*. Table 7.9 summarises these hourly costs.

**Table 7.9 The 'weighted' unit cost for contact time by service**

| *Service* | *Cost per working hour, incl. Steering Group* | *Av. % time spent on direct and telephone contact, and in meetings with family* | *Weighted cost: per contact hour* |
|---|---|---|---|
| A | £31.20 | 52% | £60.00[1] |
| B | £25.30 | 53% | £47.75 |
| C | £54.50 | 29% | £169.15 |
| D | £37.50 | 40% | £93.75 |
| E | £42.40 | 35% | £121.15 |
| *Average[1]* | *£38.20* | *42%* | *£98.35* |

Notes: 1. Calculated as ((31.20/52)*48)+31.20=60.00

The other health, social care and education services used by the young people participating in Stage 3 are also described and their costs estimated (section 7.4.3). Again the data come from Stage 3 of the study, the Family Survey in which respondents were asked to complete a reduced version of the *Client Service Receipt Inventory* that would allow parents to record the young person's service use over the previous three months[3] in a manner commensurate with cost estimation (Beecham and Knapp, 2002).

For these services, unit costs were taken from an established annual compendium (Curtis, 2008) or estimated using a comparable methodology that reflected long-run marginal opportunity costs (see the Appendix to this chapter for details). The frequency and duration with which each young person used each service use was then multiplied by the unit cost for that service. These costs were then summed to arrive at total cost of the support package for each young person.

### 7.4.2 The costs of providing transition support to families

***Transition families***

Data were collected from 110 families who were still receiving support from the transition services.[4] Seventy-one of these families reporting having a single transition worker: 34 supported by Service A, seven supported by Service B, 15 supported by Service C, nine supported by Service D and six supported by Service E. Twenty-seven families weren't sure and nine didn't know. As with the post-transition families (see below) the person supporting them was most likely to be a transition worker (19 families), a social worker (22 families) or a Connexions worker (24 families). Sixty-two families reported the length of time they had been in contact with the transition worker, ranging from one to 73 months, although 33 of the families had been in contact for between six and 24 months.

Forty families reported seeing the transition worker in the last three months, most commonly just once or twice (37 families). Visits lasted between ten minutes and five hours with two peaks at 30 minutes (17 families) and 60 minutes (27 families). Twenty-two of the 67 families answering the question 'would you like to see this person more/less often?' said they would, but most (66 per cent) said that this level of contact was about right. Just one person wanted to see the transition team member less often.

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[3] This retrospective period was chosen as a good compromise between getting a clear picture of the variations in service use across a range of provider organisations and families, and the reduction in accuracy that comes if respondents are asked to cast their minds too far back.

[4] See also 5.1.5. These data are repeated here as they form the basis of the estimated cost of transition worker support received by the families. The costs are focussed on a sub-sample of all those responding to the Family Survey.

Families were also asked how often they had spoken to their worker on the telephone in the last three months. Forty families had done so, commonly just once or twice (30 families) but one family had ten telephone contacts. In the main, the calls lasted between five and 20 minutes (34 families). For 73 per cent of the families, this level of contact was about right with 16 people wanting more telephone contact and one person wanting less.

If the family had a single person to support them through transition, the questionnaire asks parents to record how often they had seen someone to help with transition over the past three months and typically how long the visits lasted. Similar questions were asked about telephone calls. For each family, these data of *use* of the transition service were converted to costs using the weighted unit cost per hour for each site (Table 7.9).[5]

Table 7.10 shows the costs per site for contacts and telephone calls together; overall, telephone calls comprised 14.6 per cent of the total cost. Our use of the weighted unit cost means the time taken by (the costs of) other activities associated with that person's transition (assessments, liaison, and so on) have been included *pro rata* for the level of contact. In four of the five sites, the standard deviation is lower than the mean figure, implying a skewed cost distribution. A median value that is lower than the mean suggests this skew is due to one or two relatively high values. The data in the final column for Site C, for example, show very wide range of values.

**Table 7.10 Cost of contact and telephone calls with the transition workers over three months**

| Service (n) | Mean cost (sd) | Median cost | Range (min-max) |
|---|---:|---:|---:|
| A (32 families) | £72.88 (71.56) | £58.00 | £0 - £300.00 |
| B (7 families) | £126.20 (101.75) | £95.50 | £15.92 - £286.50 |
| C (11 families) | £511.04 (654.33) | £296.01 | £0 - £1877.56 |
| D (9 families) | £127.61 (100.30) | £93.75 | £0 - £304.69 |
| E (5 families) | £218.07 (65.66) | £181.73 | £151.44 - £302.88 |
| *All sites (64 families)* | *£173.05 (314.27)* | *£87.29* | *£0 - £1877.56* |

In total just 64 families in all sites provided all the data required for these cost calculations; that is they responded to the postal questionnaire, had a single person to support them through transition, and answered the relevant questions. Even when data from all the sites are viewed as one sample, there remains a significant positive skew (see Figure 7.1). In fact, the mean cost of transition support for this sample of

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[5] Where a figure for the duration of the contact or telephone call was given but not for the frequency just we assumed one contact or call had been made over the previous three months (ten families). Where the frequency of contacts/calls was given but not the duration, the mean duration for that site was used (nine families). Where either contacts or telephone calls have been recorded but the other is missing we have assumed this to be zero (no cost).

64 families is £173, again with a large standard deviation (£314; see Figure 7.1). The median is lower at £87.30. The histogram bars hide some of the variation:

- Five families had not seen their transition worker nor spoken to them on the telephone. Their cost for the transition support over the three months prior to completing the research questionnaire is £0.
- Transition support costs for 16 families were less than £49.
- Transition support costs for 16 families were between £50 and £100.
- Transition support costs for 12 families were between £120 and £199.
- Transition support costs for 12 families were between £100 and £370.
- Just a few families received much higher (cost) levels of support – three families received support levels costing more than £500 in the three months prior to interview.

**Figure 7.1 Costs of transition contact and telephone calls (64 cases)**

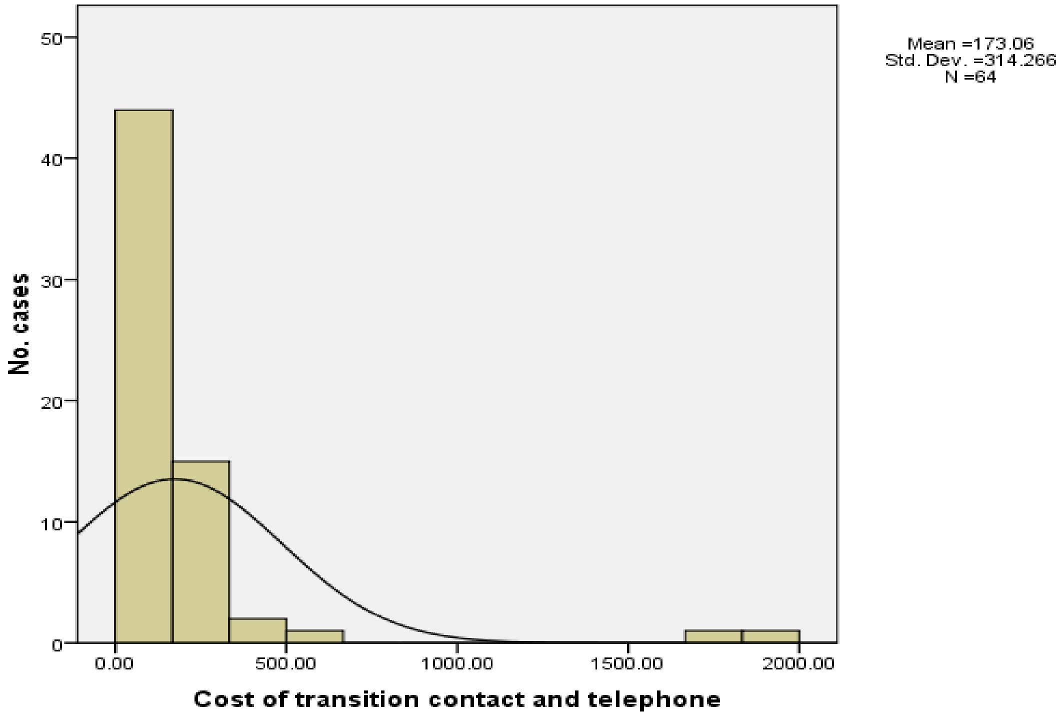
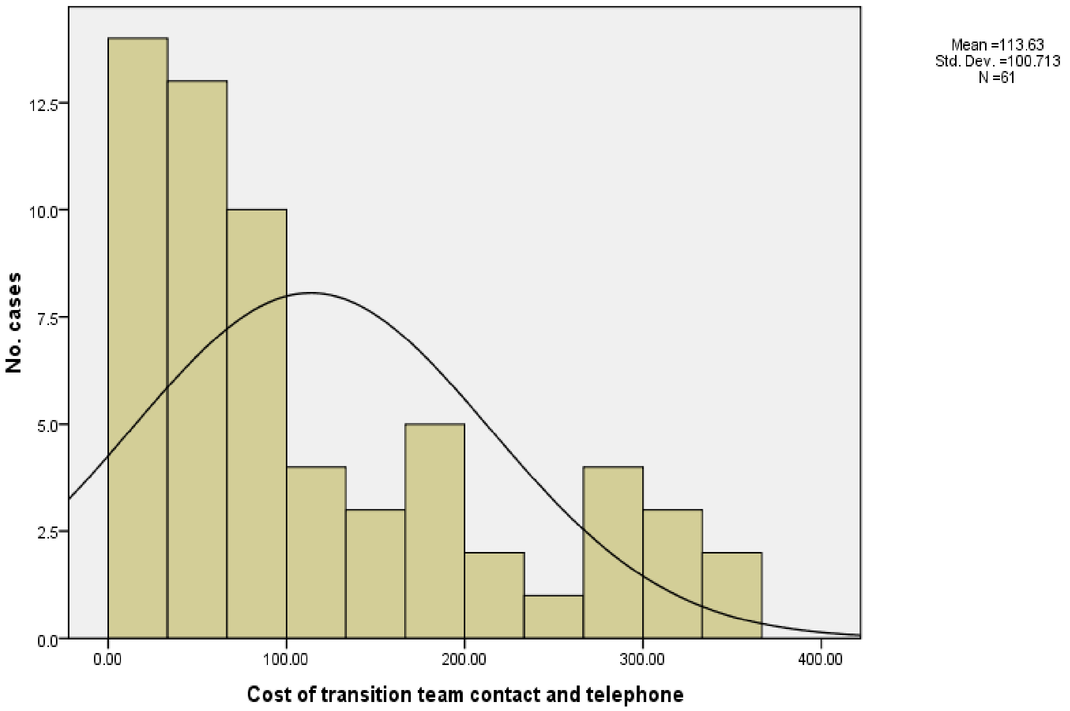


Figure 7.2 shows the distribution if these three highest cost cases are removed. Each was of the three families was supported by Service C (which had the highest weighted cost per hour) and either had a relatively high number of visits or relatively longer visits. One family had been with the service for six months and one for 24 months. The third family did not answer this question.

**Figure 7.2 Costs of transition contact and telephone calls (61 cases)**



Unsurprisingly the mean cost has dropped considerably for this smaller sample; £113.60 over the three months, or just under £10 per week. Compared to the full sample of 64 young people and families the median is also lower at £84.60 and is now much closer to the mean, but both distributions remain significantly different from normal (p<0.000).

### *Cost variations*

We explored the data to assess whether these variations in the costs of contact and calls with the transition team were associated with some key characteristics, outcomes and service-related variables (see also section 5.3). Some of these potential explanatory variables were linked to the young person: age, gender, whether they had an autistic spectrum disorder, their mean difficulties score, the number of unmet needs for support, and whether the family had a copy of the transition plan. Others described the parents and family: the impact of the transition service on their stress levels; whether the family income came mainly from paid employment; their unmet needs, their satisfaction with the transition service, and the parents' mean MPOC rating.

There were no significant associations between any of these variables and the costs of contact and telephone calls with the transition team for either the full sample of 64 young people or the smaller sample without the three highest cost young people.

***Post-transition families***

The costs of support from the transition teams could not be estimated for this group as they were not asked about the intensity of their contact. Transition may have occurred some time ago so recall accuracy was likely to be poor; the average age of the young people was 19.5 (range 18-22 years) and on average transition support had started 3-4 years earlier at 15.75 years old (range 13-19 years).

Twenty of the families reported they had received transition support for between one month and five years (see also Section 5.2.5). Half of the families reported periods of between six months and two years. Twenty-eight had a single transition worker to support them through transition: seven families in Service A and in Service D, three families in Service B, two families in Service C, and nine families in Service E. The families reported this to be either a transition worker (nine families, five of whom were supported by Service A) or a social worker (nine families, six of whom were supported by Service E) and for seven families it was a Connexions worker (five of whom were supported by Service D). A key-worker, a nurse and a specialist careers advisor each supported one family.

Nine families said they would have liked to have seen this worker more often and 16 felt the level of contact was about right; two-thirds of the families were satisfied with the support they received (30 answering this question). When asked separately about transition in health services, 14 out of 23 families felt the transition from child to adult health had been managed ‘well’ or ‘OK’, and the figures were 16 (26 families answered) and 18 (24 families answered) for social care and education respectively.

### 7.4.3 The costs of supporting young people during and after transition

Responses to the questions from the *Client Service Receipt Inventory* in the Family Survey have allowed us to look at the range of services used by young people in the study (see also section 5.1.5). We included a list of discrete services (see Table 7.11) as well as open questions for parents to complete with details about use of non-listed services, perhaps local or innovative services.

A wide range of services was used by the two samples in the study in the three months prior to completing the questionnaire (Table 7.11). Generally, use of the general practitioner (GP) is quite high with more than half of both groups having seen their GP in the last three months. The proportion of young people seeing a hospital doctor (outpatient clinic) is just under half for the pre-transition group and just over a third for the post-transition group, similar figures to those for the Connexions personal advisors. Both adult and child social workers are listed for both groups with about 45 per cent of each sample having been in touch with a social worker in the previous three months.

**Table 7.11 Use of services and service costs for the three months prior to completing the questionnaire**

| *Service* | *Pre-transition sample (N=105)* | | *Post-transition sample (N=23)* | |
|---|---|---|---|---|
| | *% using (N)* | *Mean cost (range) per person* | *% using (N)* | *Mean cost (range) per person* |
| *Primary care* | | | | |
| GP | 55% (58) | £37 (£0 - £288) | 52% (12) | £33 (£0-£216) |
| Other primary care[1] | 0% | £0 | 13% (3) | £3 (£0-£54) |
| *Hospital* | | | | |
| Hospital doctor | 48% (50) | £135 (£0 - £815) | 39% (9) | £92 (£0 - £652) |
| A&E | 10% (10) | £13 (£0 - £222) | 9% (2) | £19 (£0 - £333) |
| Inpatient stays | 7% (7) | £24 (£0 - £498) | 4% (1) | £76 (£0 - £1,743) |
| *Mental health* | | | | |
| Psychologist | 12% (13) | £18 (£0 - £720) | 0% | £0 |
| Psychiatrist | 6% (6) | £14 (£0 - £239) | 0% | £0 |
| *Community health* | | | | |
| Community nurse | 10% (10) | £18 (£0 - £138) | 26% (6) | £10 (£0 - £69) |
| Community paediatrician | 10% (10) | £14 (£0 - £246) | 13% (3) | £16 (£0 - £123) |
| Physiotherapist | 22% (23) | £135 (£0 - £3,600) | 22% (5) | £55 (£0 - £720) |
| Speech & lang. therapist | 38% (40) | £156 (£0 - £2,310) | 22% (5) | £47 (£0 - £462) |
| Occupational therapy | 22% (23) | £83 (£0 - £1,236) | 9% (2) | £9 (£0 - £103) |
| Other community health[2] | 0% | £0 | 9% (2) | £4 (£0 - £81) |
| *School based services* | | | | |
| School nurse | 35% (37) | £74 (£0 - £1,560) | 4% (1) | £1 (£0 - £26) |
| Connexions | 45 % (47) | £15 (£0 - £96) | 39% (9) | £11 (£0 - £48) |
| *Social care services* | | | | |
| Child social worker | 30% (32) | £72 (£0 - £1,380) | 13% (3) | £30 (£0 - £414) |
| Adult social worker | 16% (17) | £28 (£0 - £276) | 35% (8) | £66 (£0 - £552) |
| Voluntary worker | 2% (2) | £2 (£0 - £176) | 4% (1) | £17 (£0 - £396) |
| Short breaks | 30% (30) | £145 (£0 - £1,915) | 17% (4) | £104 (£0 - £863) |
| Other social care[3] | 0% | £0 | 13% (3) | £73 (£0 - £1,242) |

Notes: 1. Practice nurse, dentist
2. Chiropodist, diabetic nurse
3. Care support worker, care agency worker, autism support group.

Of course, the two samples – pre-transition and post-transition – are not directly comparable. These are not young people followed before and after transition and nor are they two samples either randomly selected or specifically selected and matched for age, gender, needs and so on. The post-transition sample in particular, with only 23 young people from all of the five sites, is unlikely to be representative of all young people moving on from each transition service. Yet, it is also worth noting that the table does reflect what has been found in other studies (see Chapter 1; Beecham *et al*., 2009; Beecham *et al*., 2010). Post-transition, young people tend to have a lower use of services than pre- transition. In this study this is particularly so for specialist health services – hospital doctors, psychiatrists, psychologists, speech and language therapists and occupational therapists. Among social care services, use of short-breaks drops dramatically; indeed, many interviewees commented on the lower availability of respite care in adult services compared to children's services. Other services where there is a reduction in the rate of service use are age-specific, such as the school nurse and child social worker.

Mean costs per young person are also shown in Table 7.11 where £0 means that this service was not used, and the rates of service use indicate that the figure applies to a high proportion of the young people. The cost range for each service is wide. For example, 92 of the pre-transition sample were not admitted to hospital; their cost for inpatient stays is therefore £0. The seven young people admitted to hospital in the pre-transition sample each stayed one or two days (mean costs for users of this service £360). For the post-transition sample, just one of the 23 young people stayed in hospital but the costs of the much longer seven-day admission are £1,743 leading to a higher mean cost per person in the sample. Generally, mean costs are lower for the post-transition group than for the pre-transition group. When set alongside the information on the service use *rates* this suggests that, with the exception of social work, not only are the post-transition group less likely to use specialist services but when they do, they receive a lower intensity of service.

**Table 7.12 Service costs by group over three months prior to completing the questionnaire**

| *Service category* | *Pre-transition sample* | *Post-transition sample* |
|---|---|---|
| | *Mean £ per person (range)* | *Mean £ per person (range)* |
| Primary care | £37 (£0 - £288) | £36 (£0 - £225) |
| Hospital | £171 (£0 - £1,424) | £187 (£0 - £2,402) |
| Mental health | £31 (£0 - £720) | £0 |
| Community health | £406 (£0- £5,760) | £141 (£0 - £1,285) |
| School-based services | £89 (£0 - £1,584) | £13 (£0 - £50) |
| Social care services | £246 (£0 - £2,467) | £290 (£0 - £1,380) |
| Residential services (incl. education & accommodation[1]) | £5,278 (£218 - £9,882) | £4,308 (£2,160 - (£7,546) |
| *Total costs* | *£6,259 (£1,212 - £13,600)* | *£5,047 (£3,081 - £9,153)* |

Notes: 1. Includes living at home

In Table 7.12 the costs data have been grouped in line with the categories set out in Table 7.11, approximating agency responsibility. Accommodation and education services have been included, combined into one category because of the complexity of disaggregating accommodation and care costs from education costs for those that were in residential schools and colleges (five young people) and the need to include the costs of 'living at home' so that the *scope* of the cost calculations were the same for all young people (see Berridge *et al*., 2002) and the Appendix attached to this chapter). In the pre-transition group, one young person was adopted, one is in a 52-week residential college, and 20 young people spent between two and six days in a residential establishment.

Residential services (including both education and accommodation) absorb the lion's share of the costs of these care packages at 84 per cent. The remaining costs (on average, just under £1,000) are mainly borne by hospital and community health services (59 per cent) and other social care services (25 per cent).

As in the previous section, we explored the data to assess whether these variations in the costs of support packages were associated with some key characteristics, outcomes and service-related variables. Some of these potential explanatory variables were linked to the young person: age, gender, whether they had an autistic spectrum disorder, their mean difficulties score, their unmet needs for support, and whether the family had a copy of the transition plan. Others described the parents and family; the impact of the transition service on their stress levels, whether the family income came mainly from paid employment, their unmet needs, their satisfaction with the transition service, and the MPOC scores. (See also section 5.3.)

There was only one significant association with costs; the mean young person's difficulties score. This measure was positively associated with the costs of social care ($p<0.000$; 12.4 per cent) and the cost of the young persons' service package excluding education and accommodation costs ($p=0.001$; 10.7 per cent). Cost associations with the total cost of including education and accommodation ($p=0.048$; three per cent) and with the cost of primary care ($p=0.037$; 3.5 per cent) were also positive but show a weaker association. On the whole these findings are encouraging because each cost association suggests a perfectly sensible direction of influence – that higher young people's needs are associated with higher support costs. However, the percentage figure following the p value for each variable shows that young people's needs explain only a relatively small proportion of the costs.

## 7.5 Summary

The national survey of transition teams generated slightly less finance data than other comparable surveys in children's and adult services. This poor response may be due to the complexity of the multi-agency partnerships, unwillingness (or no perceived need) to share financial data between partners and with the research, or the complexity in the teams' working practices. The data provided in this survey (nine services) were not sufficient to enable us to calculate full costs of those providing some financial data, nor sufficient to extrapolate the costs to other teams in the survey. However, we were able to make broad estimates of staffing costs for a further 12 teams, in turn allowing us to estimate a ‘unit (staffing) cost’ per currently supported case. The paucity of data coming directly from the teams, however, means that these costs are indicative of the costs of any single particular team. While our use of nationally applicable staffing means they may have wider generalisability, calls from services, providers and commissioners for an improved evidence base on the cost-effectiveness of such services cannot be met without a greater willingness from them to provide good quality information on costs.

The unit costs for the five transition teams studied in more depth were estimated, again using nationally applicable data. The cost per working hour reflects the full cost of the team – including managers, administration support, transition workers and supervision – divided by the number of hours available for transition support. These costs are driven by the professional mix in the team and the costs of employing those professionals. The Steering Groups add about £2 per working hour to the team costs; these costs are influenced by the size, composition and frequency of the meetings. The average cost per case for each of these five services was estimated. They show considerable variation; the driver here is not only the costs of the team but also the number of cases they reported supporting in the national survey. The costs per case range from £460 per year to more than £3,000 per annum. The average, however (£1,800) was similar to that estimated for the 12 teams in the national survey.

The final section looked more closely at the costs of service packages received by families currently supported by the transitions team and those *post*-transition. These are user-level support costs. On average, our analysis suggests young people’s support from the transition teams costs £173 over a three month period, although the range was wide (£0-£1,880) with three families receiving relatively high cost levels of support. These young people also use a range of other services comprising the ‘support package’ at an average cost of £6,250 over three months. Again the range was wide but there was some evidence that young people with higher needs received more costly levels of support. Information on the support packages for *post*-transition young people reflects findings from other research with lower levels of support (costs) provided after the transition to adult services.

# Appendix 7 Estimating unit costs

## A7.1 Data used to estimate transition team staffing costs for the national survey

### Table A7.1 Data used to estimate the staffing costs for the national survey

| *Staff member from …* | *Cost pa* | *Source and notes* |
|---|---|---|
| Directorate of Children's Services<br>(Child social worker) | £33,000 | Curtis 2007 (Schema 10.3); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hour pa. |
| *C&YP social care*<br>*(Child social worker)* | *£33,000* | *Curtis 2007 (Schema 10.3); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hour pa.* |
| Adult social care<br>(Adult social worker) | £32,656 | Curtis 2007 (10.2); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hour pa. |
| Primary care trust<br>(Community nurse) | £32,457 | Curtis 2007 (9.3); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hour pa. |
| Education<br>(Classroom teacher) | £36,471 | Main pay scale point 4 salary & SEN allowance, plus employer NI (12.7%) and superannuation. (14.1%) contributions. Working 195 days p.a = 1265 hours |
| Connexions<br>(#112 Grade 4 £22542 - £26924) | £31,386 | Mid-point salary, plus employer NI (12.7%) and superannuation. (14.1%) contributions. Working 42 weeks*37.5 hours = 1522 hours pa. |
| Adult Learning Disability<br>(Adult social worker) | £32,656 | Curtis 2007 (10.2); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hours pa. |
| C&A mental health services<br>(Generic m-d CAMHS team member) | £66,798 | Curtis 2007 (11.7); average salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hours pa. |
| Learning Disability Partnership Board<br>(Adult social worker) | £32,656 | Curtis 2007 (10.2); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hours pa. |
| Special grants or funding<br>(Two child social workers and one social work assistant @ £23,768) | £89,768 | #32: LPSA funds 2 transition workers and one advocate. Curtis 2007 (10.3, 10.4); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hour pa. |
| Manager<br>(Social work team leader; 18/19 teams are based in social care). | £42,670 | Curtis 2007 (10.1); salary plus employers NI and superannuation. Working 42 weeks*37.5 hours = 1522 hour pa. |

Capital overheads in social care services are estimated at £2,413 pa for team leaders, for health care the figure is £2,384 (Curtis, 2007).

## A7.2 Cost estimation methods for the five transition teams studied in greater depth

The cost estimation approach underlying this research takes the basic principles inherent in economics and applies them to the specific field of social care services (see for example, Beecham, 2000). Our interest is in obtaining the best approximation of the *long-run marginal opportunity cost* of the services used, including the transition teams.

As described in Chapter 1, transition services are intended as an important component of child and adult services so the cost of expanding the service is an appropriate measure. Thus, *short-run marginal costs*, which include only the costs of running the service on a day-to-day basis will underestimate the costs of providing *more* of the service. Our approach is to include these revenue (recurrent) costs as well as the overheads that accrue to the managing agency. Thus the full costs of providing the service are accounted for rather than the costs of squeezing just one or two more young people into an existing service.

The second major element of cost estimation is finding an appropriate *unit of measurement* for the unit cost. Broadly speaking, unit costs can be envisaged in a number of ways. Costs per annum, for example, are a common feature of social services accounting systems and provide a baseline for further calculations; the *unit* is a year. For many evaluations, however, because our interest is in the service users, our focus should be on estimating a unit cost that is commensurate with the way in which families and young people use the service. Thus, young people use residential or foster care as an overnight stay so the cost *per day* or cost *per week* would be common and appropriate currencies. Young people may use a whole range of different day care or day activity services for a number of mornings or afternoons each week thus the unit cost is sensibly measured as the *cost per session.* Young people and families have hospital outpatient appointments, this unit cost is best conceptualised as a *cost per attendance*. Each of these has an inherent compatibility with the way the service is used.

In estimating unit costs for peripatetic services, that is where the front-line worker is mobile and commonly provides support for the family in their own home, the situation is slightly more complicated. The notion of a *cost per working hour* is useful; that is, the total (per annum) costs divided by the total number of hours that the staff provide care and support. A peripatetic service may be a single worker or several workers organised into a team (as with many of these transition workers) so the total number of hours that the staff in that team provide care should reflect all care staff for which costs have been included. Of course, the total costs are broader than just salary costs. Transition workers need, for example, a base (if nothing else they need a place to write case-notes or make telephone calls), some form of transportation, administrative and clerical assistance, supervision, etc.

Another unit of measurement might be a cost-per-hour ‘weighted’ for activities undertaken. Perhaps the data on the way young people and families use a service is expressed as the number and duration of face-to-face contacts; say four visits over a month each lasting about an hour. We know, however, that the workers will have to travel to the family’s house to make that face-to-face contact; this has extra time implications, hence extra costs. They may have to follow this visit with completing an assessment form or writing a report. Identifying and quantifying the activities linked with or enabling face-to-face contact allows a *cost per contact* to be estimated. This will invariably be higher than the cost per working hour – perhaps more than doubling the amount of time spent actually seeing the family. For example, about ten years ago Carr-Hill *et al.* (1999) found that face-to-face contacts absorbed only 40 per cent of children and family social workers’ time, later work on the 2001 Children in Need Survey found 66 per cent of social workers’ time was spent on non-child related activities (Bebbington *et al*., 2003). By identifying the time contributions of professionals and other staff to, say, a review meeting or an operation in hospital and then combining these data with the relevant costs per hour a *unit cost per event* can be calculated, or a *unit cost per process* such as an assessment (see, for example, Cleaver *et al*., 2002).

Although the *unit of measurement* may be different for any given unit cost and there may even be a different scope of costs included, its estimation is most easily undertaken by following four simple stages; describe clearly the components of the service (or event, process, etc) for which costs are required, identify the activity and unit (or units) of measurement, estimate the cost implications for each component, and finally calculate total and unit costs (Beecham, 1995; 2000). These four stages underpin the activities undertaken to estimate the costs of the transition teams. Section 7.3.1 shows the result of the cost estimation work on the five transition teams that participated in the study.

## A7.3 Unit costs estimations for the wider support package services

Parents whose children used the transition services in the five study areas were asked to complete a questionnaire. Part of this was an amended version of the *Client Service Receipt Inventory* (Beecham and Knapp, 1992; 2001) which allows service use to be recorded in a manner commensurate with estimating the costs of support packages. Unit costs were attached to each of the service used to allow calculation of the total support package cost. Where the number of contacts was missing but we knew some service was provided, this was replaced with the series mean rounded to the closest whole number or replaced with one if the mean was less than one.

Most unit costs for health and social care services were taken from an annual compendium of nationally applicable unit costs (Curtis, 2008). Table A7.2 shows those used in this part of the study. However, the coverage of children's service is quite poor in this volume and we estimated the costs of some services specifically for this research. Education support, for example, whether in special needs schools or as additional support within mainstream school required considerable attention. One challenge for this type of research in children's services is the intersection between education and living circumstances, some young people receive their education in residential schools, others live in children's homes and attend mainstream schools, and yet others may live at home most of the time and attend a special needs day school. We describe how we estimated costs for these services below.

### Table A7.2 Unit costs for service use reports in the family survey data

| *Service* | *Cost 2007/08* | *Source* |
|---|---|---|
| GP | £36 per surgery consultation | Curtis 2008, p.109 |
| Hospital doc | £163 per hour | Curtis 2008, p.159 (consultant: medical) |
| Child SW | £138 per hour | Curtis 2008, p.114 (same as ASW) |
| Adult SW | £138 per hour | Curtis 2008, p.114 |
| Physiotherapist | £60 per contact | NHS reference costs national average (community therapy services, child one-to-one) |
| Speech & language therapist | £77 per contact | NHS reference costs national average (community therapy services, child one-to-one) |
| Psychologist | £72 per hour | Curtis 2008, p.97 (clinical psychologist) |
| Psychiatrist | £239 per hour | Curtis 2008, p.161 (consultant psychiatric, patient-related hour) |
| Community nurse | £68 per hour,<br>£23 per visit (20 mins) | Curtis 2008, p.101 (hour spent with patient) |
| Community paediatrician | £123 per hour | Curtis 2008, p.159 (patient related hour, but with salary from job ads 75-100k ⊐ 87.5k) |
| Occupational therapist | £103 per contact | NHS reference costs national average (community therapy services, child one-to-one) |
| Voluntary worker | £11 per hour | ASHE 2008 (median hourly earnings excluding overtime, part & full time, men & women) |
| School/college nurse | £79 per hour,<br>£26 per visit (20min) | Curtis 2008, p.103 (hour client contact, as health visitor) |
| Connexions worker | £24 per 30mins,<br>£47 per hour | Own calculation based on salary from jobs.guardian.co.uk/, on-costs & overheads & time as social worker |
| A&E | £111 per unit | Curtis 2008, p.81 (national average, weighted average of attendances) |
| Inpatient stay | £249 per bed day | Curtis 2008, p.81 (national average, weighted av. All patient rehab stays) |
| Short break services | £69 per session | Coventry: standard rates (day care after-school or local day trip). Overnight stays range from £211 (vol org) to £318. www.lacommissioning.info/cs/groups/short_breaks_for_disabled_children/media/p/187.aspx |
| GP nurse | £9 per surgery consultation | Curtis 2008, p.106. Consultation = 15.5 mins; £33 per hour of client contact |
| Community chiropodist | £11 per visit | Curtis 2008, p.96 |
| Dentist | £16 (band 1 treatment) | NHS dental charges for 07/08 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_073215.pdf |
| Specialist nurse (diabetic) | £81 per hour | Curtis 2008, p.104 |

### School and college

Mainstream schooling was used as a reference point for the calculation of other types of education establishments. The average expenditure per pupil per day in mainstream education was taken from the CIPFA analysis of RO1 returns (Education Actuals, 2007/08), based on 190 school days. The R01 does not differentiate between pupils with and without SEN, and with or without statement within mainstream schools.

The report ‘Making sense of SEN’ (New Philanthropy Capital, 2006) estimated the average spend per pupil in mainstream schools for those without special Educational Needs (SEN), those with SEN without an accompanying Statement and SEN pupils with a Statement. The SFR *Special Educational Needs in England, January 2008* shows that, on average, 2.8 per cent of pupils across England had statements of SEN, of which 56.6 per cent were placed in mainstream schools. In secondary schools, 17.8 per cent of pupils had SEN but no statement. Compared to a non-SEN pupil, the expenditure for a pupil with SEN without a statement was 26 per cent higher, and for those with a statement it was 97 per cent higher.

The R01 returns report expenditure on special needs schools but do not distinguish between residential and day schools. ‘Recoupment charges’ are charges made by the receiving local authorities for pupils placed by other authorities within its SEN facilities. This information was not available for all areas participating in this study, so we have used the recoupment charges published by Surrey local authority to adjust existing costs data in each area. Using the cost of mainstream provision in Surrey for non-SEN pupils – again calculated from R01 returns – as the reference point, we estimated the ‘multiplier’ that represented the cost difference between this and the cost per day in a special unit within mainstream education, special schools with day provision (key stages 4 & 5) and special residential schools (key stages 4&5) as multiples of mainstream education.

For residential schools, the cost per day for Surrey was used for all pupils as the cost in the Greater London Area was substantially higher compared to other areas, and it was assumed that residential placements were more likely to be out of authority for pupils from London.

### Table A7.3 Mainstream school cost multipliers

| *Area* | *Mainstream* | | | |
|---|---|---|---|---|
| | No SEN | SEN, no statement | SEN, with statement | Special needs unit |
| A | 23 | 28 | 45 | 59 |
| B | 26 | 33 | 51 | 68 |
| C | 32 | 41 | 61 | 85 |
| D | 31 | 39 | 60 | 80 |
| E | 23 | 29 | 45 | 60 |
| Surrey | 23 | 29 | 45 | 60 |
| *Multiple of mainstream school* | *1x* | *1.3x* | *2x* | *2.6x* |

### Table A7.4 Special needs school cost multipliers

| *Area* | *Special school (day)* | | *Special school (residential)* | |
|---|---|---|---|---|
| | Key stage 4 | Key stage 5 | Key stage 4 | Key stage 5 |
| A | 96 | 100 | 199 | 202 |
| B | 110 | 115 | 228 | 233 |
| C | 137 | 143 | 285 | 291 |
| D | 130 | 135 | 269 | 275 |
| E | 97 | 102 | 202 | 206 |
| Surrey | 96 | 101 | 200 | 204 |
| *Multiple of mainstream school* | *4.2x* | *4.4x* | *8.8x* | *9x* |

### Other education families

*Further Education College*
Pupil numbers and funding per head £5,620 average, plus special needs uplift £4,500.
Cost per day £53.

*Living skills/Enterprise Centre*
Courses usually provided in Further Education colleges.

*Residential College*
A review of the information on independent sector colleges with residential provision for special needs suggests a cost of £118 per day. See http://www.indschools.co.uk. The ISC census (2008) shows very similar figures. The average fee for boarding in sixth form was £7,701 per term and £122 per day.

*Day services*
£47 per session (Curtis 2008).

There were quite a few inconsistencies in the education data. For example, one young person was reported as in a special school and in a residential college, while at the same time being placed in a residential home with 52 week provision. It was assumed that this pattern had to do with the order of the questions. This could, indeed, be a residential placement in a special needs college for 52 weeks a year but this type of placement is rare and was not specifically listed as an option. For the cost estimations, if the question allowing parents to list several education placements over the week had been completed, these data were used (this also allowed part-time education to be costed). If the young person was in higher or further education, this option was selected over the broader school descriptions. In this way, the most specific answer was given priority; in this example, a residential facility that provides education is a residential college, but also more broadly a special school. Where information on education was missing we assumed the young person attended a further education college.

## Residential facilities and living at home

*Residential home*
£1,131 per week (Curtis 2008).

*Care worker (LA; Curtis 2008)*
£18 per hour face-to-face weekday contact (assuming two hours per day).

*Living with adoptive or foster parents*
The Fostering Network recommended minimum allowance for outside London, age 16+ has been used: £209.86 per week.
http://www.fostering.net/resources/statistics/recommended-minimum-allowances.

One adopted young person in the pre-transition group was living in a residential placement. We have assumed that the adoption allowance was not paid to the parents in this case.

*Living at home*
The young people in the study live in a range of environments. For example, some receive ‘board and lodging’ alongside their education arrangements in residential school. To ensure that we were covering a similar scope of costs for all young people it was necessary to also include a cost estimate for those that lived at home. To estimate the costs of living at home we have used two source of data; the Family Spending Survey and the self-coded NS-SEC (http://www.ons.gov.uk/about-statistics/classifications/current/ns-sec/self-coded/index.html). The parents’

occupation reported on the questionnaire was matched to the occupational class, enabling us to identify the national median weekly wage (excluding overtime) for full-time, part-time, men and women for that group and thus, depending on marital/cohabitation status we could calculated the weekly income for the household in which the young person lived. In turn, this income information allowed us to estimate the weekly cost of housing and other living expenses per resident using data provided in the Family Spending Survey which reports expenditure by income decile. If the young person was in a residential placement (such as a residential school), the costs of living at home were adjusted for the period away (commonly 38 weeks but one young person was in a 52 week placement). Where data were missing the lowest income group was used. We have replaced cost of accommodation at home by this figure if lower (three cases in POST sample).

# Chapter 8: Discussion and Conclusions

Past research has provided considerable evidence that the transition of disabled young people and those with complex health needs from children's to adult services, and to adulthood more generally, has been problematic. The problems in provision of appropriate, coordinated and responsive services have been recognised in government policy and guidance, and in recent years a number of policies introduced new types of support for transition, ranging from the introduction of personal advisers through the Connexions service and the specific requirements for transition planning set out in the Special Educational Needs and Disability Act 2001 and the *Special Educational Needs Code of Practice* (Department for Education and Skills, 2001) to the new guidance issued by the Department of Health and Department for Children, Schools and Families in 2007 and 2008 and the setting up of the Transition Support Programme to help local areas to improve practice. Research indicates that transition services have varied considerably in how they are structured, which agencies are involved and the support they provide for young people and their families. The range of processes and changes involved in transition clearly requires a coordinated multi-agency approach but there is considerable evidence that this has been difficult to achieve, and that many disabled young people and their families experience a lack of coordination and inadequate preparation for transition (for example, Kirk, 2008; CSCI, 2007; Cope, 2003; Heslop *et al*., 2002; Forbes *et al*., 2002). In addition, shortfalls in provision of adolescent and adult services have exacerbated these problems (for example, Audit Commission, 2000, 2002; Dee and Byers, 2003). A poor transition in turn is likely to lead to poor outcomes for young people and their families.

There has been relatively little research on the effectiveness of transition services. However, evidence suggests that some factors may improve transition. These include coordination between agencies with good communication and collaboration at intra and inter-agency levels; transition workers or teams; active involvement of young people and their families and good information provision; and support for young people which includes a focus on their own aspirations and ambitions (CSCI, 2007; Heslop *et al*., 2002, 2007; Forbes *at al*., 2002). However, there is still limited evidence on what works to promote smooth transition and good outcomes for young people and families. This research therefore set out to investigate the impact on young people and parents of different models of transition services, the specific factors within these services that were related to better outcomes, and the costs of the services.

This chapter brings together findings from the different stages of the study and draws out the implications of the findings for policy and practice. We start by setting this in context by discussing the strengths and limitations of the study.

## 8.1 Strengths and limitations of the study

The study employed a multi-method approach and obtained the views on the transition services of a range of groups of respondents: managers and practitioners, parents and young people. This allowed a broad exploration of the services, their effects and how these effects were produced. Quantitative research included survey data on transition services across England, more detailed data on families' experiences of services in five case study areas and statistical analysis of the relationships between aspects of these services and outcomes for families. These quantitative analyses were designed to facilitate generalisation of results. Qualitative research explored in depth managers' and practitioners' experiences and views of the services, highlighting aspects that appeared to be important in providing a good service and barriers that affected this. Interviews with a small sub-group of families provided illuminating detail about the ways in which the services had an impact on their lives. These data facilitated interpretation of the processes and mechanisms which produced the statistical relationships found in the quantitative data. In addition, the triangulation of data from different groups of respondents and different methods, and the fact that there was considerable consistency between these sets of data enhances the validity of the findings (Bryman, 1988).

Nevertheless, the study has significant limitations. The survey of multi-agency transition services produced only a snapshot in time and the reliability of survey responses is limited, responses for different professionals in the same service may not concur (McConachie *et al*., 1999). This became clear in this study during further exploration with services approached to be case studies, when anomalies were found between information provided in the survey and more detailed investigation of the services. In addition, although the response rate to our initial screening questionnaire was good, only 34 of the 50 services identified by this then completed a more detailed questionnaire. Some non-completers informed us that this was because their service was currently not a multi-agency one, but for others we were unable to get any information about reasons for non-completion. This means it is difficult to calculate a true response rate. Clearly, the survey does not provide an exhaustive picture of multi-agency transition services and some services were not detected. In addition, since the survey was carried out in 2007-8, there have been many developments in transition services, not least those instigated by the Transition Support Programme, including the setting up of new services and changes and positive developments in existing ones. We experienced considerable difficulties in recruiting case study sites, and some of those originally selected on the basis of survey responses, turned out to be less developed or have less multi-agency involvement than first thought when more detailed investigation was undertaken. This raises concerns about the reliability of the survey responses, similar to those raised by McConachie *et al*. (1999).

A real challenge to the economic component of this study was the unwillingness of transition services participating in the national survey to provide data on the expenditure, and indeed some found it difficult to identify their full staff profile or the number of young people supported by the services. While the staffing costs, estimated for around a third of the responding teams, will have captured around 80 per cent of the total costs with a fair degree of accuracy, these do not represent the full costs of providing such a service. Even in the five case study sites, very few expenditure data were forthcoming. While there are many reasons for not making these data available (for example, confidentiality, lack of access), progressing towards cost-effectiveness studies of transition services will be difficult without greater willingness to release such information to researchers.

A further limitation of the study is the low response rates for the family survey. As noted in Chapter 2, there may have been a number of reasons for this: some families having had little contact with the service and therefore being unable to answer the questions; transition being a particularly stressful time in families' lives, as noted in previous research; reliance on staff who were already hard pressed, particularly where services were understaffed, to identify and locate families who used or had used the service and send out questionnaires; postal problems in the service with the lowest response rate; and young people being unable to complete questionnaires. Some of these reasons were confirmed by those who returned uncompleted questionnaires. As, for ethical reasons, we have no data on families who did not return questionnaires, we could not compare respondents with non-respondents. The lowest response rates were in the two coordinating services where it is possible that the transition services were less identifiable to families as their support was provided by existing general services, although the proportion of respondents saying they had one transition worker to support them was similar in these services to two of the other services. This may suggest that respondents from these services were only those who received a more responsive service but this is not borne out by the satisfaction ratings as one coordinating service had the highest satisfaction rate and the other the lowest. In general, satisfaction ratings do not suggest any particular pattern of response relating to whether respondents were those who were happy with the services.

Although the research aimed to obtain the views of disabled young people, numbers of respondents to the questionnaire were too low for any detailed statistical analysis. Nevertheless, a range of views were obtained. Similarly, the number of young people who provided additional comments in the questionnaires was low and it was not always clear whether these were young people's own views or those of a parent or professional who had written them. The difficulties and delays experienced in the initial stages of the project also limited the time available for interviews with young people and parents and in those families taking part, even with the use of visual methods, few young people were judged by parents as able to respond in an interview and/or were willing to do so. Ideally, more time and multiple visits would be needed to engage these young people.

## 8.2 Multi-agency transition services in England

The first stage of the research investigated the pattern of multi-agency transition services. Results of the survey carried out in 2007-8 identified 34 such services. The picture of services obtained from the survey was one of considerable diversity and complexity. Aspects of good practice, as defined in research and policy, were found in many of the services. The majority of services had all three statutory agencies (health, education and social care) involved in setting up (22) and overseeing (23) the service and in 18 of these both children's and adult social care agencies were involved. Multi-agency funding was relatively common, usually through linked dedicated or seconded workers from one or more agencies that were not the lead agency or (less often) through financial transfers between agencies. The advantage of having budgets in different agencies is that it is easier to employ a wide range of professionals within their own pay-scales and working conditions. This must be set against the disadvantages of a slower, less flexible response to staff vacancies or new policies when changing priorities mean one agency becomes less committed to its funding promises over time.

In addition to health, education and social care, many services had formal links with a range of other agencies, including employment, Learning and Skills Council and youth services. This suggests a commitment to promote and support multi-agency working. Parents were involved in setting up (26) and overseeing (24) many services. However, young people's involvement was only found in less than half of the services.

All services had transition workers or teams, which has been identified as good practice (Forbes *et al*., 2002), but there was considerable variability in how these functioned. Twenty-three services stated that young people had a transition worker or key worker, but this term covered a number of different types of role. In over half the services transition workers were part of wider teams rather than having a designated role working solely on transition for disabled young people. In addition, transition teams in a number of services did not work directly with a caseload of disabled young people in transition but had a coordinating role supporting other generic workers. There appears to have been no previous research exploring differences in effectiveness for these different models, so the case studies in this research covered both direct and coordinating services in order to explore both types of models.

Nearly all services offered person-centred planning to some young people, but in reality this approach was said to be limited and only ten services professed to offer it to all disabled young people in transition. Provision of information about the service for young people and parents has also been identified as an aspect of good practice (Forbes *et al*., 2002): 22 services had information for young people and 27 had information for parents. However, many noted that they were in the process of developing further or revising such information.

However, there were a number of aspects of good practice that were scarce. The involvement of health services was limited in some areas, and only a small number of services (five) had joint funding from health, education and social care. Funding was not secure for a third of the services, suggesting that these services would be particularly vulnerable to cuts.

The eligibility criteria for young people to receive the service were predominantly based on learning disability, and thus the support available for young people who had complex health needs or high functioning autism was unclear. In addition, the age at which young people exited the service varied; some services had flexibility on this so that young people could be supported until they were settled in adult services, but 11 of the services had set ages of 18 or 19 years, when it seems unlikely that young people would have been fully settled in adult services.

It is interesting to compare these findings with those of a similar survey undertaken in 2003 of multi-agency care coordination services for disabled children (Greco and Sloper, 2004). Although it must be noted that this survey included Wales and Scotland as well as England, the services identified were predominantly (26 out of 35) in England. The care coordination survey was undertaken when the development of such services was quite new in many areas, and a considerable number of authorities did not yet have a service. In this, the situation was very similar to the current stage of development of multi-agency transition services, where only seven of the services had been in existence for more than four years and 18 had been established within the last two years, and thus some of the lessons from the research on key worker services may have relevance to transition services. This research found that outcomes for families varied between services and a number of factors were related to better outcomes (Sloper *et al.,* 2006). These included the service having a dedicated manager whose role included inducting key workers and organising ongoing training and supervision specific to the role. A clear understanding of the key worker role was also central to the effectiveness of the service.

There are some similarities and differences between the findings of the two surveys. They both showed similar levels of short-term funding. However, eligibility criteria for the care coordination services seemed to be less focused on learning disability, with the majority of these services focusing on children with complex needs requiring significant involvement of two or more agencies. The difference may reflect the greater emphasis in adult services, who were not involved in any of the care coordination services, on learning disability and responding to Valuing People (Department of Health 2001). A higher proportion of care coordination services had a dedicated manager with responsibility for overseeing the day to day running of the services (31 out of 35, 89 per cent, compared with 24 out of 34, 71 per cent for the transition services). Similarly, the proportion of services having key/transition workers who worked with families was higher for the care coordination services (30 out of 35, 86 per cent compared with 23 out of 34, 68 per cent, for transition services). However, more transition services had designated key/transition workers (20 out of 23, 87 per cent compared with only eight out of 30, 27 per cent for care coordination services). In relation to training, extent of provision of ongoing training for key/transition workers was the same (83 per cent), but more care coordination services provided special induction training (68 compared with 48 per cent). Positively, the transition survey demonstrated that specific services were being developed and resources being made available to support transition. Specialist roles and workers were developing and the improvement of transition was high on the agenda. Given the findings of the key worker research about the importance of clarity about the role of the key workers and having training for that role, the current research explored, in the case study areas, whether these factors were important in outcomes of transition services for young people and families.

## 8.3 Different models of transition services in practice

The next stages of the research set out to explore in more detail how different models of transition services worked in practice and their impact on young people and parents. Five services were chosen as case studies to cover a spread of urban and rural areas, demographic characteristics, whether transition teams had a direct role with families or a coordinating role in supporting other services, whether transition workers were designated (working solely on transition) or non-designated (working on transition with some young people as part of their normal professional role), and the range of professionals employed as transition workers. Each of the five services had a very different staff profile in terms of numbers and professional mix, and had different levels of administrative and supervisory support. In turn their costs per working hour varied considerably (from £22 - £52). Using data on the intensity of transition support received, as reported by those participating in the Family Survey, the costs of providing support over a three month period also varied. Five families had not had any contact with their transition worker over that period. For the other families the costs were between £50 and £370, with three families receiving support levels of between £500 and £2000.

Interviews with managers, practitioners and steering group members in these areas, and data from parents and young people who received the service indicated a number of positive features of the services, but also some areas of concern. Overall, half of the pre-transition parents and two-thirds of the post-transition parents were satisfied with the transition services but this varied considerably between services. Staff and managers identified positive features of their services and advantages in coordination and continuity of services for young people and families, but also pointed to a number of areas for improvement.

Existing research indicates that transition is a particularly stressful time for parents with problems around coordination and availability of services contributing to this stress (for example, Wikler, 1986; Rapanaro *et al*., 2007). It was hoped that provision of more coordinated services would reduce parental stress, but only 24 per cent of pre-transition parents felt that this was the case, with two-thirds feeling that contact with the transition services had increased their levels of stress. For post-transition parents looking back on their experience of the transition services, the picture was slightly better with equal numbers (40 per cent) feeling that the services had reduced or increased their stress levels. It may be that the somewhat more positive picture for post-transition parents is influenced by the fact that their son or daughter has made the transition to adult services, was supported in this by the transition service, and there is now less uncertainty for them. However, over two-thirds of parents felt that transitions from children’s to adult services in health and social care were poorly managed, and a quarter felt that transition from school to further education (FE) was poorly managed. The low numbers in the post-transition sample mean that these data should be viewed with caution, but they suggest that even with support from a dedicated transition service, there are still considerable problems with the processes of transition and the links between children’s and adult services.

The aim of this research was to identify important ways in which models of multi-agency transition service varied and to investigate the influence of these variations on the outcomes for young people and their families. A number of key aspects of the services were identified from previous research and from interviews with staff, and these were then explored further in the analysis of the family survey data:

- Whether young people and families have a transition worker to support them through transition.
- Whether families have received a written transition plan.
- Type of transition workers (designated or non-designated).
- Transition workers having specific training for the role.
- Clarity on the transition worker role.
- Transition workers setting up and negotiating funding for the adult care package.
- The transition manager having strategic involvement.
- Person-centred planning being used for all young people.

- Parent involvement in steering the service.
- Young people's involvement in steering the service.

In addition, relationships between outcomes and three other factors were explored. These were young people's level of difficulties, type of school attended and diagnosis of an autistic spectrum condition. These were not found to be significant, apart from a positive relationship between level of difficulties and increased parental stress as a result of contact with the transition service. It should be noted that the young people with ASC in this study nearly all had severe learning disabilities and a number had additional conditions, such as epilepsy, so it is not clear whether the experiences of young people with high functioning autism would be different.

## 8.4 Factors related to outcomes for young people and parents

Four outcome measures were used in the study: satisfaction with the transition service; parents' unmet transition needs; young people's unmet transition needs; and impact of the transition service on parental stress. For each measure, multivariate analysis was used to identify the factors most strongly related to outcome.
There was considerable consistency in the results of the analysis for the four outcome measures. First, having a transition worker to support the young person and family was a strong predictor of all four outcomes, for example, not having a transition worker increased the odds of contact with the transition service increasing parental stress by over eight times. For all outcomes, when this variable entered the multivariate analysis the type of transition worker employed by the service (designated or non-designated) was no longer significant. Families' responses showed that there was considerable variation both within and between the case study services on whether families had a transition worker. Some families were supported by transition teams that worked directly with young people and families and some families supported by coordinating transition services had someone who they identified as one worker who supported them through transition, and it was this that was most important to outcomes. In addition, having a transition worker was significantly related to MPOC scores, which measured the processes of care provided by services in general, suggesting that when families have a single transition worker, this worker is able to coordinate services better for the family. The results of the young people's questionnaires also highlight the importance of transition workers. They indicated that where young people had one transition worker to support them the workers provided a range of support and information, and the vast majority of young people were positive about their relationship with the worker, for example, feeling that they were listened to and asked for their ideas, and that the worker would help them to think about what they wanted and find things out for them.

Secondly, the family having a written transition plan was significantly related to satisfaction and parent unmet transition needs in multivariate analysis and was significant at the bivariate level for the other two outcomes. Given that there is a statutory requirement for all young people over the age of 14 who have a statement of SEN to have a transition plan, we asked parents whether they had a written plan. It was hypothesised that having this would at least indicate that they were aware of, and had information about, plans for the young person and thus were able to have some input into these as plans progressed and were reviewed. It was of considerable concern that less than half the pre-transition parents in all services, and only two out of 28 families in one service, had a written copy of the transition plan. Two-thirds of post-transition families had such a plan. The age at which parents were aware that transition planning had started also varied considerably ranging from 13 to 22, again suggesting a lack of parental awareness of such planning in some families or even a lack of compliance with statutory requirements. Thus it is not surprising that there were high levels of unmet needs for information about transition, and that these were higher for families who did not have a transition worker. Although families who had a transition worker were significantly more likely to have a written plan, having a written plan retained significance in analyses of satisfaction and parent unmet needs even after entry of the variable of having a transition worker, underlining the importance of ensuring that families are aware of, and fully involved in, transition planning.

Thirdly, the transition service manager having strategic level involvement was a predictor of parents' satisfaction and unmet transition needs, and was significant at the bivariate level for young people's unmet needs. Transition managers had this role in three of the five services, being members of various multi-agency strategic groups (in addition to the transition service steering group on which all transition managers sat). These managers were able to 'champion' the transition service and drive the service by providing communication between strategic and operational levels. This could have impacted on parents' satisfaction and unmet need by ensuring that the needs of disabled young people at transition were high on the agenda for all the services involved, thus making it more likely that a broader range of needs was addressed in development of the services, and that the different services were more responsive to the needs of such young people and their families.

Five variables were related to outcomes at the bivariate level but were not significant in the multivariate analyses, when more strongly related variables entered the equation. These variables were whether the transition workers set up the adult service package and negotiated funding for it, whether person-centred planning was used for all disabled young people in transition, whether the role of the transition workers was clear, whether the service had designated transition workers, and whether there was parental involvement in the steering group. There were problems of multicollinearity between service level variables as these were clustered in the sample because they were the same for all families receiving a particular service. It is notable, but not surprising, that the variables most strongly related to outcomes were the family level ones of having a transition worker and transition plan, where there was variability both within and between services. Nevertheless it is useful to consider the possible effects of these less strongly related variables.

Having the transition workers set up the adult service package and negotiate funding for it may provide a more responsive and young person centred service, as the transition workers in the services that included this worked with young people and families over a period of time, building up a relationship and getting to know their needs. In addition, having the same worker providing support right across transition until an adult care package was agreed and implemented could reduce uncertainty for families, promote a better coordinated package of care, and allow some flexibility over the point of transfer. All these factors are indicated as important in transition (for example, Forbes *et al*., 2002, Heslop *et al*., 2007). In contrast where this was not the case and the transition service 'handed the young person over' to adult services (in two services at age 18), this required the young person and family to build a new set of relationships and may involve further uncertainty and change at a vulnerable time. In transition services that ceased to support young people when they reached 18 or on transfer to adult services, transition workers expressed frustration that transition plans that they had drawn up with families were rejected once the young person moved to adult services. A period of co-working between staff based in children's and adult services was also thought to help ensure that transition plans were put in place.

Person-centred planning has the potential to provide a more holistic approach, to facilitate young people's involvement in planning and produce packages of care that are more responsive to young people's needs and aspirations. It is disappointing that only one service sought to provide PCP for all disabled young people at transition. In common with Robertson *et al*. (2005), our results indicate that provision of PCP for all young people may result in more positive impacts of the transition service on young people and parents. Robertson *et al*. also noted that implementation of PCP was patchy and our findings indicate that this is still the case. Although transition workers in all three of the services where transition workers worked directly with young people had received training in PCP, those in two of these services felt that they did not have the resources or capacity to put PCP into practice. In the two coordinating services, provision of PCP was also variable depending on the lead agency for the young person, or still in development.

Clarity on the role of the key worker was found to be important in research on key workers for disabled children (Sloper et al. 2006) and as transition workers have a similar role for disabled young people, it was thought likely that it would be important here as well. In this study, four of the five services did seem to be clear about the transition worker role, and in only one service did workers feel they lacked clarity. Although this variable had a significant bivariate relationship with parents' satisfaction and unmet needs, the finding should be viewed with caution as it relates only to one service where there were low numbers of respondents. Nevertheless, it seems clear that transition workers need to understand their role in order to be effective in it.

Many of the managers and practitioners we interviewed felt that designated transition workers were more effective, and could build up expertise around transition and an ongoing relationship with young people and their families over the transition period. In addition, having designated workers in both children's and adult services could give young people specialist support throughout the transition to adulthood period. In the quantitative analysis, a service having designated workers was significantly related to outcomes at the bivariate level but, as noted above, the family level variable of whether the family had one transition worker to support them was more strongly related to all outcomes and entered the multivariate equations. There was variability between and within services with and without designated workers in whether families had a transition worker. This was not related to the age of the young person but could be related to the problem of staff shortages that was raised by both staff and families in all the services. Interpreting these findings is difficult, but it may be that while designated transition workers have advantages in being able to build up specific expertise, for families it is crucial that they actually have an on-going transition worker who supports them through transition. Thus transition services are likely to be more effective if they have designated transition workers, but this can only happen for individual young people and families if they have a transition worker supporting them. If lack of resources in services and/or staffing problems mean that some families do not have transition workers, this compromises the effectiveness of the service.

The final variable to show bivariate relationships with outcomes of satisfaction and parents' and young people's unmet needs was parental involvement on the service steering group. Two services had parents on their steering groups. Although young people's involvement, which was only currently the case in one service, was not significantly related to outcomes, the effect of parents' involvement may have provided a valuable perspective in the services' development and helped to keep ideas grounded in the experiences of young people and families. Clearly, while parents on the steering group can provide this valuable input, they cannot ensure that the service is properly staffed, and that all families have a transition worker and receive copies of transition plans. These factors in the day to day operation of the service have the greatest impact on families. Despite this, the findings indicate that some of the reservations expressed by staff about parental involvement are not supported by the data.

One service variable, specific training for transition team members on transition, was not significantly related to outcomes. Only one service had such training and staff in others reported that this was a gap in their training. By contrast, this variable was found to be significantly related to the outcomes of key worker services for disabled children (Sloper *et al*., 2006). However, practitioners in the current study also reported that they did not have the resources to put training into practice so it may not be surprising that the relationship between training and outcomes was not significant.

The amount of variance explained in outcome scores, particularly young people's unmet needs scores, indicates that other factors outside those measured for the transition services are affecting outcomes for families. This is not surprising as the resources available for young people in the area have a large effect on young people's and their parents' experiences. A transition service cannot provide access to services that do not exist, and the detailed figures on unmet needs suggest that there are still too few services for young people both before and after transition, for instance in areas such as leisure and employment opportunities. This finding is consistent with other research (for example, Beresford and Clarke, 2009; Sloper *et al*., 2006; Townsley *et al*., 2004).

It is notable that none of these outcome variables were associated with the costs of transition support, the summary measure of the frequency and duration of contact. As with the findings from the key worker study referred to earlier, this perhaps indicates that once a transition worker is in contact with a family it is the quality of that service that is important in generating good outcomes rather than just the quantity of support. While the cost variation analysis of the support packages found some associations with the young people's needs scores (higher levels of need were associated with higher cost support packages) only a small proportion of variation was explained (a maximum of 12 per cent) suggesting that targeting remains a challenge for these young people, and perhaps a challenge for the professionals well who are faced with too few services for this client group.

The findings from the quantitative analysis were corroborated and further illuminated by the qualitative data from staff and families. Key themes emerging from this were multi-agency working, the valuable role played by transition workers but also the constraints on this role, meeting young people's needs and the lack of services/ opportunities in adult services, and demand for and supply of services. These are discussed below.

## 8.5 Multi-agency working

Steering groups in all of the services had multi-agency involvement covering children's and adult social care, education and health. Involvement of other agencies differed between the services, three had representation from CAMHS, two had representatives from employment services, but only one service had a representative from special schools, and one other service had representation from housing, leisure and voluntary organisations. Although all services had health practitioners on their steering groups, only three had managers from health. The very different compositions of these groups and the varying frequency of their meetings led to very different costs, but on average these important functions were undertaken at the additional cost of around £2 per working hour for the team.

Key roles of the steering groups were to ensure multi-agency involvement in and support for the transition service; encourage communication and problem solving between agencies; identify and respond to gaps or difficulties within services and the transition process; and drive change in adult services. There were varying degrees of success in carrying out these roles, examples of agencies working together to drive change were found, but in one service it was felt that the steering group lacked the authority to influence commissioning. Research on multi-agency working points to the importance of multi-agency steering groups but also emphasises the importance of strong commitment from all agencies and their senior management and strong leadership (for example, Hudson *et al*., 2002; Cameron and Lart, 2003). The findings from the current study suggest that this commitment and leadership was not well-developed, with evidence that some agencies, especially health, lacked commitment and did not appear to recognise the importance of senior managers being members of steering groups. Transition services clearly require central involvement at management levels of both children's and adult services, so the lack of consistent involvement of adult social care in one of our case study services was worrying.

For multi-agency working to be successful, it has to happen at many levels. Transition teams and workers are crucial to the coordination of services for young people and families, and in all services they played a key role in liaising with a range of agencies. The coordinating services, which had less of a direct role with young people and families, played a key role in ensuring that assessments and plans were completed and implemented by the relevant workers and agencies. In the other services, the transition workers took responsibility for developing transition plans for young people and ensuring their implementation, working directly with the young person and also liaising with other agencies. Staff reported that key benefits of the transition workers' and teams' roles were in increasing communication between agencies, promoting better understanding of each other's roles, having a central point of contact and providing continuity for young people, their families and other practitioners.

The benefits of information sharing and the importance of compatibility between different agencies' IT systems have been highlighted in other research on multi-agency working (Hudson *et al*., 2002; Cameron *et al*., 2000), but our findings suggest that problems of information sharing have still not been solved. Four services experienced problems in sharing information because IT systems in different agencies were incompatible and this severely hampered communication.

Those services where workers from different agencies were co-located felt that this facilitated communication, but incompatible IT systems were still problematic. On the positive side, one service was successfully developing systems whereby children's and adult social care, education and health could share information that was placed on a single database.

If transition services are to be successful in coordinating the wide range of agencies involved with disabled young people, it is important that knowledge of the service is widespread across such agencies. Unfortunately this was not always the case. Knowledge of the service in schools and colleges young people attend would seem to be vital, yet this was mixed across services and in different schools and colleges within the same area. Only one service appeared to have been successful in ensuring that all relevant schools and colleges engaged with the service. In this service, the transition manager had been proactive in visiting schools, attending open evenings to introduce the service to young people and parents, sending relevant reports and information to schools, and ensuring that the name of a young person's transition worker was included on the school's database. This service was located in a relatively small local authority which made such engagement easier, but the mixed findings from the other four services suggest that this approach could be valuable in all transition services.

In four services knowledge across health and social care was said to be good and was underpinned by awareness raising and promotion of the transition services, close working with other agencies by transition workers and transition managers, and communication with health services being facilitated in the three teams that had nurses attached to them. Chronic understaffing was a key cause of poorer communication in the fifth service.

The facilitators and barriers to multi-agency working that were identified in our interviews were similar to those identified in other studies of multi-agency working (Sloper, 2004; Townsley *et al*., 2004). Facilitators included authority and leadership of senior managers and multi-agency strategic groups; commitment of key individuals; promotion of understanding of the roles of other agencies and professionals; good communication and clear processes and plans; a history of partnership working; systems to support multi-agency working so that links were not dependent on a few key personnel; and co-location of agencies and workers. Key factors that hindered multi-agency working and the transition services in general were under-staffing of the transition services which affected all services to some degree; uncertainty and conflict around funding decisions and such decisions being made too late so transition plans could not be agreed until the last minute and families faced long periods of uncertainty; lack of service provision; lack of consistent engagement of some agencies, particularly health in four services and adult social care in one; competing priorities and targets set by government for services; limitations imposed by different funding streams; lack of a common transition assessment; different ages for transition in different services; and organisational restructuring.

It is clear that further work is needed to ensure equal commitment to disabled young people and transition from all relevant agencies and to ensure that transition teams are realistically funded and staffed.

## 8.6 The role of transition workers

Young people and parents valued the support they received from transition workers, and as noted above, transition workers were crucial in building relationships with young people and families and ensuring coordination and continuity of services for young people. However, they faced considerable constraints in doing this, which were outside their control, and many of these impacted directly on young people. A key source of frustration was the limited range of options available to disabled young people. In addition, when carefully formulated transition plans were rejected by adult funding panels, the transition workers could feel that they were unable to meet young people's needs. Planning was also constrained by processes and funding pressures within adult services that caused decisions to be delayed, again highlighting the importance of commitment to transition planning from adult services.

Staffing issues were a key constraint on transition services. All services encountered staff shortages to some extent, with posts being left vacant, lack of maternity cover and general understaffing of the services. The result of this was that transition workers did not have as much time as was needed to work with young people and explore opportunities and aspirations. This was exacerbated by a lack of administrative support for many of the transition workers. Transition workers also felt that they lacked time and expertise to work effectively with young people who had communication difficulties.

Other studies have found that these type of problems are common among services for disabled children and young people (for example, Townsley *et al*., 2004; Greco *et al*., 2005; Franklin and Sloper, 2009). If multi-agency coordinating services are to function effectively, there needs to be informed planning and resource allocation which is reviewed in a timely manner when there are staff changes. However, among the five case study areas it was very unusual for a manager in one agency to know the full details of the staff time or other resources provided by another agency, or the details of the funding or expenditure. Without this knowledge, it is hard to see how the services could function optimally.

## 8.7 Meeting young people’s needs

As noted above, transition workers and families encountered problems in meeting young people’s needs because of the lack of services and opportunities for disabled young people, and this was common across all the case study areas. Previous research has found that young people’s priorities and concerns were inadequately addressed in the transition process and shortfalls in provision were common in both specialist and community services (for example, CSCI, 2007; Morris, 2002; Heslop *et al*., 2002). The results of our family survey confirmed that, despite the multi-agency composition of the services, the young people experienced high levels of unmet need in many areas of their lives, both leading up to and after transition to adult services. The results may be partly affected by the fact that three of the five services had only been recently set up or re-launched, so families may not have experienced the full impact of these new services at the time of the research. Similarly, across all services, newly developed innovative practices may not have had sufficient time to take effect.

Comparison between pre and post-transition results is limited by the small sample post-transition. However, parents’ responses indicate that unmet need was high for young people post-transition, but not as high as for young people pre-transition with regard to information needs, leisure and social life, benefits/finances, housing, further education, career/employment opportunities, and adult relationships and sexuality. This suggests that young people’s needs in these areas had to some extent at least been met during the transition process. However, levels of unmet need did not decrease for young people post-transition with regard to independent living skills and help with future goals and aspirations. This lack of any progression suggests transition support was particularly weak in these areas. Key to both these areas is PCP, where young people’s aspirations and future goals are identified and the skills and support they will need to enable them to achieve these goals are also addressed. Despite the government’s promotion of PCP and evidence endorsing its success (for example, Robertson *et al*., 2005), interviews with staff confirmed PCP was not routinely practiced with all young people using their service. Transition workers need time and training to communicate and build a relationship with young people to be able to carry out PCP effectively.

The findings also point to a lack of services and options for young people, particularly around employment, housing and social and leisure activities, and in some areas there were difficulties in access to FE college courses. This is consistent with the findings of Morris ( 2002), Dee and Bryers (2003) and Beresford and Clarke (2009). Some staff shared a frustration at the lack of accessible services and opportunities for them. As one senior social care manager said:

> ‘..you can get the assessment process right, you can get a dedicated team set up and you can try and improve….information and

> communication between different agencies, but the bottom line is actually our young people need access to services when they leave school in terms of employment, housing, ....education…leisure…’

Improved multi-agency commissioning of services, based on the priorities and concerns of disabled young people and their families, and greater engagement of transition services with a broader range of agencies, is needed to address these deficiencies. In order to be more effective, transition services should monitor, and have strategies for responding to, unmet need.

However, there was evidence of some good practice, particularly in the provision of transition workers to work directly with young people and their families, and to support them by providing information and advice about the transition process and adult services, liaising with all the relevant agencies, and facilitating young people’s access to services. In this way transition workers were able to build up a body of knowledge and expertise around transition to act as a reference point for both families and other services/agencies involved in their care. On the other hand, staff acknowledged considerable gaps in provision and interviews also revealed problems with understaffing across all services, which meant that not all young people had the support of a transition worker or were able to secure the holistic support they needed. It is important that these services are adequately staffed and systems are in place in all agencies which provide staff to replace staff who leave.

Transition workers often felt powerless to address issues such as lack of appropriate social and leisure opportunities, education, housing and employment options. Despite this, the pockets of innovative practice which emerged from the sattf interviews demonstrate how transition services can help to address some of the unmet need young people experience as they transfer from children’s to adult services. Some services had produced information for young people about transition itself and more generally about options available in leisure, travel, employment, and housing in accessible formats, including paper, DVD and website. A number of initiatives to address the paucity of leisure provision for disabled young people were highlighted; one service provided ‘taster’ sessions of short breaks in supported living facilities; and although staff in all areas reported few opportunities for disabled young people to enter paid employment, they also highlighted a number of initiatives to help young people with work preparation and work experience.

Transition workers also felt that they tried to address young people’s concerns during transition planning and that exploring and planning for future goals was central to their work. They highlighted the valuable role of person-centred planning in this, but again some felt that they were constrained by lack of capacity in the transition service.

Whilst a good transition service can help maximise young people’s access to services that exist in their area, it cannot provide services that do not exist. No matter how good the transition service may be, it will be constrained by both its own funding and resources, and by what is actually available in the area for a young person to transition to. If there are minimal options and opportunities then transition will inevitably be limited. This lack of options in many areas was reported by both staff and parents.

## 8.8 Demand for and supply of services

The eligibility criteria for the 34 services who responded to our survey were quite restrictive, with a main focus on young people with learning disabilities and/or statements of SEN. The case study transition services were no different and interviewees expressed concern about groups of young people that were excluded from their service, particularly young people with moderate learning disabilities, autistic spectrum conditions without severe learning disability, and mental health needs. One of the key drivers of eligibility criteria for the services appeared to be eligibility for adult social care, and the learning disability focus of *Valuing People* may have been influential in the focus of the services. Although the focus of the research was both disabled young people and those with complex health needs, we were unable to find multi-agency services that provided a transition service for young people with complex health needs who did not have a learning disability. The nearest to this was the case study service which had a part time transition worker post to support young people with physical or sensory disabilities. However, this person worked across the whole of a large county and was not able to provide the individual support to young people that the other transition workers in the service provided for young people with learning disabilities. There are some multi-disciplinary services within health that support young people through transition from child to adult health services (for example, Bent *et al*., 2002) but these tend not to be truly multi-agency. New guidance on transition planning for young people with complex health needs and disabilities (*Moving on Well,* Department of Health/Department for Children, Schools and Families, 2008) and the broader focus of *Progression Through Partnership* (HM Government, 2007) may help to change this situation.

The other factor affecting supply of the transition services to young people was the staff shortages which are discussed above, and constrained both the supply of transition workers for young people and the activities transition workers were able to carry out. The effects of this were highlighted in the family survey where although all families approached for the survey were identified by the case study services as receiving, or having received if post-transition, a service from them, the numbers who had a transition worker varied from under half to over 80 per cent in the different services.

## 8.9 Implications for policy and practice

The findings of the research concur with policy recommendations and guidance, and also highlight the extent to which these still need to be implemented in practice. Whilst both the survey and the case studies in this research indicate that some progress appears to have been made in providing better coordination of services at transition in line with the recommendations of the National Service Framework (2004) Standard 8, it is clear that this is patchy and transition support for disabled young people and their families needs further development.

Since 2004, further policies and guidance, particularly *A Transition Guide for all Services* (Department for Children, Schools and Families and Department of Health, 2007) and *Transition: Moving on Well* (Department of Health and Department of Children, Schools and Families, 2008), have provided more detail on good practice in transition planning. The Transition Support Programme, which runs until March 2011, is helping local areas to implement this guidance. Our findings strongly support the principles set out in this guidance and the five principles set out in Transition Information Network's *TransMap* (2009) as the basis of effective transition services:

- Comprehensive multi-agency engagement.
- The full participation of young people and their families.
- The provision of high quality information.
- Effective transition planning.
- An array of opportunities for living life.

The findings indicate some of the barriers services faced in developing such a service, the worryingly high levels of unmet need experienced by disabled young people both pre and post-transition even when there is a multi-agency transition service operating in their locality, and the lack of impact of such services on ameliorating parental stress, with over a third of parents indicating that contact with the service actually increased their stress. Conversely, the findings also point to some of the key factors in providing a good service with positive impacts for young people and families. To help those developing transition services, we make the following recommendations:

### 8.9.1 Development and management of the service

Multi-agency commitment is essential at both strategic and operational levels. This should include contribution of funding and resources and senior level involvement from all agencies, including both children's and adult services, in a multi-agency steering group that develops and oversees the service. The lack of consistent engagement of some key agencies, particularly health, was disappointing and it was suggested that this was attributable in part to competing priorities and targets set by government for different services and limitations of different funding streams. If steering groups are to develop a truly holistic service, they need to have consistent involvement of all relevant agencies. If any members leave the steering group, they should be quickly replaced, so that commitment is not lost. The involvement of parents in this group helps to keep a focus on the needs of young people and families, and in addition ways should be found to facilitate young people's involvement in accessible and meaningful ways.

Part of the role of the steering group is to facilitate information sharing between agencies, but incompatible IT systems present a barrier to this. One case study service was managing to overcome this, and the development of information sharing systems should be prioritised by the steering group. The group also needs to ensure adequate staffing of the transition service and to have systems in place to replace staff who leave so that the service can continue to support families and can maintain the multi-agency team. This was a significant problem in some of our case study services and non-replacement of staff meant that the teams could not fulfil their role and/or that input from a key agency (for example, health) was missing. A high proportion of staff identified better staffing levels as a key improvement needed in their services.

Coordinated and timely funding decisions are crucial to implementation of young people's transition plans, yet transition workers struggled to get plans agreed by and implemented in adult services. This appeared to be better handled in services where the transition workers who supported young people pre-transition negotiated the care package with adult services and continued to support young people until they were settled in adult services, rather than 'handing them over' at age 18 or 19, and in some cases finding that a carefully formulated transition package was then rejected in adult services. When developing services, systems for handling negotiation and funding of adult care packages are crucial. In addition, earlier involvement (before age 17) of transition workers with young people was recommended by staff in the case study services. Differences between agencies in age of transition to adult services can be problematic, and in some areas there was a gap in provision between child and adult health services so that young people were left without services such as physiotherapy. It is important that these issues are addressed at a strategic multi-agency level.

When developing a transition service, a key question is who the service is for. Both our survey and the case studies indicated that existing multi-agency transition services are largely focused on young people with severe learning disabilities. Clearly, these are not the only group of disabled young people who need coordinated support through transition. There is a need, highlighted by managers and staff in the services, to extend the eligibility criteria so that young people with less severe learning disabilities, higher functioning ASCs, and complex health needs without learning disability are supported.

In developing a service, consideration should be given to the model to be espoused. The main models explored in this study were services which had a transition team whose members worked directly with young people and families, and coordinating services, where a transition team or transition manager/coordinator supported existing services in working with young people through transition. Whilst there appeared to be somewhat greater advantages for families from designated teams, the coordinating model worked relatively well in an area where the transition manager supported a virtual team of social workers from children's and adult services who worked directly with the young people. This was a small area with good relationships between services and it may be that this model is more suited to that type of locality.

It is important that knowledge of the transition service is widespread among agencies that work with disabled young people, yet this was often not the case. The steering group and the manager of the transition service have crucial roles to play in ensuring that other agencies are aware of and understand the role of the service. In particular schools and colleges need to be informed of the name of any student's transition worker and kept up to date with relevant reports. It also appears to be valuable for the service manager to have input at key strategic groups, both as a champion of the transition service and in providing communication between operational and strategic levels of the service.

A vital part of the planning and management of a transition service is monitoring process, outcomes and levels of unmet need. This did not appear to be happening effectively. The lack of written transition plans for families, the impacts on parental stress, the high levels of unmet need, and reports of low levels of support for young people in out of area placements all suggest that services have a long way to go before they can be seen to be addressing most of the priorities of young people and their families. Some of this may be attributable to the fact that some of the services were still developing. The managers and practitioners we interviewed recognised the lack of resources and opportunities for young people and highlighted the need for improvements in many of the areas of unmet need found in the research. However, few identified support to address parental stress, importance of ensuring young people and parents had copies of transition plans, or coordinating and ensuring adequacy of support for young people in out of area placements, as important areas for improvement in their services.

### 8.9.2 The role of the transition workers and teams

There should be a clear definition of the role of transition workers, whether these are designated or non-designated. This should include their coordination role in working across agencies, their role with the young person and their parents, their role in negotiating a care package with adult services, and the extent of their involvement with young people after transfer to adult services. The service manager should ensure that all transition workers understand their role and explain it to young people and families. Similarly, the manager and team should ensure that other services in the locality understand the role. In order to carry out the role, transition workers need training, including on the roles and procedures of different agencies and organisations involved in providing support for disabled young people, person-centred planning, specific conditions and disabilities, and communication with disabled young people.

Past research has found a lack of attention to young people's own aspirations in transition planning, and person-centred planning is a means of addressing this. However, only one of our case study transition teams implemented PCP with all young people. In other areas, staff said they wanted to implement it, and some had been trained in PCP but said they did not have the capacity to do it. The resource implications of PCP clearly need to be addressed when developing transition services and making decisions about staffing levels. In addition, the role of independent advocates and their relationship with transition teams should be considered. Although the evidence on independent advocacy is limited, a recent review (Townsley *et al*., 2009), suggests that advocacy can lead to increased involvement of young people in transition planning, better quality service provision following transition, and have positive effects on professionals' behaviour and knowledge and disabled young people's personal development.

### 8.9.3 Type of transition worker

The findings suggest that services which have designated transition workers are likely to be more effective for young people and families than those with non-designated workers. One of the issues raised by staff who worked on transition as part of a broader case load was the difficulty they faced in prioritising transition, and the effect of the demands of other aspects of their work, particularly child protection. These workers felt that they were not able to give enough time and attention to transition cases. This impacted on their ability to support person-centred planning and to have the time to build up a relationship with young people and communicate with those young people who had communication impairments.

The professional backgrounds of transition workers varied between and within services, as is appropriate for multi-agency services. The most common professional background was social work. We were not able to compare effects for families of different professions as we did not have accurate information on the background of the individual transition worker for every family. However, the findings indicated that the service where transition workers were Connexions workers had higher ratings on satisfaction and lower scores on unmet needs than some of the other services. The picture is complicated because this was the service where the proportion of families who had a transition worker was highest, but it does suggest that it is not necessary for transition workers to be social workers.

### 8.9.4 Transition planning and information

Past research has identified the importance of information and good communication with young people and parents around transition (for example, Forbes et *al*., 2002; Heslop *et al*., 2002) and policy and guidance also emphasises the need for high quality information. Our findings indicate that this is a crucial part of an effective transition service. However, it is an area where further development is needed. A substantial number of families did not have a written transition plan, and many were vague about when transition planning had started for their son or daughter. It may be that some of these families had received a plan but did not recall this, but what this shows is that for many families transition plans were not clear and they had no documentation that they could refer to and that was regularly reviewed with them. It is important therefore that services prioritise young people’s and parents’ involvement in drawing up transition plans and in regularly reviewing these plans, and ensure that families have a record of all plans that are made.

The other aspect of information is ensuring the young people and parents have information about the transition service and about opportunities available for young people. Three of the case study services had comprehensive information packs, and DVDs and a website also provided examples of good practice in information provision. Provision of information and ensuring that this is used with, and accessible for, young people and parents is an important aspect of a transition service.

### 8.9.5 Meeting young people’s needs

Transition services cannot directly meet all needs and they are dependent on the resources and other services available in their local area. Our findings on unmet need suggest that transition workers are important in finding opportunities for young people, and interviews with staff provided some examples of good and innovative practice in local areas, some of which were connected to policy programmes like *Getting a Life*. However, there are still considerable shortfalls in opportunities for young people to be involved in positive activities both before and after transition to adult services, particularly a lack of options around employment, housing and social and leisure activities. It is important that holistic assessment of needs is part of the multi-agency transition service and that the service collates data on unmet needs to inform future service development. This study was carried out before the new policies of *Valuing People Now* and *Valuing Employment Now* (HM Government, 2009a and b) were published and before the Individual Budgets pilots for disabled children commenced. These initiatives have the potential to make a substantial difference to the unmet needs found in this research. However, it will be important that such developments are not limited to support for young people with severe learning disabilities and, as has been suggested for transition services, that they address the needs of a broader range of disabled young people.

The difficulties that some areas experienced in access for young people with severe or profound disabilities to FE college courses were of concern, and limited the opportunities available to young people. Funding policies linked to academic progression may disadvantage these young people. This varied considerably between different FE colleges and different areas, and is clearly an issue that needs to be addressed in many areas. As yet it is unclear what impact the recent changes in the administration of funding for FE, from the closure of the Learning and Skills Council to the creation of the Young People's Learning Agency and the Skills Funding Agency (*The Apprenticeships, Skills, Children and Learning Act 2009 (Consequential Amendments) (England and Wales) Order 2010*), will have on education provision for disabled young people.

A wider issue about the negative effects of the different performance indicators and targets that different agencies had to work to was raised by a number of managers and practitioners, and is also noted in section 8.9.1. This tended to militate against meeting young people's needs by limiting how resources could be used, limiting flexibility in transition planning, and preventing the development of a common transition assessment. Whilst considerable progress has been made over recent years in joint working for disabled children and young people, conflicting performance management regimes are still barriers to a truly coordinated and holistic approach to meeting young people's needs. This issue requires action at both central and local levels and has been highlighted by the *Total Place* initiative (www.localleadership.gov.uk/totalplace) which was launched after this research was completed.

The current economic situation and the expected cuts in public services raise serious concerns about their potential impact on transition services for disabled young people. This research indicates that such services are often fragile and dependent on short term funding. Such funding is likely to be at risk. In addition, at times of cuts individual agencies may withdraw from multi-agency initiatives that are still in their infancy. If this happens, it could lead to even higher levels of unmet need and poorer outcomes for disabled young people transferring to adult services.

## 8.10 Implications for future research

In Chapter 1, we summarised the findings and recommendations of previous research, and the gaps in current knowledge. This study has contributed further evidence on which aspects of transition services make a difference to the experiences of disabled young people and their parents. It confirms many of the conclusions of Forbes *et al*.'s review (20002): for example, the importance of multi-agency transition services and specialist transition workers who can understand the issues and anxieties faced by young people and parents, can introduce young people to adult services and support them to adjust to their new care package; of transition planning and provision of information; and the importance of parent involvement in service planning. It also points to some of the developments that are needed to support such services to function effectively. The study has also provided some much needed information on the costs of transition teams, the ways they support young people and families and the costs of that support.

However, it is a cross-sectional study and further exploration following the experiences of young people and the services that support them as they move from children's to adult services would help to further define good practice and needs for future development in services. In addition, research on the effects of the newer policy developments and how they impact on practice would be valuable. The cross-sectional design of this study has meant that it has not been able to explore the cost-effectiveness of different models of transition services. In the first instance, short-term studies would be possible but they would require a larger sample, a comparative design, and data collected over time: at the minimum as young people are identified for transition support and after they have transferred to adult services but longer-term outcomes, following young people through to adulthood would be ideal.

The research set out to examine multi-agency transition services for disabled young people and those with complex health needs. It is disappointing that we were unable to find any such services that covered a broad span of disability. The focus of services' eligibility criteria on learning disability means that the findings have little to say about support for young people with complex health needs or those with ASC who do not have a learning disability. Whilst we found no differences in outcomes between young people with ASC who did have a learning disability and the rest of the sample, staff had concerns about support for young people with higher functioning ASC. Further research is needed on the experiences of this group. When exploring possibilities for case study areas, we were unable to find a multi-agency service for young people with complex health needs, but did find health based services. It would be useful to investigate such services and the ways in which they address the broader needs of young people and involve other agencies.

Although the transition services in this study involved a number of agencies, the study did not look at the impact of the work of the transition services on other agencies and professionals outside the service itself. A further research area is how transition workers are perceived by and assist with the work of, or generate more work for, other agencies, such as Youth Services, Housing, and the Benefits Agency. Finally, more in-depth work with young people is needed to explore their experiences of transition services and their aspirations for adult life.

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