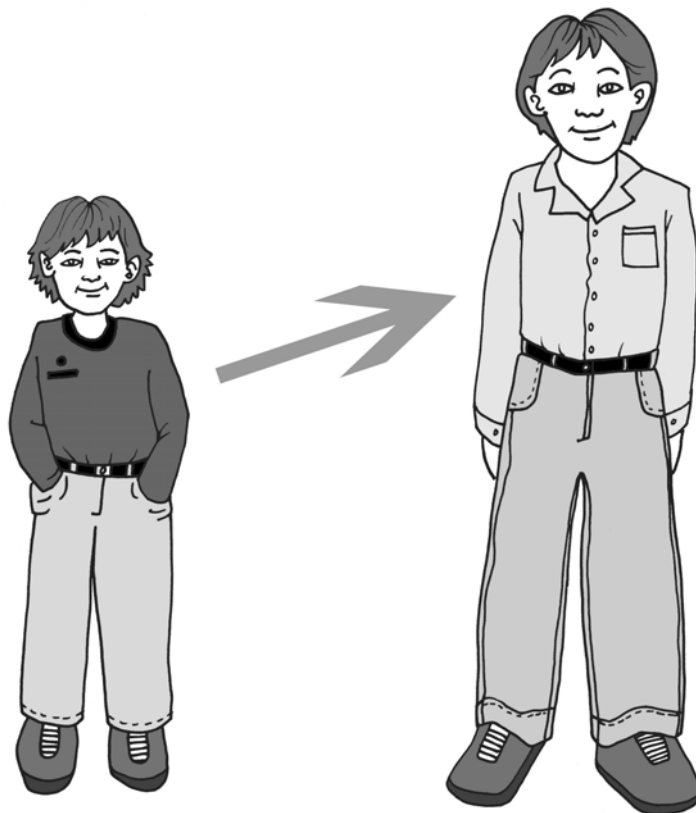


The Road Ahead?

Literature Review

What does the literature tell us about the information needs of young people with learning difficulties and their families at transition?



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Introduction

This report is about the information needs of young people with learning difficulties and their families at transition to adulthood. It summarises key themes from the UK literature (journal articles, magazine articles, conference and research reports, books, and unpublished documents) about the process and experience of transition for young people with learning difficulties and their families. It also draws out key areas of information need for young people and families in the form of a list of topic areas and questions at the end of each main section.

The literature review is just one part of a wider project called '*The Road Ahead?*', commissioned by SCIE (Social Care Institute for Excellence) from the Norah Fry Research Centre (University of Bristol) in collaboration with the Home Farm Trust and North Somerset People First. The aim of the project was to find out what young people with learning difficulties and their families wanted from a website about transition. The work involved extensive consultation with young people and families, as well as a review of existing resources for young people, families and supporters.

Appendix A gives more details of '*The Road Ahead?*' project; Appendix B outlines the search strategies used for this literature review.

1

What is transition to adulthood?

The process of moving from childhood to adulthood is a difficult time for most young people. As Heslop et al (2002) put it:

'We make many transitions in our lives, but perhaps the one with the most far-reaching consequences is the transition into adulthood.' (Heslop et al, 2002)

Alongside the many physical and emotional changes that are part and parcel of adolescence, growing up also involves changes in roles, relationships, expectations and status - within family, amongst friends and within the wider community of home, school and work. For many young people, leaving school or leaving home at this life-stage can mean huge changes in the environments where they live and spend their days. As if these challenges were not enough, for the vast majority of young people with learning difficulties the process of transition to adulthood has an extra dimension: managing the move from services for children, to services for adults. As Heslop et al (2002) point out, this is not simply a case of moving from one set of organisations targeted at children to a parallel entity concerned with adults. The reality is that the two sets of services tend to be organised in very different ways and to have very different cultures.

The literature in this field refers to many and varied ways of conceptualising the notion of transition to adulthood. Some authors have looked at what factors make a 'successful' transition for young people, whilst others have focused on socially determined 'markers' of adult status. Ward and Thompson (1997; quoted in Clegg et al, 2001) identified the following factors which make transition successful for young disabled people: employment, independent living, economic self-sufficiency, uptake of postsecondary education, adult role-taking and social participation. Hudson (2003) proposes a three-fold framework for addressing transition for young people with learning difficulties. The framework includes paying attention to inputs (what does a successful transition programme need to cover?), process (how is the programme to be delivered?), and outcomes (how can effectiveness be determined?). He goes on to suggest that indicators of a successful transition for young people with learning difficulties might include: a high uptake of post-secondary school education, employment or economic self-sufficiency, personal independence, social competence, taking up an adult role at home and/or in society.

Fish (1986; quoted in Mitchell, 1999) identified a number of markers of adult status, including: employment, useful work and valued activity, personal

autonomy, independent living, social interaction and community participation. Similarly Ferguson et al (1998; quoted in Blacher, 2001) suggests that transition to adulthood for young people with learning difficulties may be conceptualised in terms of (a) status transitions (events directly involving the young person such as leaving school, getting a job, moving out of the parents' home); (b) family life transition (changes or disruptions to the family's established routines and responsibilities that make daily life manageable); and (c) bureaucratic transition (the shift to adult services).

Mitchell (1999) points out that most notions of adulthood refer to culturally valued markers and symbols of social respect and status, thus inferring that elements of power, independence and autonomy are involved in the transition to adulthood. Her own study (of special school leavers) advocated a more flexible notion of transition, which acknowledges gradual changes within the life-course and respects the ideas and aspirations of families and young people.

An acceptance that achieving adult status is qualitatively different for young people with learning difficulties is central to much of the literature covered for this review. From the point of view of those involved in providing services to young people with learning difficulties, transition to adulthood begins at age 14 (Year 9) and continues until the young person leaves school (age 16 or 19) or post-compulsory education (up to age 25). However, the reality is that planning for the future is an evolving process, with the recognition that leaving school or college is just one step along the path of a longer journey (Heslop et al, 2002). As Mitchell (1999) has noted, transition to adulthood for special school leavers continued over the whole life-course. For people with learning difficulties, for example, the adult marker of leaving home may not occur until much later life, or when a parent or carer dies. Similarly, Hussain et al's (2002) study of the experiences of South Asian disabled young people and their families found that for these young people, independence was more about exercising control over their lives than about leaving the family home. Research by Skill (2003) the National Bureau for Students with Disabilities, emphasised the importance of **interdependence** (as opposed to independence) as a marker of success at transition for young people with learning difficulties from a South Asian background.

Indeed, several authors have pointed out that generic notions of transition and adulthood do not necessarily ring true for all young people. Small et al (2003) argue that the experience of transition for young people with learning difficulties is markedly different to the experience of transition for other young people. They make the point that recent developments in the sociology of youth, which emphasise an individualised notion of choice and opportunity, have not recognised the centrality and importance of social networks and family relationships in the lives of young people with learning difficulties. In a similar vein, Tisdall (1994) argues that models of transition lack a consensus on the criteria for a 'successful' transition and fail to incorporate the views of young

people into the debate. The author advocates a model of transition based on citizenship which would include greater connexions between advocacy organisations of disabled people and young disabled people.

So how do young people with learning difficulties conceptualise transition? Very few published studies have asked young people about what transition to adulthood means to them. A rare exception is Heslop et al's (2002) study which asked young people with learning difficulties what would make them feel 'grown up'. One of the most frequent responses was 'a job', alongside responses to do with chronological age, the passing of birthdays, getting married and moving away from home. For many young people in this study, getting a job and thus having money that they had earned themselves was **the** marker of adulthood.

Mitchell's (1999) study also highlighted a number of important factors and signifiers of 'adulthood' for special school leavers:

'Ian valued having his own front door key. For Laura, caring for her disabled boyfriend provided an important sense of self-worth and a recognised social role.' (Mitchell, 1999)

As these examples demonstrate, one defining feature of the sorts of goals and perceptions that young people with learning difficulties have at transition is that these are almost always commonplace and realistic. Williams' (2003) work with young people with learning difficulties with mental health needs found that they wanted some very ordinary things at transition: work, independent living, friendships.

A number of pieces of smaller-scale consultation work with young disabled people and young people with learning difficulties in the UK have highlighted that many young people have spent time thinking about future choices and what being an adult means to them. A weekend drama workshop/consultation with 18 young disabled people in England (Barnardo's, undated) identified the following key issues at transition: leaving home, getting a job, friendships and relationships, but also found that these are often the last issues to be discussed by professionals. When asked what transition meant to them, the young people gave the following replies:

- Growing up
- Progression from one experience to another
- Maturity and doing things differently
- Rights and responsibilities to yourself and others
- Making your own choices and decisions
- Taking risks and making mistakes
- Changes from being treated like a child at school and an adult at college
- Big steps (from school to college)
- Taking exams

- Leaving home and the family
- Living with who you want to
- Friendships - leaving old friends and making new ones
- Job opportunities and working
- Emotional transition and that is not just about your body
- Anger, stress and frustration
- Get on well and not to be treated as different to other young people
- Relationships and forming close sexual relationships. (Barnardo's, undated)

Another consultation with young disabled people in Southampton (England) had broadly similar findings. The main things young people wanted to achieve at transition were to go to college, to go to work and get a job, to earn money or to leave home (Choices Advocacy, undated).

For families, perceptions about what transition to adulthood might mean for their son or daughter will most certainly be tinged with fear and anxiety about the future (Ward et al, 2003d; Goupil et al, 2002; Mitchell, 1999). The families involved in Mitchell's (1999) research experienced conflicting emotions at transition. They wanted to encourage future aspirations, but also feared undue disappointment for their son or daughter. The role that families play in promoting and encouraging positive, appropriate and realistic goals for their adult children is a common theme in the literature on transition. Cooney's (2002) study found that parents' goals for their adult son or daughter with disabilities included having a sense of fulfilment through the use of talents and abilities, contributing to the greater community and keeping him or her safe from harm. Parents emphasised their youngster's strengths and capabilities and were positive about his or her ability to achieve a promising adulthood. This was not reflected by professionals who focused on areas of limitation and discrepancy and tried to match young people's 'needs' to the current service situation.

Transition can be a very challenging time for families on many levels and will also mean a transition for them, into a new role as parents of young adults (Russell, 2003). For non-disabled youngsters, there is an expectation that parental involvement and influence in the young person's life will diminish with the transition to adulthood. But for young people with learning difficulties, this is a time when more, not less, parental involvement is likely and indeed necessary. Some of the families involved in Heslop et al's (2002) study found that they had less independence from their youngsters as they approached adulthood than when they were still at school. This is a theme to which we will return in section five.

Key areas of information need for young people with learning difficulties and their families:

- What does the transition to adulthood mean to young people with learning difficulties? What does it mean for their families?

- What sorts of life changes might young people with learning difficulties and families expect at transition? Over what period of time?
- What do young people and families think makes for a 'successful' transition?
- The importance of recognising that transition is a process, not a series of discrete events. And that transition to adulthood may be achieved in many different ways and time-frames. Transition to adulthood for people with learning difficulties may take significantly longer than for other young people and indeed 'markers' of adult status may continue to be achieved throughout life, not just between the ages of 14-25.
- There will be different issues to consider for young men, young women, young people from Black and minority ethnic groups, young people with high individual support needs, and young people living away from home. Transition to adulthood means different things to different people.

2

Changes at transition

Transition to adulthood is a time of change and includes coping with:

- Changes involved in becoming an adult – legally, socially and physically.
- Changes related to the move from children's services to services for adults.

Legal, social and physical changes

Becoming an adult involves a shift in legal status. For young people with learning difficulties, legal changes will involve the right to vote and the legal right to make their own decisions, with support if necessary. Legally, adulthood occurs when a young person reaches the age of 18, although in reality many young people will have taken steps towards adulthood long before this.

Decision making is an important part of both becoming an adult and the transition process itself. But young people with learning difficulties often get very little practice in making choices until they are presented with what can seem like an overwhelming array of decisions to make about the future (Thoma et al, 2001). A recent action research project in England (Carnaby et al, 2003) evaluated the involvement of students with learning difficulties in their transition review meetings during their final year of special school. The researchers found that many students were excluded from meaningful discussion, mainly due to a lack practice and preparation. The school developed more individualised ways of working using person-centred techniques to enhance meaning, and staff spent time and effort with the young person and their family over several sessions to ensure that the transition review meeting was not the first time for discussion and decision making about the student's future.

As well as opportunities for practice in decision making, young people and families also need information about support to make choices. There is scant published evidence of the provision of independent advocates and peer-support schemes for young people with learning difficulties. One exception is the 'Trans-active Project' (Pennington, 2001) which set up a buddying scheme pairing young people with learning difficulties from special schools with their mainstream peers. The project wanted young people with learning difficulties to be able to make more informed choices about their future through sharing experiences with non-disabled youngsters. The project provided support for the initial bonding process via a residential weekend. Teenagers then worked together on different topics relating to transition, such as advocacy, education, living skills, working, leisure and friendship. By using photos, video clips and other multi-media

techniques each child was able to create a CD Rom (or 'transition passport') to express their views and spell out their own choices. Interestingly, the project found that mixing with non-disabled peers in this way broadened the horizons of young people with learning difficulties and encouraged them to aim 'higher' in terms of their future goals than they would otherwise have done.

The new Connexions service also offers opportunities for practice and support in decision making through the provision of a Personal Adviser for all young people with learning difficulties. In their study of the role of Connexions in supporting young people with disabilities and/or learning difficulties, Rowland-Crosby et al (2003a) found that young people appreciated the preparatory meetings and individual planning work that their Personal Adviser offered. In a separate study of the Personal Adviser role in two special schools and an FE college in Lewisham (England), students said that they liked having an independent person with whom they could discuss their plans and ambitions. Families also liked having someone who had no other agenda and would try to understand their needs, even if they had no immediate way of meeting them (Grove and Giraud-Saunders, 2003). A fuller discussion of the role of Connexions in supporting young people at transition follows in section four.

Another element of legal and social change at transition relates to benefits and financial matters. As Heslop et al (2002) have noted, financial resources are a key factor in young people's participation in activities that are part of becoming an independent adult. At transition, some of the benefits that were previously paid to a parent, or carer will start to be paid directly to the young person with learning difficulties. At the age of 16, young disabled people can also claim new benefits relating to their adult status. A consistent theme from the literature is that young people with learning difficulties and families need more information about benefits and how these change at transition (Ward et al, 2003d; Edinburgh Youth Social Inclusion Partnership, 2001; O'Sullivan, 2001). Very few of the parents involved in Heslop et al's (2002) study had received good, accurate information from professionals about claiming benefits at transition. Their information was gleaned in an ad-hoc way from a variety of sources – information days at school, benefits promotional events, organisations for disabled people or carers, or just by chance.

Managing and handling money can also be a great source of anxiety to youngsters, and many young people with learning difficulties have reported worries and difficulties in this area (Ward et al, 2003d). Access to money and learning how to budget appropriately are important aspects of the transition to adulthood. Yet few of the young people involved in Heslop et al's (2002) study managed their own money, or had received support to do so.

The Life Options Project in Wales is supporting families and young people with learning difficulties at transition (Life Options, undated). One of the key areas covered focuses on support to 'control your own money and benefits'. There is a

particular emphasis on exploring the use of direct payments and the Independent Living Fund to enable financial independence and support a wider range of options at transition. For young disabled people, it is well established that direct payments, the Independent Living Fund and Disability Living Allowance are key benefits for supporting transition, leaving home and enabling autonomous adulthood (Hendey and Pascall, 2001). The role of direct payments in transition planning is relatively unexplored, but has great potential given that the Carers and Disabled Children Act 2000 extended direct payments to disabled 16 and 17 year olds (Hudson, 2003). However, it appears that some social services departments are not encouraging the discussion of direct payments with young people as part of their transition from children's services to adult services (Rowland-Crosby et al, 2003a) and take-up of direct payments by young people with learning difficulties is very low (Hudson, 2003). Russell (2003) suggests that it is vital to develop the role of the Independent Living Fund, the Access to Work Scheme and direct payments for younger disabled people to encourage flexible and appropriate personal support and enhanced access to education, training and employment.

In tandem with the move towards legal independence (in terms of decision making and financial matters) comes an emphasis on social independence. This involves developing independent adult friendships and relationships and taking more responsibility for one's health and personal safety.

Safety and risk is a major concern for families and young people with learning difficulties at transition (Ward et al, 2003d; Heslop et al, 2002). At transition parents may face the dilemma of wanting to create opportunities for independence for the young adult and wanting to assure that health and safety needs are met. They understand the importance of independence and letting go but they often do not know whether their child can do an activity or whether or not it is safe to try (Thorin et al, 1996). Parents may expect adult services to create the same sort of 'safe' environment previously provided by school and may favour 'special' clubs, segregated day services and facilities with high levels of supervision and transport available door-to-door (McConkey and Smyth, 2003).

The literature points to a strong need for more information and support for parents in coping with issues of safety and risk at transition (Ward et al, 2003d), as it is one of the key areas that can inhibit young people's moves towards independence (Heslop et al, 2002). The only study found by this review which focused entirely on the topic of safety and risk as it relates to young people with learning difficulties at transition is the work of McConkey and Smyth (2003). This study explored and compared parents' perceptions of risk with the perceptions of their teenage sons or daughters who had just left school. Parental reports stressed the amount of care and supervision required by the young people. They talked about the need to attend to the young person's personal care needs (washing, dressing, feeding, shaving), household tasks (cooking, laundry), the need for constant supervision, the need to be escorted outside, help with travel,

giving medication, managing money, giving prompts and reminders, reading and writing, telling the time. Parents viewed their youngsters as vulnerable to various hazards commonly undertaken by non-disabled teenagers such as crossing the road, staying in the house alone, using household appliances, using public transport, going out with friends with learning difficulties, and going to town on their own. Less than half (45%) of the parents interviewed were prepared to risk their son or daughter learning to do any of these tasks, and 44% rated their youngster as being unable to do any of the tasks. In contrast, only 22% of young people rated themselves as being unable to do any of the tasks. Parents had a particular fear of sexual abuse against their son or daughter, although for young people, the bigger risk – going by their own reports – was verbal abuse and bullying from peers (McConkey and Smyth, 2003). The authors suggest that this sort of danger-avoidance strategy restricts young people's freedom of choice and autonomy and may lead to loneliness and inactivity. The alternative is what they have termed a 'shared risk' strategy where parents, young people and professionals explore their mutual perceptions of hazards and work together to reduce risks.

The model of parental risk-taking posited by McConkey and Smyth is interesting, novel and potentially very significant as a tool for supporting families and young people with learning difficulties to cope with risk and uncertainty during the transition to adulthood. It involves professionals, families and young people working actively together to identify the key elements in managing the risks inherent in moving towards adulthood and independence. It also highlights the need to promote and confirm the competencies of young people through continuing education and the need to practise these in real-life settings rather than in classrooms. Implementing the model requires close partnership between young people, parents and professionals, parent-to-parent contact (in terms of sharing experiences and learning from each other), and parental involvement in life-skills training. It also requires greater emphasis on self-advocacy, and advocacy, for young people, to enable them to demonstrate their competence, argue for positive consequences, propose conditions that are acceptable to them and become active collaborators with others in assessing risks (McConkey and Smyth, 2003).

Taking increased responsibility for one's health is another aspect of the changing nature of relationships between young people and their families at transition. Any move into independent living away from the family home will involve changes in routine, exercise and diet. Young people with learning difficulties need information about how to keep themselves well and healthy by eating a balanced diet, doing exercise and feeling good about themselves. They will also need information about getting regular health checks (Pearson et al, undated). By 2005 all young people with learning difficulties moving from children's to adult services should be offered a Health Action Plan to help them be more actively involved in their own health and well-being (Department of Health, 2001). Families and young people need information about what this means for them,

and how the health action planning process will be implemented and managed (Ward et al, 2003c).

Another aspect of life that will almost certainly change in the move towards adulthood is the nature of friendships and relationships. It is inevitable that friendships will come and go as young people move on from school or college and into other learning or work-based environments (Heslop et al, 2002).

The issue of friendship was one that was most prominent in interviews with young people with learning difficulties at transition carried out by Heslop et al (2002). Young people were concerned both about the difficulty of leaving friends behind when they moved on from school or college, and about the issue of boyfriend/girlfriend relationships. Many other studies have identified that friendships and relationships are two of the most important aspects of young people's lives at transition (Morris, 2001, 2002; Pennington, 2001; Smyth and McConkey, 2003; Williams, 2003; Barnardo's, undated).

Several studies have shown that young people with learning difficulties face numerous barriers to an independent social life, and to sustaining friendships (Edinburgh Youth Social Inclusion Partnership, 2001; Morris, 2002). Morris (2002) suggests that some of these barriers – lack of one-to-one support, independent access to transport and communication technology, high degree of adult surveillance, lack of access to a peer-group – should and could be the focus for input during transition planning. And yet discussions about friendships are rarely reflected in assessments, reviews and transition planning (Morris, 2002; Heslop et al, 2002). The young people involved in the 'My Voice, My Choice' consultation had a range of ideas for promoting and sustaining friendships including the following:

- Be pro-active in inviting friends round.
- Positive body language about young disabled people having friends.
- Finding things in common and sharing common interests and opportunities.
- Involving us in making decisions and giving us real choices and the things we want to do.
- Treating everyone the same as equals.
- Being able to take friends for a coffee or a pint.
- Be around friends when they are feeling down or unhappy.
- Understand that we want to have a normal social life. (Barnardo's, undated)

Sexuality and sexual relationships with boyfriends/girlfriends also feature as important issues in transition to adulthood for all young people, but may be overlooked or not viewed as important by professionals and families of young people with learning difficulties (Morris, 2002). Sex education should be covered as part of the national curriculum for all young people with learning difficulties. However, many young people will need much more input than this, particularly in terms of handling relationships and the emotional complexity that is involved in

developing and sustaining adult sexual relationships. It is also important to include issues on same sex relationships as part of sex and relationship education. Young disabled lesbian, gay and bisexual people need support and information relevant to their own experience (Stewart and Ray, 2001).

Half of the young people interviewed by Heslop et al (2002) had a boyfriend or girlfriend and many of them mentioned the difficulties of negotiating roles and boundaries within this friendship. Parents too talked about the difficulties inherent in supporting their son or daughter's developing relationships. Feelings and views were mixed – some parents did not believe that a sexual relationship was possible for their youngster whilst others were more relaxed and accepted that it was happening. However, almost all parents involved in Heslop et al's (2002) study described feeling 'at a loss' as to where to go for advice or support. This finding is mirrored by the work of Clegg et al (2001) who found that parents of young people with learning difficulties reported being unable to obtain advice about issues relating to sexuality, body changes and maturation during the transition to adulthood. There is a clear need for more support and information to enable parents to have the opportunity to explore their thoughts and feelings about their son or daughter's developing sexuality and adult relationships.

Changes related to the move to adult health and social services

For most young people with learning difficulties and their families, transition to adulthood also involves managing the move from children's services to those aimed at adults. Overwhelming evidence from the literature suggests that this aspect of transition is likely to be characterised by a poorly co-ordinated hand-over and reduced quality of service (Rosen, 1995; O'Sullivan, 2001; Ward et al, 2003c).

The move to adult social services is not automatic, and in most cases will involve an assessment (for all children aged 14 and over with a statement of special educational need) against the criteria of the Disabled Person's Act 1986. If, following the assessment, a young person is thought to require services from the local authority on leaving school, then a social worker is supposed to take responsibility for co-ordinating with the school and should attend transition review meetings until the young person leaves full-time education. Once a young person reaches the age of 18, their needs are assessed under the NHS and Community Care Act 1990 and a Community Care Assessment is carried out. If the person is eligible for support from the local authority under this assessment, then a Care Plan will be drawn up outlining what support is needed and how it will be provided. The disabled person or their carer should get a copy of the Care Plan and it should be reviewed regularly. If the person is not eligible for community care, the social worker should give advice about other organisations that might be able to offer support. If the person disagrees with the result of the assessment, they can appeal against it.

The explanation outlined above is a pen picture of what **should** happen in the transfer between children's and adult social services. The reality, as recent research has shown, is rather different. Rowland-Crosby et al (2002) have found that social workers and other social services staff are unlikely to be involved at transition, despite the duty placed upon them to play a role in transition review meetings. In their study, there was only one example of social services and Connexions working together successfully and this was where there was a transition co-ordinator in place who was working alongside the Connexions Personal Adviser. Similarly, Heslop et al (2002) found that for more than 40% of the families involved in their study, transfer to adult social services had not been dealt with at all at transition. Although a small number of families mentioned good relationships with a social worker, rather more talked about late involvement of social services, a lack of input at transition planning meetings, lack of commitment to the young person, and a lack of co-ordination between children's and adult social work teams. Other specific issues highlighted by other studies include: difficulties in accessing assessments, funding and provision of equipment (Morris, 2002; quoted in Thornton, 2003) and confusion about who pays for communication equipment with the result that many families may end up doing so themselves (Morris, 1999).

Positive examples of a successful move to adult social services appeared to be where families and young people had been supported by a nominated transition worker from social services, or where a good relationship had been developed with a committed and efficient social worker. Clearly there is a need for accurate information for families and young people about their rights to services and support from adult social work teams at transition, and about the roles played by social workers and/or transition workers and how these interlink with the roles of other key professionals. Information about making complaints and appeals may also be appropriate here, given the context of poor service delivery and failure to meet statutory responsibilities.

Regarding health services, many children with learning difficulties will see a paediatrician if they have to attend hospital for treatment. They may also see professionals from the community child health service. In most areas of the UK, the expectation is that between the ages of 16 to 18 a young person with learning difficulties will transfer to adult health specialists or be seen in an adult clinic. A range of legislation sets out the duties of health agencies to provide services during transition (Heslop et al, 2002). The Code of Practice (DfES, 2001) says that health professionals involved in the management and care of the young person should provide advice towards transition plans in writing and where possible, attend the annual review meeting in Year 9. They should advise on the services that are likely to be required and should discuss the transfer to adult health care services with the young person, their parents and their GP. They should facilitate any referrals and transfer of records, subject to informed consent and should liaise with Connexions (Ward et al, 2003c). Young people with learning difficulties at transition have also been identified as a priority group to

receive a Health Action Plan (Department of Health, 2001) which should cover a young person's need for health intervention as well as health promotion.

However, despite the policy rhetoric, studies have shown that transfer arrangements to adult health services for young people with learning difficulties are not working well (Heslop et al, 2002; Ward et al, 2003c; Morris, 1999; O'Sullivan, 2001). Problems have included:

- Poor hand over – young people and parents did not get to meet the adult team prior to the next outpatient appointment or hospital admission (Heslop et al, 2002).
- Reduced quality of service – regular appointments were replaced with 'as you need us' approach (Heslop et al, 2002).
- Increased likelihood that health problems were overlooked or mis-diagnosed, and continuity and consistency lost (Heslop et al, 2002).
- Diminished therapy services (O'Sullivan, 2001).
- Conflicting advice from paediatric and adult therapists (O'Sullivan, 2001).
- Hospital service transitions were unco-ordinated (O'Sullivan, 2001).
- Lack of information about how to find adult health services – no provision of written information such as a list of addresses (O'Sullivan, 2001).

Ward et al (2003c) highlighted that where hand-held records were available for families, which had information on the health of the youngster and could be taken from children's to adult service, these were highly valued and appeared to be a useful way of facilitating a smoother transition. Young people themselves say they want more information about their medical conditions, impairments and treatments at transition, but research shows that this is not always given to them or not in ways that they could use (Morris, 1999).

Two studies from the USA also make helpful suggestions about how to better prepare for the transition to adult health services. Rosen (1995) suggests that:

- Preparations for transfer should include an introduction, preferably by the current paediatric provider to the new physician and care co-ordinator.
- Differences in practice philosophies and style between the current paediatric setting and proposed adult setting should be discussed fully.
- A careful transition plan, created together by patient, family, and existing and new providers, can safeguard against unexpected or abrupt changes in management.

A second North American study conducted by Geenen et al (2003) looked at the role of health care providers during the transition of adolescents with disabilities and special health care needs (including children with developmental disability and multiple disabilities). The study sought to clarify what the role of health care providers should be in assisting young people during transition, and found that the following activities were important to families:

- Taking care of my child's general health
- Taking care of my child's disability
- Co-ordinating my child's health with other health professionals
- Helping my child get health insurance
- Helping me find a health care provider when my child becomes an adult
- Teaching my child to manage own health
- Working with the school to co-ordinate care
- Discussing with my child how to take care of his or her health to be successful at work
- Connecting my child to other services in the community
- Screening my child for mental health problems
- Talking to my child about drugs and alcohol
- Talking to my child about sexual issues
- Helping my child apply for or keep Social Security income.

The importance of a co-ordinated approach to health care transfer is vital to ensure that a young person's health needs continue to be adequately and appropriately met. A recent retrospective cohort study (Bent et al, 2002) compared outcomes for young people with physical disabilities at transition to adult health services. One group of young people were receiving unco-ordinated, ah-hoc health services. Another group were receiving a more co-ordinated YAT (young adult team) approach. YAT services involve multi-disciplinary specialist teams developed specifically to facilitate transition from childhood to adulthood services, and typically include a consultant, psychologist, therapists and a social worker. These professionals are likely to be working in most health services, but the pattern of service delivery is usually individual professionals working in isolation. This very extensive and carefully constructed study found that young disabled people who had access to YAT services were more likely than those who used ad hoc services to participate in society. It also found that both types of service cost the same amount to provide.

Key areas of information need for young people with learning difficulties and their families:

- Becoming an adult involves a shift in legal status. What changes might young people with learning difficulties and families expect to family life, routines, responsibilities, and in the shift from childhood to adult services?
- Making your own decisions – what sorts of decisions do adults make? What practice and support can young people with learning difficulties (and families) get to help them learn to make their own decisions?
- Looking after yourself – what sorts of things might families expect to do less of/get more support with as a young person with learning difficulties becomes an adult? What sorts of things might young people with learning difficulties

learn to do for themselves, or get support to do for themselves? Issues about safety and risk.

- Looking after your health – what might this involve? How do young people at transition get a Health Action Plan? How will having a Health Action Plan help?
- Getting around – access to transport and equipment; issues around safety and risk; options for transport and travel; changes to transport arrangements; coping with unpredictability of public transport.
- Money and benefits – new, age-related benefits; changes to existing benefits; carers' needs assessments; earning money through paid work; learning about money management; having a bank account; direct payments, ILF, DLA as crucial to support transition to adulthood.
- Friendships – importance of friends; leaving/moving school, college or home; staying in touch with old friends; making new friends; how support from friends can help at transition; buddying.
- Girlfriends, boyfriends, sex and sexuality – issues for young people and families; where to get information, support and advice.
- Moving to adult social services - what is supposed to happen? What are young people's and families' rights to social services at transition? What to do if things don't work as they should – complaints and appeals.
- Moving to adult health services – what is supposed to happen? What to do if things don't work as they should – complaints and appeals. How do young people at transition get a Health Action Plan? How will having a Health Action Plan help? What about hand-held records?
- There will be different issues to consider for young men, young women, young people from minority ethnic groups, young people with high individual support needs, and young people living away from home.

3

Choices at transition

The transition to adulthood involves making active choices about the future, as well as responding to a number of changes to individual and family life. These choices fall into two main areas:

- Leaving school - choices about how to spend one's time
- Leaving home - choices about where to live.

Leaving school - choices about how to spend one's time

The vast majority of young people with learning difficulties will be in full-time education until the age of 16 or 18/19. At Year 11 and again at Year 13, young people will be presented with the choice of continuing their education (either by staying on at school until Year 13, or by leaving school and continuing FE elsewhere), entering employment, or engaging in other forms of daytime activity.

Leaving school to **continue education** may involve considering choices about whether to go to another school or sixth form, to go a local college or to go away to college. Leaving school can be a very traumatic event for young people with learning difficulties. Half of the young people interviewed for Heslop et al's (2002) study said that they had been sad or upset to leave school. Others, however, expressed a wish to move on and do others things. Heslop et al (2002) found that the following factors made the transition from school easier for young people and their families:

- Regular visits, over a period of time, to possible future options.
- The involvement of the young person in reaching decisions about where they were to move on to.
- The early agreement of funding so that there could be a gradual supported introduction to the young person's new learning environment.
- Positive support, encouragement, practical help and information for young people and families from the school.

This study also found that young people liked seeing videos or brochures about possible further education options and choosing which to visit. Information days at school or college and discussing options with their teachers, friends or families were also important (Ward et al, 2003a).

Further education appears to be a very popular progression route for young people with learning difficulties. However, organising funding for further education, particularly for placements at residential colleges, and making appeals when college choices are turned down are noted in the literature as particularly difficult issues for families at transition (Heslop et al, 2002).

Heslop et al (2002) found that 78% of the young people with learning difficulties in their study who were in their first placement after school were in further education. There seemed to be an expectation for young people and their parents that college or further education was the 'next step'. In Mitchell's study (1999) of special school leavers, 94% remained in some form of education full or part-time time after leaving school. Similarly, in another English study of school-based transition programmes for young people with moderate learning difficulties, the majority of students leaving special schools were attending college, with training or work-based learning being the second most common destination (Collaborative Group for Learning Disability in the North West, undated). Nevertheless, it also seems that for students with high individual support needs, there are few opportunities for participation in further education (Florian et al, 2000b). This finding supports an earlier study by the same authors (Florian et al, 2000a) that confirmed the widely held view that students with high individual support needs have few opportunities to participate in community life as adults. This 1999 survey found that of the 505 young people represented aged **over 19**, 39% remained in school, 24% moved onto day centres, 2% stayed at home, and only 19% went onto part-time or full-time courses in residential or further education colleges (the remainder did a combination of activities, or results were missing).

Rowland-Crosby et al (2002) suggest that colleges (or on-site sixth forms) are often seen as the only progression route for many young people with learning difficulties and/or disabilities. Their research also found that learning choices were often restricted to courses based around independence or life skills and that there was little parity between provision for non-disabled young people and that for disabled young people. Morris (2002) adds that many further education placements for young people with learning difficulties are more concerned with meeting care needs than educational needs. Indeed, some researchers have suggested that in the absence of information about other choices, going to college can be seen as a way of putting off a 'crisis' (Edinburgh Youth Social Inclusion Partnership, 2001).

Heslop et al's (2002) research found that most young people with learning difficulties quickly settled into college and enjoyed further education. Young people talked about the fact that going to college makes them feel 'grown up'. For families and young people, going away to a residential college may be seen as an important step on the road to adulthood and may indeed offer a 'surrogate' mode of transition (Mitchell, 1999). It involves moving away and acquiring more independence, the loosening of familial bonds, letting go and limited risk taking,

social independence and the development of an adult social life without family input, the development of educational or vocational skills, particularly life-skills and practical preparation for a more independent future (Mitchell, 1999). Heslop et al (2002) suggest that time at college can give young people and parents a chance to take stock and relax in the knowledge that the next change will not happen for a few more years yet.

Interestingly, despite a focus on the importance of going away to college as a means of encouraging independence, the young people involved in Rowland-Crosby et al's (2003b) research said that they would rather go to a local college. These researchers make the point that there is a rising number of out-of-area post-16 Learning and Skills Council funded placements. Although young people with learning difficulties may be less likely to be offered an out-of-area placement than other young disabled people, such placements should only arise if there is no suitable provision at local colleges. They go on to suggest that using out-of-area placements may mean that local gaps in provision are not recorded so the situation becomes self-perpetuating (Rowland-Crosby et al, 2003b).

The issue of 'what to do?' after college or further education will follow an all too brief period of independence for most young people, as after residential college the only real option may be to return to the family home (Mitchell, 1999). Sinson's (1995) study of ex-residential college students found that families' concerns post-college focused on their youngsters' future accommodation needs, community reintegration, and danger of social isolation from local peers. For those attending local colleges, post-education outcomes are also an issue and O'Sullivan (2001) reminds us that young people with learning difficulties need planning for what happens when they leave college.

Finding employment is another choice that young people with learning difficulties should be able to make at transition, either after leaving school or after leaving further education. Young people should be able to consider options along a continuum which includes work experience, supported employment, sheltered workshops or social firms, voluntary work and ordinary, paid work.

Having a job is central to one's self-esteem and self-confidence and can positively affect the way one is perceived by others (Heslop et al, 2002). Indeed Hendeby and Pascall (2001) found that for the young disabled people involved in their research on transition, employment was central to their sense of themselves as adults, and there was a widespread feeling that paid work was the best route away from poverty and social exclusion and into social relationships and citizenship. Work and employment is highly valued by young disabled people and their families (Mitchell, 1999) and parents in particular value paid work and wages for their youngsters (McNair and Rusch, 1991). The financial independence that paid work brings is a definite aspiration for many young disabled people and people with learning difficulties (Barnardo's, undated).

However, research has shown that many people with learning difficulties fail to progress from education and training to any form of employment, paid, supported or voluntary (Beyer et al, 1996). Jacobsen (2003) suggests that in reality, individuals often remain at college for many years, sometimes repeating courses or returning to the day centre from which they were originally referred, only to come back to college a few years later. The transition to work from training or employment can be particularly hard for people with learning difficulties. Jacobsen (2003) examined vocational courses or training that included support for the transition to work. Key factors for the successful development of transition to work provision were:

- Support of senior managers
- Recognition that employment is a realistic goal for people with learning difficulties
- Training packages to suit the individual learner
- Finding out at the start of the course what area of employment the learner is interested in and what opportunities are available locally
- Partnership working
- Secure funding for the provision
- Clear and accurate information on how individuals' benefits are likely to be affected
- Provision that is part of an overall strategy for people with learning difficulties (Jacobsen, 2003).

Work experience can be a good way to get a feel for the world of work. But recent research has found that the provision of work experience, especially that available to young people with learning difficulties in Years 10, 11 and 12, is very different across the UK (Rowland-Crosby et al, 2002). The Disabled Children's component of the National Service Framework for Children in Wales has as one of its key actions that young people with learning difficulties should have access to a range of work experience opportunities in community settings at transition (National Assembly for Wales, 2004).

Supported employment is also a chosen option for many people with learning difficulties. But provision of supported employment varies and projects are often short-term and fragile. Schools and colleges often lack information about supported employment options and there are low levels of awareness about the Access to Work schemes amongst employers and young disabled people (Morris, 2002). In their study of the role of Connexions Personal Advisers (PAs), Grove and Giraud-Saunders (2003) found that despite efforts of the project team to raise awareness of the profile of work and employment as a potential option for young people with learning difficulties, this issue hardly featured in the role of the PAs they interviewed. They suggest that work should become much more central to the support offered by Education and Connexions staff. This must be matched by close working between PAs and careers advisers and include

development links with local supported employment agencies where they exist (Grove and Giraud-Saunders, 2003).

For young people with learning difficulties, finding paid employment in ordinary jobs is rare but possible. Of the 109 young school leavers with learning difficulties included in Heslop et al's (2002) research, four had experience of paid work, with three of these currently in paid employment (supermarket, catering, hairdressing). This finding is consistent with research which shows that although people with learning difficulties have been saying for years that they want proper jobs, very few are actually employed (Grove and Giraud-Saunders, 2003). A comparative European study identified some core skills needed by young people with learning difficulties to access paid employment. It concluded that for young people throughout Europe there are shared employability skills of punctuality, reliability, flexibility and a capacity to work in a team. The findings echoed previous work about the need for effective training to get young people into work, and on-going support to enable them to sustain employment once they had got a job (McAnespie, et al, 2000).

O'Brien (undated; quoted in Morris, 2001) believes that a conceptual shift is needed in order to expand employment opportunities for young people with learning difficulties and involves moving the focus from the person alone to the person **plus** a skilled job coach. Potentially this would increase the number and variety of jobs available. The emphasis in this approach is very much on support within and outside the (ordinary) workplace. This concurs with the views of young people themselves (e.g. Barnardo's, undated) who state that helpful things about having and keeping a job include:

- Being shown what to do (the ropes)
- Being welcomed positively
- Support and access
- Constructive criticism
- Money in your pocket
- New challenges and opportunities
- Learning new skills and developing existing ones
- Getting on with new work
- Meeting new colleagues
- Opportunities to wider social/leisure activities
- Being treated as an equal
- More choices.

If further education or work is not acceptable or possible, some young people with learning difficulties may choose to spend their time engaged in other forms of **daytime activity**. The most likely option will be some form of day service package, provided by the young person's local authority and specified in their Care Plan. In many areas this is likely to include attendance at a day activity centre for people with learning difficulties. Day centres were used by about a

quarter of the young people in Heslop et al's (2002) study. All but one of the young people had moved to day activity centres **after** a period at college. Some of these young people described feelings of boredom and said that there were skills that they would have liked to develop but were not offered the chance to by their day centre (e.g. first aid, using a computer). Two young people explained that transition to day services had been helped by visiting a variety of places, allowing plenty of time to settle in, and trying a number of activities before making the final choice.

More personalised options for day activities are growing, and the Department of Health has directed local authorities to modernise day services by 2006 with the aim of ensuring that resources are focused on providing new opportunities for people with learning difficulties to lead full and purposeful lives (Department of Health, 2001). This is also something that most parents want for their youngsters. Mitchell's (1999) study found that parents wanted their school-leaver son or daughter's future activities to be both 'purposeful' and 'meaningful'.

The provision of person-centred planning and use of direct payments is central to any move away from fixed daytime programmes towards individualised action plans designed to establish the activities that an individual wishes to engage in, and the support needed for these (Hudson, 2003). Person centred planning discovers and acts on what is important to a person and design and delivery of services is based upon a knowledge and understanding of what is important to a person. A fuller discussion of the role that person centred planning can play at transition follows in section four.

Choices about how to spend one's time involve thinking about leisure and transport options. Leisure options are often not considered during planning for transition to adulthood, yet this is an important area of focus for young people with learning difficulties (Goupil et al, 2002). Young people will need information about what leisure options are available to them as young adults, how they can access these, and what support is available. Leisure activities (such as sport, evening classes, and other forms of socialising) are an excellent way to meet and make friends. Social exclusion is big issue for all young disabled people. Morris's (2001) research found that this meant having no friends, finding it difficult to do the kinds of things that non-disabled young people do (such as shopping, going to the cinema, clubbing), feeling unsafe, being harassed and bullied and not having control over spending money. Many young people with learning difficulties find it difficult to spend time with friends away from their families. For example, although the young people in this Northern Irish study were actively involved in leisure activities outside of the home, these were done mostly in the company of family members (Smyth and McConkey, 2003).

Access to and support to use transport can also make the difference between a range of options and restricted choice. Despite this, Ward et al (2003d) found that post-school transport arrangements were rarely covered in transition

planning. O'Sullivan (2001) found that free and accessible transport was felt to be very important in enabling young people with learning difficulties and young disabled people to participate in leisure activities and also in part-time work. Rowland-Crosby et al (2002) found that poor transport links and poor access to transport had a negative impact on young people's choices and aspirations at transition. In rural areas, a lack of public transport and the withdrawal of free transport (by the local authority) at age 19 curtailed many young people's further education choices and restricted their choice of future employment (Rowland-Crosby et al, 2002). The notion of independent travel can be a source of anxiety for young people with learning difficulties and parents (Ward et al, 2003d). Parents may have concerns about young people's safety when travelling independently, and young people can be worried about the unpredictability of public transport.

Leaving home - choices about where to live

Leaving the family home is another choice that some young people with learning difficulties may wish to make at transition. Some young people will leave home to enter residential further education (college, University, out-of-area placement at another school or specialist college). Other young people may simply feel the need to 'leave home' and get their own place like others of their non-disabled peers. However leaving the family home and getting a place of one's own is a transition that is fast becoming difficult to achieve for all young people and often needs a lot of parental support (Morrow and Richards, 1996). For young people with learning difficulties, leaving home may also be something that happens several times, with varying degrees of success and with young people returning to the family home when housing options break down.

Young people with learning difficulties wishing to leave home will need to consider whether to live alone, or with other people. They will also need to decide where they want to live – with another family (family placement or adult fostering), in a small group home, in larger residential accommodation, in sheltered housing or a living support network, or in their own house that they are renting or buying themselves (King, 2000). Services should also help young people and their families to consider what level of support they are likely to need at home, in the morning, during the day, in the evening, and overnight and how this support will be provided (King, 2000).

Despite the seeming promise of housing choices at transition, the reality is that the vast majority of young people continue to live at home with their family. Families are often very happy for their son or daughter to continue living in the family home, but if this is the case, then it is important for carers' needs to be considered, particularly in terms of access to short breaks services and the entitlement to a carer's assessment (Valuing People Support Team, 2003). Three-fifths of the young people who had left school and were involved in Heslop et al's (2002) research still lived at home. For those young people who had left

home, few options existed beyond local authority-run residential or group homes. Of the 272 parents responding to Heslop et al's questionnaire, only one mother reported that her son had found his own flat and was receiving 24-hour support to live independently. The other respondents described living arrangements as being at home, in residential care or at residential college. Similarly, Smyth and McConkey (2003) found that the majority of those young people with learning difficulties involved in their Northern Irish study were continuing to live with the family albeit for different reasons. Interestingly, however, there was a strong parental emphasis on fostering the young person's independence. Only a minority of families envisaged that their son or daughter would move into a residential care setting.

Morris (2002) points out that young disabled people wanting to move into their own home face huge barriers: shortage of suitable housing, segregated housing, difficulties bringing housing and support together, and a failure of housing and social services to work together. The only option is often to move into particular residential accommodation, a decision which is all too often determined by vacancies rather than young people's choices about where to live and who with. For young disabled people with high support needs, there is an almost inevitable assumption that they will move into a residential or nursing home and that this is rarely seen as one step in the transition to adulthood – the assumption is that they will be there for the rest of their lives. (Morris, 2002).

Heslop et al's (2002) research adds that for young people with learning difficulties, the likelihood that they will be able to move into appropriate accommodation of their own choosing, with the right level of support, largely depends on statutory and voluntary sector input. In their survey, only 11% of families and young people had received information about housing options at transition. Parents described a process that was haphazard and uncertain and a complete lack of information about this topic:

'This sounds a bit bizarre really, but, I mean... we have no idea of what the process is for him to go into his own form of residence, whether it was sheltered accommodation or in somewhere [residential]. We haven't got a clue, have we, how that works... no idea!' (Parent, quoted in Heslop et al, 2002).

Most parents said that leaving home was not a topic covered by school and that it had been left to them. Indeed, housing transition seemed to be largely driven by parents themselves, involving a huge amount of energy and stress. Understandably, many felt that it was too sensitive a subject for them, as parents, to tackle with their son or daughter:

'I think she might feel she is being chucked out sort of thing...I want somebody, an adviser, to go at it gently and give her the idea to think about.' (Parent, quoted in Heslop et al, 2002).

For young people with learning difficulties and their parents, leaving home can feel both very exciting and very worrying (Cowen, 2001). There is an important need for continuous emotional and practical support, as well as for clear information about the sources and accessibility of housing, the support available for seeking benefits and the management of budgets (Barnardo's, undated).

Support to make choices at transition

Young people with learning difficulties and their families need support to consider choices and to make decisions about the future. As previously mentioned, visits to colleges, day services and employment options can help (Rowland-Crosby et al, 2003b). Work experience placements are also useful as a way of testing out whether an employment choice is the right one (Ward et al, 2003a).

Young people and families also need accurate, up-to-date and easy-to-understand information to help them make choices, alongside support from well-informed professionals (Heslop et al, 2002; Mitchell and Sloper, 2000). However, research shows that there is a lack of easily accessible information for parents and young people about what future possibilities might be (Ward et al, 2003c). Families say they want more information about choices: speakers from different agencies to talk to, resource packs for the young person and their family, examples of choices made by other students, and links with other parents who had already been through the process (Ward et al, 2003a).

The notion of 'choice' of provision can be very unclear to many young people with learning difficulties (Rowland-Crosby et al, 2003b). Various tools have been developed to support the decision making process, particularly at transition. A Canadian study of individualised transition planning for students with learning difficulties piloted three different planning tools for use with young people, families and professionals together. These were MAPS (Making Action Plans), 'Preparing for the future' materials and the American Association for Mental Retardation's adaptive skills areas framework. No one instrument was found to be all-encompassing or fully able to capture adequately all the planning requirements for facilitating a student's transition. But the MAPs process provided a unique guide to thinking and discussion about 'dreams' and 'fears' for the future (Goupil, et al, 2002). An English study examined whether Talking Mats, a light-technology augmentative framework, could be used successfully to consider choices about the future with young adults with a learning and communication impairment. The authors found that the 12 young people involved in the study were able to use Talking Mats to indicate their likes and dislikes, to express views about choices, and to express opinions not previously known to their families and carers. The mats allowed differences of opinion to be explored and were used as a vehicle for further, deeper discussion (Cameron and Murphy, 2002).

Morris (2002) reminds us that young disabled people who do not have parents to argue on their behalf or whose parents are not familiar with the system are often disadvantaged in accessing information and making choices at transition. She also points out that young disabled people from Black and minority ethnic communities are particularly disadvantaged at transition. Services know very little about their needs and views and they and their families find it especially difficult to get information about options and possibilities. Low expectations can also inhibit their choices (Morris, 2002).

The reality of available options and provision at transition

The literature on this topic highlights a clear consensus that there is a serious lack of options and provision for young people with learning difficulties as they move into adulthood. Young people with learning difficulties are not able to access the same range of opportunities as their non-disabled peers (O'Sullivan, 2001). Moreover, although the young disabled people in Rowland-Crosby et al's (2002) research were able to express their choices, these could not be realised as local provision did not match up. Ward et al (2003d) found that young people with learning difficulties did what was expected, or available, rather than what they really wanted.

Ward et al (2003c) also found that there were few post-school options available to young people particularly in relation to housing and employment. This lack of choice meant that whether or not young people had received transition planning made little difference to what happened to them after school (Ward et al, 2003d). Teacher and parental (sometimes low) expectations for young people's future choices may be more a reflection of lack of local provision than a real recognition of what young people want. The experience of young people with learning difficulties in the Scottish project (Edinburgh Youth Social Inclusion Partnership, 2001) found that they were often presented with a very narrow range of options such as 'special' extension or life-skills college courses. Teacher and parental expectations reflected this and funding structures supported the segregated college course option.

As Armstrong and Davies (1995) put it, the best laid plans have little chance of realisation if opportunities are not available. Thus the experience of transition to adulthood for young people with learning difficulties will differ across the UK and is likely to be strongly related to the structure and availability of provision and mechanisms for introducing more person-centred approaches. In theory, in England, the collection and synthesis of data about young people's progression choices by local Learning and Skills Councils (gleaned from the Section 140 assessment conducted by Connexions) is supposed to support the planning and development of a range of locally available opportunities and choices for young people, but in practice this is not happening (Rowland-Crosby et al, 2003a).

Key areas of information need for young people with learning difficulties and their families

There are lots of choices that young people with learning difficulties can make. Young people and families need information about all of these. Transition is not just about leaving school and going to college.

- Choices about further education – staying at the same school; going to another school; going to a local college; going to a residential college – funding for and other implications of this; impact of the Disability Discrimination Act on FE choices; other sorts of learning opportunities.
- Choices about careers and employment – work experience; sheltered workshops and social firms; supported employment; voluntary work; ordinary jobs; impact on self-esteem and other areas of life; whom to ask for support and advice.
- Choices about what to do in the day – day activity centres; doing your own thing; using person-centred planning and direct payments to support your choices during the day.
- Choices about travel and transport – public transport; community transport; your own transport; travel concessions; how to cope with worries about independent travel and the unpredictability of public transport.
- Choices about leisure and having fun – ways to spend free time at home, or by going out; meeting new people; as a chance to have time away from adults/family members and spend time with peers.
- Choices about housing and accommodation – living alone or with others; living with a family in an adult placement; living in a group or shared house; sheltered housing/living support networks; living in your own home; whom to ask for support and advice.
- What help should young people with learning difficulties and families expect to help them make decisions about the future – e.g. Visits to college? Work experience placements? Easy information about different choices? Help, time and advice from a Connexions PA, teacher, keyworker? Talking about the future with friends? The importance of continuous emotional and practical support.
- What happens when opportunities are not available locally to support young people's choices and future plans? Impact of the Disability Discrimination Act. Making complaints and appeals.

- There will be different issues to consider for young men, young women, young people from Black and minority ethnic groups, young people with high individual support needs, and young people living away from home.

4

What to expect from services at transition

Although several different services have statutory roles to play at transition, families and young people are often understandably confused about what to expect from professionals and providers at this time. The 'Valuing People' white paper (Department of Health, 2001) states that services should ensure continuity of care and support for young people with learning difficulties and their families during the move into adulthood, and should provide equality of opportunity to enable as many disabled young people as possible to participate in education, training and employment.

The main services which should be involved in planning for transition and in implementing transition planning are:

- Connexions (and the local Learning and Skills Council)
- Social services
- Education
- Health.

A range of other professionals may also be involved in planning for the future, but do not have specific statutory duties at transition. These include: local adult education provision, local colleges, local supported employment projects, the youth service, leisure services, housing services, Job Centre Plus, local adult information, advice and guidance providers (Valuing People Support Team, 2003).

Connexions

Although a fairly recent development, Connexions should be delivering a service to all young people in England by 2006. The Connexions service can begin working with young people with learning difficulties from the age of 13 up to the age of 25 where appropriate. The main way in which Connexions offers support to young people is by providing a Personal Adviser (PA) to help them with a whole range of issues around transition. All young people with learning difficulties have the right to a Connexions PA if they want one. The role of a Connexions PA is broad and encompasses several statutory duties as well as the provision of a wide range of information and advice individualised to the needs and interests of the young person.

A Connexions PA has to attend the transition review for young people in Year 9 and co-ordinate the resulting transition plan (under the DfES SEN Code of

Practice 2001). Once the transition plan is in place, the Connexions PA is responsible for ensuring that the plan is implemented. The PA can (and should where possible) continue to attend annual reviews for the young person until they leave school or up until a person's 25th birthday where needed.

In addition to playing a role in the transition planning instigated by Education, Connexions PAs also undertake their own form of planning with young people, using an Assessment, Planning, Implementation and Review framework (APIR) and resulting in a Personal Action Plan. The Connexions service also has to carry out an assessment (Section 140 assessment) when a young person is in Year 11 of school (age 16). This assessment is to take account of what the young person wants to do and what support they will need to achieve this. The information gathered from the Section 140 assessment should then be passed to local Learning and Skills Councils (LLSC) so that they can identify gaps in provision and profile training and learning needs and support for this group as a whole. Recent research (Rowland-Crosby et al, 2003b) has found, however, that this information sharing does not appear to be happening. Completed Section 140 assessments are simply being forwarded to the 'destination' as a way of clarifying what the young person will be doing and what their support needs are. As the authors point out, not only is this duplicating the education-led transition plan but it also means that information about the whole local population of learners with learning difficulties/disabilities is not being actively shared with LLSCs (Rowland-Crosby et al, 2003b).

On a more positive note, Grove and Giraud-Saunders (2003) suggest that the advent of the Connexions PA seems like a promising means of improving the experience of transition and outcomes for students and families. Connexions PAs are supposed to be 'multi-skilled workers' who can provide a full range of advice, information and support at transition. In their study of the PA role in two special schools and a further education college in Lewisham (England), Grove and Giraud-Saunders found that there was general agreement amongst professionals and parents that the main components of the PA's role were to co-ordinate transition planning, provide information about options, help to access resources and advocate for students and families where necessary. And in Rowland-Crosby et al's (2003b) research, families felt that the presence of a PA at Transition Review Meetings was very positive in that there was an extra person speaking up for them. Young people with learning difficulties/disabilities also said they valued the independence, expertise and support offered by a PA.

Rowland-Crosby et al (2003b) have found that young people with learning difficulties and/or disabilities have clear views about the sort of help and support they want from a PA:

- An approachable person, who smiles and has a good sense of humour.
- Someone who looks at me when they are talking to me and speaks clearly and slowly.

- Someone who isn't patronising and treats me like a grown-up.
- Someone who is an expert and knows what they are talking about – understands the disability or difficulty I have.
- Someone I have known for some time, who knows about what kind of support I need, who knows what I want to do when I grow up and who I can trust.
- Someone from outside of school, who I can meet with at different times.
- Someone I can call at the weekend or in the holidays if things are getting difficult.

Research by Grove and Giraud-Saunders (2003) has also found that families and professionals wanted a PA who could:

- Act as a point of co-ordination.
- Have neutral status.
- Supplying good information to services about students.
- Inform families and students of their entitlements.
- Remind agencies of their responsibilities.
- Be someone who would be straight with parents about what they had to do.
- Offer crisis management.
- Track children at risk.
- Help individuals to find appropriate and attractive activities inside and outside school.
- Connect the school and student body with the community.
- Support students to have a voice in different forums.
- Be 'good to talk to'/trusted.
- Help students to overcome barriers to accessing college and to settle down there.
- Understand child protection issues.

However, recent and on-going research into the effectiveness of the Connexions service for young people with learning difficulties has already highlighted some significant concerns about the implementation of Connexions and the role of the PA. Rowland-Crosby et al (2003b) have found that the wider role of Connexions, as more than just a careers service, is poorly understood by young people with learning difficulties and their families. Many other professionals may also be unclear about what a PA can offer (Ward et al, 2003a) and indeed PAs themselves may be less than keen to take on the broader aspects of their 'fully differentiated' role (Rowland-Crosby et al, 2003b). PAs who are already working with young people with learning difficulties have highlighted that they lack knowledge, information and training in certain areas such as mental health issues, Autistic Spectrum Disorders, adult protection, and support services more generally (Rowland-Crosby et al, 2003b).

Other issues include a lack of time, due to very large case-loads, for PAs to get to know young people in order to help them to make decisions (Rowland-Crosby

et al, 2003b), and lack of access by young people to their own copy of the Personal Action Plan despite guidance stating that young people should maintain 'ownership of the plan' and be given a copy (Rowland-Crosby et al, 2003a). Indeed, Hudson (2003) asks whether the very wide remit of Connexions may lead inevitably to PAs focusing on helping people to access education and training, rather than delivering the particular forms of practical and learning support that young people with learning difficulties require at transition. Grove and Giraud-Saunders (2003) suggest that the success of the PA role depends on building trust with parents and professionals. To be effective, PAs must have an official role in school life that enables children and families to see them as insiders, but does not completely identify them with the systems that maintain discipline or allocate places and resources. They must also have 'clout' in terms of a formal status with other agencies involved in the transition process. The literature appears to demonstrate that this role has, so far, been very difficult to achieve.

Education

When a young person (with a statement of special educational needs) reaches Year 9 (age 14) of secondary school, the Local Education Authority should organise a meeting to make plans for the future. This is called a Transition Review Meeting. This meeting will be the first point for developing the transition plan that will set out a young person's future plans and how these will be met by services. The head teacher usually has responsibility for making sure that the transition plan is written, but can delegate this task to the Connexions Personal Adviser. After the Transition Review Meeting, the transition plan is supposed to be reviewed and updated every year (with the young person and their family) until the young person leaves school (Heslop et al, 2002).

The purpose of the Transition Review Meeting is to discuss the young person's progress at school, look at how they support is helping, look at what their educational, and other targets might be for the coming year, think about what support the young person needs to make a smooth transition to adult life in general, including the transition to further education or work if appropriate (Valuing People Support Team, 2003). The 2001 revised SEN Code of Practice also stresses the importance of ensuring that young people are involved in making choices and decisions and that parents are treated as partners throughout the transition planning process (Ward et al, 2003d).

Despite legislation and guidance to the contrary, some young people with learning difficulties are continuing to leave the English school system without any form of planning (Ward et al, 2003a). In their study, Ward et al found that one in five young people with learning difficulties who had already left school had done so without any planning at all, despite the legal requirement. Of the young people involved in the study who were still at school, only two-thirds of them had a transition plan.

Several studies have highlighted a lack of involvement in the transition process by young people with learning difficulties and their families alike (Heslop et al, 2002; Morris, 2002, quoted in Thornton, 2003; O'Sullivan, 2001). Morris (1999) also points out that it is common for social services and education departments to assume that communication impairment precludes the possibility of giving an opinion. She stresses that if young people with high levels of support need are to be involved in transition planning, methods must be developed that do not rely solely on holding meetings or on verbal and written communication. Two studies have also highlighted that topics covered in transition planning are not those of most importance to young people (Heslop et al, 2002; Morris, 2002, quoted in Thornton, 2003).

As Ward et al (2003a) remind us, parental involvement is a fundamental principle of the Code of Practice. There is a general right to involvement and a specific right to documentation. Parents should be invited to Transition Review Meetings and receive copies of each review report. The transition plan should document parental expectations for the young person and include contributions that parents can make towards helping their child move towards adulthood. It should also include parents' own support and practical care needs for the future.

Parents involved in Heslop et al's (2002) study suggested that there should be better preparation for Transition Planning Meetings. They wanted more advice and guidance, to be told who would be attending meetings, and to know what were the duties and obligations of these people were to make sure meetings were effective. Parents also wanted a named person to co-ordinate the transition planning process. Smooth transitions were helped when families had access to key professionals who were consistent figures at planning meetings and who got to know the young person well (Ward et al, 2003b).

Clearly there is work to be done on improving the transition planning offered by and based within Education services. An English study conducted by Carnaby et al (2003) showed that reflection and feedback on the process of transition planning can enable education professionals to improve and refine their practice to the benefit of young people and families. The first phase of this study evaluated the involvement of students with learning difficulties in transition review meetings. The researchers found that many students were excluded from meaningful discussion in their planning meeting, and highlighted the fact that students with high individual support needs were particularly vulnerable to exclusion. Recommendations were made for improving practice in terms of inclusion and participation. Four years later, phase two of the study re-assessed ways in which practice in these areas had improved. The school had developed more individualised ways of working using person-centred techniques to enhance meaning for students including:

- All students being involved in their meetings for at least 80% of the time.

- Time and effort spent with the person and their family before the meeting.
- Inclusion in meetings focusing on the student and their plans and being aided by appropriate and individualised materials.
- Issues relating to health being discussed at a separate meeting so these were acknowledged but set in a context of the young person's strengths and achievements across their life.
- Timing of meetings scheduled to meet parent need and not to clash with the young person's favourite activities.
- Contact with outside professional is encouraged prior to the meeting – nobody to come to the meeting who has not met the student before.
- The role of friendships and relationships being explicitly acknowledged as an important topic for discussion and friends being present if desired.
- The transition review meeting not being the first time that the student's future was discussed, but was part of on-going work to support the move to adulthood.

Professionals and families also highlighted additional possibilities for future work to support better transition planning, which included:

- Workshops for parents where transition could be discussed in terms of immediate events but also within the context of adult life for people with learning difficulties.
- Presentations from professionals, adult learning difficulties services, and other parents.
- Clarification about the role of careers advice and Connexions.
- Setting up buddy systems whereby students visiting employment and further education settings could make contact with ex-students already there and spend with them talking about what happens.
- Video recordings and photos of future options when visits are made to support discussion on return to school (Carnaby et al, 2003).

Social services

The main issues relating to the role and responsibility of social services departments at transition have already been spelt out in section two. Suffice to say that the role of social services professionals at transition may take many forms. The very least to expect is that a social services representative will attend transition review meetings so that information can be shared and the move to adult services planned and implemented as smoothly as possible. Some social services departments have Transition Workers, based either in children's or adult services and their role should be made clear to families and young people.

As explained in section two, social services have a duty to carry out an assessment of need for children aged 14 and over with a statement of special

educational need if it appears that they are likely to need input from the adult social services team. If the young person meets the service's local eligibility criteria, services must be provided from the age of 18. The Valuing People Support Team (2003) suggests that services should be agreed and put in place **before** the young person stops receiving support from children's social services, although in reality this may be difficult due to age-limited responsibilities of different agencies.

Health

As outlined in section two, many children with learning difficulties will be receiving health care support from a community child health team and from one or more hospital specialists. The main issues relating to the role and responsibilities of health care staff at transition have already been covered. To summarise:

- Health professionals involved in the management and care of the young person should provide advice towards transition plans in writing.
- They should attend the transition review meeting in Year 9 where possible or send a report if they cannot attend.
- They should advise on the services that are likely to be required and should discuss the transfer to adult health care services with the young person, their parents and their GP.
- They should facilitate any referrals and transfer of records, subject to informed consent and should liaise with Connexions (Ward et al, 2003c).

Transition planning and the role of person centred planning

As we have seen, several agencies play a role in the transition planning process, and consequently there may be several plans made for the young person with learning difficulties. These might include the transition plan, the Connexions Action Plan, and in some places, the Individual Learning Plan. Some young people may also have a Health Action Plan, a Care Plan (from social services), or a separate person centred plan. Rowland-Crosby et al's (2003b) research has shown that young people and families are confused about the nature of the different plans and assessments, and professionals also feel there is a proliferation of plans and consequently a lot of duplication and extra work. As these researchers point out, given the number of different plans, and the likelihood that there will be much overlap, who takes responsibility for delivery and implementation? Connexions PAs should take responsibility for the Connexions Personal Action Plan, but it is unclear whether they are in a position to be able to hold those participating in the delivery of a transition plan responsible or accountable for its implementation (Rowland-Crosby et al, 2003b). The Qualifications and Curriculum Authority (2003) clarify that the most effective transition programmes have a clear focus, coherent provision and a strong

emphasis on meeting the needs of individuals within a framework of flexible provision. They have devised a list of questions to provide guidance and evaluative material for schools and colleges so they can measure their progress towards this end.

Several authors have stressed the importance of an holistic, person-centred approach to transition planning that encompasses broader aspects of planning for adult life (Ward et al, 2003d; O'Sullivan, 2001; Bond, 1999). Research shows, however, that current transition planning techniques tend to be focused on limited, short-term goals, and do not take a 'whole life' approach which encompasses young people's previous goals and dreams as well as their new hopes for the future. Clegg et al (2001) found that the process of transition planning may be perceived by some professionals as an opportunity for a 'fresh start'. Parents on the other hand are more likely to see transition as part of the continuity between children's and adult services. The authors recommend that an understanding of the young person's history and a historical perspective should be an essential prerequisite of person-centred planning and stress the importance of valuing continuity.

Person-centred approaches to planning (such as Essential Lifestyle Planning, MAPS and PATH) appear to be the way forward in terms of ensuring that transition plans really reflect the aspirations of young people for their future adult lives (Hudson, 2003). By 2003, all local agencies should have introduced the option of person-centred planning for young people with learning difficulties who will be moving from children's to adult services (Department of Health, 2001). Person centred planning should be facilitated independently of agency assessment for resources and services (Valuing People Support Team, 2003). The Valuing People Support Team's (2003) 'Information Pack for Transition Champions' states that a person-centred approach to planning at transition should:

1. Discover what is important to the young person, what support they want and need, and what are their dreams and aspirations.
2. Explore what could be possible to enable people to get the lives they want.
3. Explore what is practical and possible locally to achieve things that are important to the young person.

Although different agencies have their own statutory requirements for planning, these can and should incorporate person-centred approaches and be conducted in person-centred ways (Valuing People Support Team, 2003).

Information provided for young people with learning difficulties to support the transition planning process needs to be culturally-appropriate and tailored to individual needs. This may mean ensuring that information is translated into a community language, put on audio or video-tape, or put into pictures or symbols. In a recent project designed to improve the quality of life of people with 'profound

and complex learning difficulties' during periods of transition, Dee and Byers (2003) explored ways of involving young people in recognising and recording their own progress and achievements across services in formats that were meaningful to them.

Other areas of service and policy development in relation to transition

The issue of transition to adulthood for young people with learning difficulties and their families has received some focused attention within a range of service and policy developments.

The '**Valuing People**' white paper (Department of Health, 2001) emphasises the need for effective links to be in place between children's and adult services in both health and social care. It also identifies young disabled people at transition as being a priority for person-centred planning (Ward et al, 2003d).

The white paper set in motion the establishment of local **Learning Disability Partnership Boards** (LDPBs) in all local authority areas. Hudson (2003) explains that LDPBs are a main part of new partnership machinery, along with the Connexions service, for improving services at transition. LDPBs are not statutory bodies and cannot appoint staff or hold budgets, but they are still capable of being important partnership forums. They have a number of important roles including: developing and implementing Joint Investment Plans, overseeing inter-agency planning and commissioning, ensuring use of the Health Act flexibilities, and ensuring arrangements are in place to achieve a smooth transition to adult life for young people. Each LDPB is also supposed to identify a 'transition champion' who will take lead responsibility for transition issues (Ward et al, 2003c).

The SEN Action Programme for England was published in February 2004 and will last over 10 years. It sets out the English government's objectives and priorities with respect to supporting children and young people with special educational needs and disabilities to realise their potential. There is a focus on improving outcomes for children and young people. This includes improving outcomes for young people making the transition between school, further education, work based learning, employment and adult life, with a further focus on (a) improving transition planning and (b) improving post-16 opportunities.

Through the Action Programme, the Department for Education and Skills plans to work across government to:

- Support schools, local authorities and other agencies to improve the quality of transition planning, specialist expertise of Connexions service and arrangements for person centred planning.

- Develop ways of monitoring the effectiveness of transition planning and transition standards.
- Maintain a single reference point for information on transition.
- Set national standards to support a smooth transition through the National Service Framework.
- Work with the Learning and Skills Council to expand educational and training opportunities.
- Develop new opportunities for transition to work – by strengthening links between LDPBs and employers, clear information on benefit rules, and use examples of good practice where young people with learning difficulties have gained employment.

Russell (2003) states that it is important to ensure that the new DfES SEN Action Programme is used as an opportunity to review transition planning in the light of wider changes, such as the introduction of the 14-19 curriculum (with greater flexibilities for work related options) and a stronger focus on achievement for pupils.

Both the English government and the National Assembly for Wales are in the process of finalising details of their respective **National Service Framework (NSF) for Children**, which both include a module on services to disabled children. Both Disabled Children's modules have sections on transition.

The draft NSF for Wales (National Assembly for Wales, 2004) has a section called Transition Services (childhood to adulthood). It proposes that there should be one multi-agency plan for each young person which specifies arrangements for continuing support and services including: personal support; housing requirements (including supported housing); education and training; careers including specialist advice; employment; social relationships including leisure activities; short breaks; practical and other skills; financial support (including benefits and direct payments); health needs including genetic counselling and sexual health; continuing care; appropriate transport; communication needs. Two significant 'key actions' of the NSF for Wales are that all young people with learning difficulties should have access to a 'transition key worker' and to opportunities for work experience as part of the transition planning process.

The draft NSF for England (Department of Health, 2003) has a section called Transitions (including from children's to adult services) and proposes the development of inter-agency protocols on transition covering health, social services, education, careers, housing, leisure, transport and benefits/welfare rights. Other issues highlighted include: the involvement of young people and carers in the transition planning process; information provision to families (specialist and mainstream); training for Connexions PAs; implementation of Valuing People person centred planning guidance for young people with learning difficulties; use of direct payments for 16 and 17 year olds; how services will support young people to have a social life, network of friends and relationships

including advice on sexuality, friendships, contraception and consent; how services will encourage healthy lifestyles and access to health promotion; arrangements for managing the transition of those with life limiting conditions, high levels of needs and those in residential schools/living away from home; how transition plans will meet the needs of Black and minority ethnic children; and arrangements for addressing the needs of wider family and siblings. Russell (2003) suggests that the forthcoming NSF for England could set standards for transition which could provide a template for the Connexions service and help break down some of the current barriers to effective planning at transition.

There is no doubt that for transition to be a positive and effective experience for young people with learning difficulties and their families, services and professionals must engage in **multi-agency working**. Hudson (2003) intimates that the scale and complexity of the partnership remit needed to deliver successful transition planning is daunting and will require a level of collaborative sophistication which has not been achieved in the past. In an article which considers the extent to which new service developments in England (e.g. Valuing People, Connexions, Health Action Plans, etc) can address the problems facing young people with learning difficulties at transition, he suggests that what is at stake is not only a better system of support for young people, but also the viability of partnership working as a policy tool for addressing complex issues.

Key areas of information need for young people with learning difficulties and their families

Statutory services and entitlements

- What is the role of the local Learning and Skills Council at transition?
- What should young people and families expect from school/education, social services, health services, and other services?

Connexions

- What is Connexions? What does the Connexions service offer young people with learning difficulties and families?
- What can young people with learning difficulties and families expect a Personal Adviser to do/help with? What training does a Connexions Personal Adviser have? How much time are they likely to spend with young people with learning difficulties and families at transition? Will they have the time to get to know young people with learning difficulties and key family members? Can they act as an advocate for young people with learning difficulties and be 'independent' of health, education and social services if needs be?

- What (equivalent) support is available in areas not covered by Connexions? (e.g. Wales where there is the suggestion of access to a 'transition key worker' as one of the National Service Framework for Wales key actions)
- What about Transitions Workers (from social services/voluntary organisations)? What is their role? How will they work together with Connexions Personal Advisers?

Transition planning

- What is transition planning? Who gets it? When does it start? How should the transition planning process work?
- Who should be involved in Transition Planning Meetings? How can we make sure that (the right) people actually turn up? Who co-ordinates transition planning?
- What is a transition plan and what does it cover? How can young people with learning difficulties and families make sure that transition planning covers all areas of planning for adult life?
- What does the transition plan look like? How can young people with learning difficulties and families make sure they get a copy? How often is the plan reviewed?
- What support can young people with learning difficulties and families get to help them to practice, plan for and take part in transition planning?
- What is a Section 140 assessment? Who co-ordinates this? What happens to the information collected? What is the Connexions Action Plan? Why is it needed? What is the Individual Learning Plan? Why is it needed? What other plans might young people and families expect? How is the information from all these different plans co-ordinated? What happens to the information collected?
- Who makes sure that something will happen as a result of the transition plan/Connexions Action Plan/Individual Learning Plan? Importance of continuity and taking the 'history' of the young person with learning difficulties into account – not just 'starting from scratch' all over again.
- Impact of new service developments, including: National Service Frameworks for England and Wales, SEN Action Programme, Valuing People white paper.

- What is the possible likely impact of the Disability Discrimination Act implementation from October 2004 regarding widening access to 'mainstream' choices and provision?
- Some young people with learning difficulties do not have a statement of special education needs. How are they supported at transition?

5

Transition and the family

Families of young people with learning difficulties play a major role at transition. The literature highlights the essential nature of family involvement and the difference it makes to effective transition. Yet this is often overlooked by professionals, to the extent that family involvement and families' views and input are frequently absent from the transition planning process (Morris, 2002).

Blacher (2001) believes that active family involvement in accessing services appears to be critical to successful transition for young adults with learning difficulties. Sibling involvement is also likely to be a critical factor both in transition success and parental well-being. Similarly, Bjarnason's (2002) exploration of the perspectives and experiences of 36 young disabled adults (16-24 years old) in Iceland found that the type and nature of early support for parents of disabled children is critical for young adults approaching adulthood in regular society or expecting to remain in the limbo of 'eternal youth' within segregated settings. And McNair and Rusch (1991) go as far as to state that in the absence of special funding or special projects, the **single most important factor** in successful transition is the parent. However, little is known about how parents can be involved, and what they perceive their role to be. In this North American study, McNair and Rusch (1991) found that parents were significantly less involved (30%) in transition programmes than they desired (70%). Parents often said that they wanted to be involved in finding job placement and community-living arrangements more often than they had the opportunity to do so. The authors suggest that parents may be a largely untapped resource in this regard, as they are likely to know and to have lived in the local community all their lives.

In England, research (Rowland-Crosby et al, 2002a) has highlighted the necessity of close working relationships and good communication between Connexions staff and parents. Parents kept Connexions PAs informed of issues they needed to be aware of where contact only with the young person was insufficient. This is a finding echoed in research by Heslop et al (2002).

Section one has already discussed some of the factors that make transition to adulthood a different experience for young people with learning difficulties. One of these differences is the recognition that more, not less (as is the norm for non-disabled youngsters) parental involvement may be necessary at transition. Day-to-day reality may mean a greater need for parental advocacy and oversight when adult services are inadequate, unavailable or unacceptable (Thorin et al, 1996). Hendey and Pascall's research (2001) with 72 disabled people in their 20s and 30s found that parents were seen as the most important resource, and

their input was key in the lives of the most independent respondents (those who were living independently and in employment). These parents had a relatively high level of social, economic and cultural resources, encouraged independence with expectations of achievement and were able to negotiate with professionals.

An acknowledgement, by professionals, of the huge role played by families at transition is essential, and should be an intrinsic part of the transition planning process (Morris, 2002). It is also important to recognise that parents may feel some discomfort, and indeed sadness, at the extent of their role in helping to plan their youngster's future, feeling compelled to make important decisions without sufficient information, knowledge, or the urging for independence that comes from non-disabled young people (Clegg et al, 2001).

There is very little research on the impact of transition on parental stress and family well-being for families of young people with learning difficulties. But some studies have highlighted the range of 'coping strategies' that families develop at this difficult time. Ward et al (2003d) found that parents coped by viewing transition as a 'balancing act, using the experiences of other siblings to guide the way, and coping with change as it arose by trial and error. The parents in Mitchell's (1999) study of school leavers recognised the need to be realistic and not to raise expectations for their young person. But they also experienced conflicting emotions – wanting to encourage aspirations, yet also fearing undue disappointment for their son or daughter.

Young people have stressed the importance of their family at transition. The young people with learning difficulties involved in Heslop et al's (2002) research talked about the importance of family contact (through visits, phone , photos, mementoes) when away from home, the encouragement they got from parents and siblings, and their pride in having a sense of a place in the family. Beginning to take on an adult role in the wider family, often in terms of supporting other family members, is something that is important to many young people with learning difficulties/disabilities. Morris (2002) found that the young disabled people she spoke to said how important it was to fulfil expectations and roles within their families, and to be part of family and community celebrations. However, many of these young people experienced major barriers to playing a full role in the wider family unit, and these issues were rarely covered in assessments and reviews (Morris, 2002).

However important the role of the family is at transition, the views and needs of the young person with learning difficulties should still be uppermost. Transition planning should be focused on the young person and their move to adulthood, **within a context** of family support and involvement where this exists. Rowland-Crosby et al (2002a) point out that young Black and Asian disabled people may have very different views to their parents about what they want to do in the future. Connexions PAs may be in the very sensitive position of having to advocate for the young person and acknowledge the strong feelings of the

parent. The authors make a plea for Connexions PAs to strengthen their links with local groups and networks to ensure that the service they offer is appropriate and respectful.

Finally, Morris (2002) reminds us that not all young people with learning difficulties have families and those who have spent a lot of their life living away from home, may not have anyone who will be there to act as advocate, information-seeker, and arbiter. Rabiee (2000) suggests that some care leavers with learning difficulties are being denied the rights and choices available to others. Without proper transition planning, when foster placements, or other care arrangements end at age 19, some young people with learning difficulties are either institutionalised in residential or day care settings, or left to live independently without appropriate support.

Key areas of information need for young people with learning difficulties and their families

- How can professionals work with families at transition? The importance of a more flexible approach.
- What coping strategies have families and young people developed for getting through the trials of transition?
- What sort of roles might young people with learning difficulties take on within the wider family?
- Confidentiality – for young people with learning difficulties; safe space and time to talk about choices, emotions, relationships, etc. The importance of separation between listening to young people with learning difficulties and involving the family.
- What different views do young people with learning difficulties, their families, supporters and staff have? The importance of person-centred planning – with a focus on the young person and their life. What happens when young people with learning difficulties want one thing and families think something else would be better?
- What about young people who are looked after away from home? Who will speak up for them at transition?
- There will be different issues to consider for young men, young women, young people from minority ethnic groups, young people with high individual support needs, and young people living away from home.

6

Feelings and emotions at transition

Transition to adulthood is an emotionally demanding time. Not only are young people experiencing body changes that can cause emotional 'ups and downs', but external changes (such as leaving school) and the need to make important decisions about the future can be stressful and challenging for young people and their families.

Young people with learning difficulties appear to be at greater risk of mental health problems than the general population. An inquiry conducted by the Foundation for People with Learning Disabilities (Carpenter, 2002) found that four out of ten young people with learning difficulties would experience mental health support needs during their adolescent years. Emerson (2002, quoted in Morgan, 2003) confirms this, estimating that one in four young people with learning difficulties will have mental health problems at any one time, compared with one in ten among young people generally. There is a wide variation in reports of prevalence of mental ill health in people with learning disabilities. The prevalence rates in adults with learning disabilities, for instance, range from 10% to 80%, depending on many factors, which include:

- a) The nature of the conditions examined.
- b) The ways in which diagnosis, or identification, was made.

Hatton (2002) reviewed prevalence studies, and found a variable rate reported – between 10-40%, depending on whether behavioural disturbance is included.

The continued confusions over assessment and diagnosis are matched by a confusion over services. Williams (2003) found that learning disability services and mental health services needed to work more closely together. Training was also an issue. Williams talked retrospectively with young people with learning difficulties and mental health needs about transition and found that only one of the professionals involved at transition had training in mental health issues, but many had nevertheless provided a lot of emotional support to the young people and their families, and had built up their own understanding of anger management and support. They felt it was important to work with the whole family, as well as building up a strong relationship with the young people themselves, but would have liked more support in their jobs.

Other research also shows that process of transition to adulthood will affect the mental health status of young people with learning difficulties and their families (Blacher, 2001). Hanley-Maxwell et al (1995, quoted in Clegg et al, 2001)

identify high levels of carer stress at transition which no amount of information could alleviate. Similarly, for all the young people with learning difficulties involved in Williams' (2003), study all had mental health issues that had escalated at the time of transition, or new problems that had emerged.

If transition is clearly a trigger for emotional issues, the service response will often be to provide a medical or psychiatric label. However, emotional distress can also be understood as a response to life stresses and to inadequacies of services. Much depends on the model of mental health support that we adopt. Williams and Heslop (in press) propose that it is important to consider a social model of mental health distress. In practice, this is the model that informs support provided, for instance, by Connexions. Personal Advisers in Connexions (Williams, 2004) claim that they respond to emotional problems by trying to improve the life chances of young people, using 'person centred approaches'. Many young people consulted as part of Rowland-Crosby et al's (2003a) study said that thinking about the future was scary, and that they were very worried about moving on from school. However, they also said that talking with a Connexions PA had helped them not to worry so much.

Emotional and psychological transition for young people has attracted very little academic attention. Many young people with learning difficulties will remain emotionally dependent on parents despite living independently, or may have conflict-ridden relationships with parents and support staff. Achieving emotional autonomy may be particularly difficult for learning disabled young people (Zetlin & Turner, 1985, quoted in Clegg et al, 2001).

Access to emotional support is essential at transition, for young people and families alike. The young disabled people involved in the My Voice, My Choice consultation wanted professionals to remember that transition is about what happens in your head as well as your body and that they needed time to talk about feelings and relationships, not just to focus on the process of transition and the move to adult services (My Voice My Choice, Barnardo's undated). Williams and Heslop (in press) found that young people with learning difficulties themselves identified friends, rather than formal services, as the single most important factor in their emotional support. Morgan (2003) outlines how the emotional resilience of young people with learning difficulties might be encouraged at transition, and suggests that these factors are crucial:

- Support for the family and working with the family from an early age.
- Attention to physical health needs – these can affect mental health.
- Support for communication – being listened to, having a communication passport.
- Awareness of bullying, abuse and loss – support through these times and to have their feelings acknowledged.
- Schools, colleges and transition – should play a role in providing options.

- Self-advocacy and circles of support – having friends around you, sticking up for others and having information about their rights make young people feel better and more positive about themselves.
- The provision of services to meet the needs of young people when they experience mental health problems – no delays, and a recognition that young people with learning difficulties do experience emotional problems.
- Access to primary care services – these are the first port of call but can be ill-equipped to deal with young people’s mental health problems.
- A need for clear pathways into services – it can be difficult to get help, and provision may be variable and patchy.
- Multi-disciplinary approach – holistic approach to meeting young people’s needs, with a range of services working together. Mental health problems can sometimes be addressed by adjusting the environment of the young person.
- Awareness and recognition of the needs of young people from Black and minority ethnic communities – they experience additional stress related to racism.

Key areas of information need for young people with learning difficulties and their families

- What sort of worries and feelings (positive and negative) might young people with learning difficulties have at transition?
- How do we recognise and diagnose symptoms of mental health distress in young people with learning difficulties?
- What emotional support is there for young people with learning difficulties? Friends, teachers, keyworkers, PAs? Websites and helplines? Recognition that ‘changes in your head’ are part of growing up.
- Feelings about growing up – emotional changes; mood swings; body changes.
- What sort of worries and feelings might families have at transition?
- What emotional support is available to families to help them deal with worries and feelings at transition? Support groups? Talking to other families? Other support/strategies?
- There will be different issues to consider for young men, young women, young people from minority ethnic groups, young people with high individual support needs, and young people living away from home.

7

Conclusions

This review has highlighted a number of areas where comprehensive, and up-to-date information about transition is urgently needed by young people with learning difficulties and their families. Although much of this information exists (in journal papers, reports, books and websites), it is not currently in formats that are easily accessible and available to young people and families. Young people and families want information about changes, choices, services and emotions at transition that they can digest and mull over at home (Rowland-Crosby et al, 2003a).

The provision of accurate and culturally-appropriate information for young people and families from Black and minority ethnic groups is essential. O'Sullivan's research (2001) found that issues faced by young disabled people and carers from Black and minority ethnic groups at transition included:

- A lack of information about services and benefits – a crucial issue where another language was spoken at home. Interpreting was not routinely available for welfare rights advice.
- Young disabled people regularly interpreted for carers in relation to their own services.
- Major disadvantages and confusion in relation to services resulted where a young person had high individual support needs and the carers had no English. These families have contact with a large number of different services which rarely use interpreters or translated material.
- Two Black carers highlighted the crucial impact of previous experience of racism and discrimination on people's approach to and experience of services.

Information needs to be individually tailored where necessary to meet the communication support needs of individual young people with learning difficulties. The Connexions PA is likely to play a key role in co-ordinating information about transition and adulthood and in ensuring it meets the needs of the young people they are supporting. But other agencies and services should also ensure that adequate and accurate information is available in appropriate formats about the options and provision they offer, and be prepared to welcome young people and families for visits, fact finding days, or face-to-face enquiries about the nature of the choices available.

Mitchell's (1999) research found that parents had particular 'fears of the unknown' associated with day services and future housing options for their disabled youngsters. These fears were often based on social evaluations and presumptions which may have been allayed by more and earlier information.

Providing accurate information at transition is very important and can help to allay some of the fears and concerns experienced during the move towards adulthood.

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Appendix A

***The Road Ahead?* project**

The Road Ahead? project was a collaboration between the Norah Fry Research Centre (University of Bristol), North Somerset People First and the Home Farm Trust. The objectives of the project were to find out (a) what information young people with learning difficulties and their families want at transition; (b) what information about transition already existed for families and young people with learning difficulties. The project also aimed to provide information to the Social Care Institute of Excellence (who had commissioned the project) about the content and format of a potential website for young people and families about transition.

The review of the literature presented in this document involved a systematic search of databases (see Appendix B) and the initial production of a list of key themes derived from the selected literature. This list of themes was sent for comment to a range of commentators and organisations in the field of learning difficulties to check that it was comprehensive and to seek their views on the way that the material might feasibly be organised for the purposes of a website. Following their feedback, the full literature review was produced, the output being this report.

Running alongside the literature review was extensive consultation work with young people and families, as well as a review of existing resources about transition. The consultation work was conducted by North Somerset People First and the Home Farm Trust, with research input and training from Beth Tarleton (Norah Fry Research Centre). The research team consisted of six young people with learning difficulties (Mark Smith, Clare Twiselton, Tim Eden, Anna Meredith, Kath Sawyer, Jo Rawlings), their supporter (Sue Hogarth), and Robina Mallett (Home Farm Trust). Focus groups were conducted in four different locations in England and Wales. The research team talked with young people, family carers and staff/supporters about their information needs and experiences at transition. Qualitative data was collected and analysed. The review of existing resources was carried out by Debby Watson, Norah Fry Research Centre. The resources review covered packs, websites, projects and other material not included in the literature review. The research team of young people and their families were involved in reviewing this material for its usefulness and accessibility.

Appendix B

Search strategy used for the literature review

Our primary search strategy was to conduct a database search, using the following database search engines:

Search engine	Total number of hits using key search terms given below	Number tagged	Hard copy obtained
IBSS (BIDS)	92	3	0
ASSIA	189	42	8
British Education Index (covers ERIC and CIJE)	1,246	64	15
PsychInfo	352	8	8
CareData	177	64	22
Medline	215	50	3
CINAHL	253	35	2
Cochrane Library	63	0	0
Dissertation Abstracts	77	4	0
SSCI	90	39	2
Sociological Abstracts	32	6	4
ZETOC	38	4	4

These databases were chosen to reflect the widest range of literature available, and because they were held in electronic form by the University of Bristol library. The following databases were not searched as they were not available through subscription to the University of Bristol or were in print format only: HIMC, SIGLE, Social Work Abstracts, NASW Clinical Register, Social Services Abstracts, Wilson Social Science Abstracts, Campbell SPECTR.

The key terms used for the search were as follows:

		Young disabled people
		Young people with learning difficulties
Transition	AND	Young people with learning disabilities
		Carers
		Families
		Families of young people
		Professionals
		People with intellectual impairments
		People with mental retardation
		People with intellectual disabilities

Out of the total number of hits per search, a number of records were tagged or marked according to the following inclusion criteria:

- English language version available.
- Reference dated between 1990 and 2003.
- Reference specifically related to young people with learning difficulties or young disabled people (where it was likely that this label would also cover young people with learning difficulties).

Abstracts, where available on-line, were then sought for the tagged references. These were scanned in respect of the above inclusion criteria, and a decision made about whether or not to obtain a hard copy of the full article or reference. Some references were not available to download and were not available in journals held by the University of Bristol. In these cases, it was not possible to order **all** of these through the University's inter-library loan service, due to a lack of time and financial resources.

In addition, a separate Google search on 'transition and young people with learning difficulties' revealed additional sources, including a reading list produced by the Virginia Commonwealth University (www.vcu.edu/rrtcweb/techlink/iandr/transition/references.html). Three references were marked and hard copies obtained from this source.

The Norah Fry Research Centre has a well-stocked library and searches were made for material relating to transition and young people with learning difficulties, producing 37 additional pieces of literature. As the review progressed it was also necessary to specifically seek out particular references to illuminate points or to clarify issues. The Norah Fry Research Centre library was used for this purpose, although additional references were not logged in terms of numbers obtained.

Once obtained, references were read in full and evidence extracted in respect of a number of emerging themes relating to the topic of transition to adulthood for young people with learning difficulties. A 'source document' was produced which summarised evidence from each reference under key theme headings. This document was used as both the basis for developing the list of themes which we shared at an early stage of the review with a range of key commentators and organisations in the field of learning difficulties, and as the 'raw data' for the full review of the literature presented in this document.

Not all of the literature obtained was referenced for this review. Only those items from which we quoted, or made direct reference to, are given in the references section.