young people with special educational needs/learning difficulties and disabilities: research into planning for adult life and services

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Executive summary

The transition to adulthood for young people with special educational needs (SEN) and/or disabilities, often referred to in post-16 contexts as learners with learning difficulties and disabilities (LLDD), is known to be difficult and not always entirely successful (Sloper *et al.*, 2010; 2011).

In March 2011, the Department for Education published a Green Paper, *Support and Aspiration: A New Approach to Special Educational Needs and Disability – A Consultation* (DfE, 2011) that makes wide-ranging proposals relating to the concerns of children and young people with SEN, learning difficulties or disabilities (LDD), their families and the professionals who work with them. This research was commissioned by the LG Group to inform their response to that Green Paper. The research aims to shed light on how young people with SEN or LDD have been prepared for adult life and adult services, and where the process of planning for this transition might be improved. The research looked at policy and practice in six local authorities, through interviews with 49 professionals, parents and young people. The key findings from these interviews are set out in this executive summary.

Planning for young people's futures

Approaches to preparing young people for adult life and planning their transition vary across local authorities. Many of the professionals supporting young people appear to focus on transition points (such as out of post-compulsory education), rather than seeing transition planning as a seamless journey.

The meaningful involvement of young people and parents or carers is the key to successful transition planning. Professionals felt that parents vary in their willingness and ability to be involved and pointed out that young people can be at odds with their parents. Parents suggested that professionals are not always well placed to gauge whether their child is capable of making complex decisions about their future.

Parents reported a general lack of good and timely information, advice and guidance about how to plan for their child's transition to adulthood. Professionals also reported struggling to fulfil their obligations in terms of transition planning due to limited capacity and high staff turnover.

Transition to post-compulsory education and/or training

Entry-level courses and foundation learning programmes at further education (FE) colleges appeared to be the default destination at the end of compulsory education for young people with low to moderate needs. Some parents and local authority staff concluded that FE courses are not always well suited to young people's needs and not all young people receive an appropriate level of challenge.

FE courses were, however, seen to offer young people a greater level of independence than schools, and opportunities both to maintain contact with friends and access a wider social network.

A change of learning environment for post-compulsory education introduces new challenges. Some parents are fearful about the transition, others struggle with the idea that a *full-time* college placement typically provides only three days of structured activity per week.

Transition to employment

Whilst many of the young people expressed interest in entering employment, adult interviewees identified a number of barriers to them doing so. These include:

- low expectations
- a lack of opportunities and support to develop essential skills
- employer discrimination.

Several local authorities had attempted to raise the expectations of families and schools, and ensure that employment was discussed with young people. A number had successful supported-employment projects, but these could only accommodate small numbers of young people and, due to a reliance on time-limited funding streams, had uncertain futures.

Transition to independent life

Young people expressed ambitions very similar to those of their peers without SEN or LDD: to have their own home, a car and a full social life. However, discussions about these ambitions were not always followed up with the actions required to realise them.

Some local authority interviewees and parents felt that young people are leaving mainstream or special schools less prepared for independence than they should be as a result of insufficient opportunities for challenge and development.

Developing approaches to transition

Initiatives recently established by local authorities to support the smooth transition of young people into adult life and services included:

- establishing multi-agency transition panels and teams
- employing transition champions and key workers
- implementing person-centred transition planning
- undertaking development work with parents and schools.

Conclusion

Professionals, parents and young people all identified historic weaknesses in transition arrangements for young people with SEN or LDD. These resulted in relatively few young people being systematically prepared for adult life. This has clear implications for the quality of life experienced by young people with SEN or LDD and their families. However, there is evidence that services and practices are developing, with positive outcomes for some young people. The changes proposed in the Green Paper (DfE, 2011) have largely been welcomed.

1 Introduction and policy context

Young people with special educational needs (SEN) and/or disabilities, often referred to in post-16 contexts as 'learners with learning difficulties and disabilities' (LLDD), may have a wide range of support needs and have drawn upon a variety of services over the course of their childhood (Lewis and Porter, 2004). These young people's transition into adulthood and adult services (over the period from 14-25 years), is often characterised by a decline in access to support (Department of Health [DoH], 2010).

Some local authorities have developed specific strategies to smooth this transition such as establishing transition panels to plan and coordinate packages of support. The transition is known to be difficult and not always entirely successful (Sloper *et al.*, 2010, 2011; Lamont *et al.*, 2009). It is widely recognised that more and better support and opportunities need to be available to disabled young people and young people with SEN or learning difficulties or disabilities (LDD) to enable them to make a successful transition into adult life.

In March 2011, the DfE published wide-ranging proposals to respond to the concerns of children and young people with SEN or LDD, their families and the professionals who work with them, and to improve outcomes for these young people in adult life. To inform their response to the Green Paper, the LG Group commissioned three research projects looking at issues relating to young people with SEN or LDD. This report presents the findings from one of these projects, exploring the transition of young people with SEN or LDD to adult life and services. The other research projects investigate local authorities' views on the Green Paper's impact on families (George *et al.*, 2011) and young people and parents' views on residential education (Poet *et al.*, 2011).

1.1 Research questions

This research project aims to shed light on how young people with SEN or LDD have been prepared for adult life and services. It looks at where the process of planning for this transition might be improved. It considers the role played by key individuals and groups, looking at how these work with and on behalf of young people with SEN or LDD. The research focuses in particular on the conversations different stakeholders have as young people approach adulthood. It also considers how young people's ambitions for their education, training, employment and independent living are developed and the steps taken to realise them. It explores policy and practice in six local authorities so that a picture is built up of transition planning and preparation through interviews with a range of professionals. It also includes the views of young people, parents and carers that were obtained through interviews.

1.2 The research process

The NFER team gathered data between March and May 2011, interviewing 49 people (a mix of professionals, parents and young people) from six local authorities. The sample of local authorities included urban and rural, unitary and county councils, and covered five English regions: the North East, the South West, the West Midlands, Yorkshire and Humber, and London. Qualitative interviews were conducted, largely face to face, with:

- 23 professionals across six local authorities. Staff were drawn from education, social care, and information, advice and guidance (IAG) services. They work in a mixture of operational and strategic roles and have varying levels of responsibility and direct contact with young people.
- eight parents across three local authorities. This included two parents with children also involved in the research, and six parents with children (aged 16-25) who were unavailable or whose disabilities were such that they were unable to contribute to the research themselves.
- 18 young people across four local authorities. These young people, seven female and 11 male, ranged

from 16-25 years of age. Almost all have a learning disability, in some cases in combination with other forms of disability. Sixteen young people were interviewed in school or college settings; one learning disabled young person was interviewed over the telephone; and one severely physically disabled young person (without a learning difficultly) contributed by email.

Due to its size and composition, the sample should not be considered representative. Moreover, the services and practices described may have changed since the interviewees experienced them. Further details on the research methods can be found in the Appendix.

1.3 Scope of the report

This report brings together the views of young people, parents and professionals on how young people with a range of SEN or LDD have been prepared for adult life and/or services. It covers:

- planning for young people's futures (Chapter 2)
- transition to post-compulsory education and/or training (Chapter 3)
- transition to employment (Chapter 4)
- transition to independent life (Chapter 5)
- developing new approaches to transition (Chapter 6).

2 Planning for young people's futures

This chapter reports on approaches to planning for young people's transition to adult life and using adult health services. It looks at the variation in transition planning both within and across the six local authorities involved in the study. It also discusses some of the key issues and challenges related to transition planning.

2.1 Summary

The main findings on planning for young people's futures are:

- Interviewees felt that transition planning typically starts too late and is too focused on short-term goals.
- Interviewees were concerned that the low expectations of parents and educational staff can limit young people's options.
- Most of the planning focuses on educational provision, but young people with SEN or LDD also need support in leading independent lives.
- The main barrier to effective planning is the lack of suitable opportunities for young adults with SEN or LDD, especially in the workplace.
- Interviewees were concerned about the lack of capacity in services, in terms of levels of staffing, staff expertise and workload.

2.2 Variation in transition planning

The SEN Code of Practice (Department for Education and Skills [DfES], 2001) provides a statutory framework for initiating transition planning. Key staff across the six local authorities involved in this study appeared to be relatively clear as to the code's requirements even though their approaches varied. While some young people and their parents felt they had received adequate support with transition planning arrangements, others, particularly parents with older children, expressed their frustrations. One parent said:

> *For the last three or four years I've known, they've said to me 'get in early'* [that is start planning for transition] *which I did. My daughter* [age 19] *is three months away from finishing school and I'm no further forward than I was four years ago.*

The definition of a young person's needs in a statement of SEN (prepared while still at school) has a strong influence on their access to support into adult life. If a child does not have a statement, there is no formal duty on schools or local authorities to ensure that a child has a year 9 transition meeting and year 10/11 reviews. Local authorities' approaches to statementing vary and it is unclear what level of transition planning and support is available for those young people with special needs that do not have a statement. Some interviewees across the six local authorities believed the support available is likely to be minimal.

Some local authority staff commented that transition planning also varies by type of educational setting. Interviewees suggested that transition planning is typically less developed in mainstream schools, particularly in relation to planning for independence (see Chapter 5). Professionals reported that in some such schools transition planning is simply 'tacked on' to the annual review of a young person's statement. Some professionals mentioned that their local authority is piloting new approaches in special schools before implementing them across mainstream schools in the area, and this could account for some differences in practice.

Interviewees reported further variation in the breadth of focus of transition plans, with some being almost entirely focused on short-term goals. Rather than seeing transition planning as a 'seamless journey', many of the professionals supporting young people and their families appear to focus on key 'transition points' such as out of post-compulsory education. Planning for employment appears to be less common (see Chapter 4). There were concerns about the lack of a holistic approach to transition and some interviewees felt that the wider needs of young people are often overlooked in the process (see Chapter 5).

Transition planning and reviewing arrangements for young people once they have left compulsory education appear particularly unsystematic. Professionals and parents expressed some doubt about the procedures in place if the original (post-compulsory) placement fails, or once a young person has completed a course. As one local authority interviewee said:

> *In reality, I don't think they* [Connexions] *work with people up to 25, because once they* [young people] *are actually placed in college they tend to drop off their books.*

Some professionals described how they are initially focusing on improving the planning and arrangements for transition at 16, before addressing processes through to the age of 25.

There also appears to be little in the way of ongoing transition planning or support for those young people who did not meet the criteria for adult social care at the age of 18. This issue is causing particular distress to some of the parents involved in this study, as one parent explained:

> *Those* [young people] *with lower to moderate needs, they can still go to college and access their choices. The profoundly disabled will probably get access to residential or nursing care but it's these young people in the middle – the severely disabled – they're the forgotten ones.*

Several professionals welcomed the proposed Education, Health and Care Plan set out in the Green Paper (DfE, 2011), seeing it as clarifying responsibilities and ensuring planning and integrated support into early adult life 'so we don't lose that person'. They felt that a plan extended to the age of 25 might provide an essential framework for tracking longer-term outcomes and intervening where education, employment and housing placements have broken down.

The professionals recognised the involvement of parents and carers as key to successful transition planning. However, the extent of parents' willingness, and indeed their ability, to be involved in the process is seen as variable (for example, parents themselves may have a learning disability). Interviewees' comments suggested that if parents have low aspirations for their child, this can hamper transition. Local authority interviewees suggested that some parents see the transition to adulthood as high risk, and their efforts to protect their child could restrict a young person's access to transition opportunities. One professional explained:

> *The hardest thing for a mother of a disabled child is to stop being a mum and let them be an adult* [...]. *They've been very protective all of that child's life.*

The fact that the legal status of young people changes at the age of 18 has considerable implications for the relationship between families and service providers. Some professionals emphasised that a key feature of transition to adult life is the increasing primacy of the young person's choices, pointing out that these may well be at odds with those of their parents. As one professional said: '[There's] a conflict of need between the child's aspirations and the parental anxiety.' This can be seen in attitudes towards day centres. Parents often see them as offering a safe environment for their child, but young people can find them constrictive and lacking in challenges. For this reason, a wide range of professionals (from across the majority of the six local authorities) were concerned by the Green Paper's emphasis on parental choice. One professional commented: 'That's a weakness, because it reinforces the idea that we're doing these services for parents.'

In contrast, the comments of several parents suggests that they felt professionals are not always best placed to gauge whether their child is capable of making decisions on complex issues. Some parents pointed out that professionals can also narrow young people's horizons during transition, due to their low aspirations and/or a limited understanding of a young person's abilities, interests and needs.

2.3 Locating suitable provision

One of the key difficulties in transition planning, highlighted by all types of interviewees, is that of identifying suitable provision for young people to move on to. This relates to all aspects of life, not just education and training. As one professional said: 'There isn't a lot out there, you have to really look.' Another local authority interviewee expressed his frustration at the difficulties this causes when discussing future possibilities with families: 'You always seem to be looking through fog. You can't see what lights are at the end of what tunnel, or what path they can take.'

Young people and their parents were acutely conscious that despite being encouraged to consider a range of potential options, their options are, in reality, limited. As one parent said: '[At the annual review] they write down what you would like [...] but you're told: "Don't get your hopes up".' Some interviewees perceived the challenging economic climate as exacerbating the situation, with one parent claiming: 'The day centres aren't even taking any referrals, because of the cuts in budgets.'

Across the case-study areas, at the end of compulsory education, transition plans for young people with low to moderate needs typically focus on the transfer to further education (FE). As one local authority interviewee explained, this was not necessarily because FE was the best place for a young person, but because: 'We haven't got enough to offer them as an alternative.' For young people with more complex needs, another local authority interviewee felt there is an 'over-use' of residential placements. In some cases, the perceived over-use of particular types of provision (FE or residential placements) is attributed to a lack of alternatives. In other cases, alternative provision is available, but considered as either low quality or unsuitable for young people with certain types of need. Opportunities appear to become yet more limited further down the line, as one college professional explained:

> *A day centre, sometimes that's the only way that the older students can go* [at the end of a college course]. *A lot of our students are higher functioning, so sometimes it's a step backwards.*

Some interviewees suggested a potential solution to the lack of provision is for families to use personal budgets to fund activities, as recommended in the Green Paper (DfE, 2011). But parents countered this with the conclusion that such grants are of no value if there is not a service available to purchase, which, in their experience, is sometimes the case. One parent described their experience of a personal budget as: 'A load of money to buy something, but there's nothing to buy.' Professionals also questioned the cost-effectiveness of the personal budgeting approach, raising the issue of economies of scale (achievable through the purchasing power of a local authority).

2.4 Access to information and information sharing

In order to make sound transition plans, parents and young people need access to good and timely information, advice and guidance (IAG). Several parents expressed dissatisfaction with the timing and quality of the information provided to them. They suggested that an outline of key transfers (for example, from children's to adult services, or from paediatric to adult health services) should be given much earlier, so that families are prepared for these important stages. Some professionals described work in their local authority intended to ensure that families have access to information at appropriate times in the transition process. They noted that families vary tremendously in their readiness to receive and respond to such information. As one professional explained:

> *It's about having enough information at the right time to help make those decisions. We try and give the information at* [age] *14, but some families are scared and say they don't want to hear about transition at this stage, they'll deal with it at the time* [...]. *Others will embrace it and start gathering information as soon as possible.*

Many parents expressed frustration at the limited guidance they had received as their child approached the end of compulsory education. In light of the limited range of options for young people with SEN or LDD post-16 (see section 2.3), this information gap may prove difficult for IAG professionals to overcome. Others reported receiving conflicting information and advice from education professionals. Some parents appear to have been provided with inaccurate information, leading to inappropriate expectations. For example, being told they have an unqualified right to publicly funded education for their child through to the age of 25 (this is discussed further in Chapter 3).

Professionals and parents across all six local authorities also commented on the lack of information sharing between agencies and sectors (for example, of transition plans, S139A[1] and other assessments). This was frustrating for professionals, but yet more so for young people and their parents (who were subjected to repeated assessments by different services, sometimes with little clear rationale). One parent expressed her frustration in the following terms:

> *It's a lack of communication among the services, no one comes together… There isn't one source that you can go to to get all the information on* [my daughter]. *She's been at school for fifteen years: children's services have that information. It's all at hand, so why do all these assessments?*

Another parent complained about the process of making apparently futile college applications:

> *We visited the college and filled in all the forms and the assessments; they then come back and say: 'Sorry, we cannot take her.' That was done when she was 16/17,* [then] *a year later we need to go through the procedure again knowing full well that I'd be told they* [the local college] *wouldn't take her. That's not right, it's an insult to parents and a waste of time.*

2.5 Capacity of professionals to support transition planning

Some parents acknowledged that capacity is an issue. They had observed professionals trying but struggling to do what they need to. The interviews with professional staff shed further light on this. Several professional interviewees (across the six local authorities) said they are struggling to fulfil their obligations in terms of transition planning due to the small number and high turnover of responsible staff. This includes Connexions personal advisors, social workers and transition support workers. They expressed concern about the impact of recent or anticipated reductions in staffing at Connexions, with one saying: 'The capacity isn't there on the front line.'

The expertise of the staff supporting young people's transition to adulthood was also questioned by some interviewees, with the perception being that certain groups of young people are better served than others. In one area, for example, a local authority interviewee described how the specialist Connexions worker mainly supported young people with learning disabilities, but had less experience of working with young people with physical disabilities. A parent said: 'I talk about university, but she [the Connexions personal advisor] kind of doesn't get that one, because her usual caseload doesn't look at universities.' Some areas had attempted to ensure access to appropriate support by introducing specialist posts (see Chapter 6).

Note

1 An S139A assessment is an assessment required under the Learning and Skills Act 2000. Its purpose is to provide a comprehensive report of the support needed by a young person with learning difficulties and disabilities, to ensure they are able to succeed in post-16 education or training, or higher education.

3 Transition to post-compulsory education and/or training

This chapter reports on the transition to post-compulsory education and/or training. It highlights issues relating to the range of post-16 education and training opportunities available to young people with SEN or LDD and the IAG provided to them and their parents or carers.

3.1 Summary

There are three main findings on planning for transition to post-compulsory education and/or training.

- Interviewees saw FE colleges as being the default destination at the end of compulsory education for young people with low to moderate needs. They felt, however, that the courses on offer do not always meet young people's needs, or offer an appropriate level of challenge.

- FE colleges were seen as offering young people a greater level of independence than school, whilst presenting opportunities both to maintain contact with their friends and access a wider social network.

- A change of learning environment introduced new challenges. Some parents were fearful about the transition, others struggled with the idea that a 'full-time' college placement typically provided only three days of structured activity per week.

3.2 The range of post-16 education and training opportunities

Comments from all types of interviewees (professionals, parents and young people) suggest that the range of post-16 education and training opportunities available to young people with SEN or LDD is extremely limited. Parents and young people described being steered towards college and talked about a lack of 'real choices' (see also Chapter 2). Comments further suggest that opportunities are not always well suited to these young people's needs. While, in many respects, there is a great deal of support for college provision, these institutions and their programmes are also associated with a range of challenges and disappointments. This is discussed further in section 3.3. This picture is consistent with the statements made in the Green Paper about the availability, range and quality of options (DfE, 2011).

Across the six case-study areas, local authority interviewees were aware of the need to develop post-16 education and training so that they accommodate a wider range of interests, abilities and needs. Work is already underway in some areas. For example, one of the case-study authorities has formed a consortium with three neighbouring local authorities to provide a larger pool of opportunities. Interviewees recognised the importance of offering provision in settings other than colleges, both within the community, and (with a view to maintaining skills) in day-centre settings. However, it would seem that such opportunities are currently limited. Staff in one local authority said there had been more scope for them to deliver skill maintenance programmes in the past:

> *What we used to do was outreach into day care provision and deliver education, so it may have been leisure, literacy or numeracy but it was education* [...]. *That's stopped now, because of funding.*

3.3 Supporting young people's transfer to post-compulsory education

Local authority interviewees described work to prepare young people for the transfer to a post-compulsory education setting. This includes equipping young people to make meaningful choices about post-16 provision by enabling them to experience a particular establishment or course before committing to it. Examples of this include offering young people taster sessions that introduce them to the college environment and culture. As one professional said, such firsthand experience is invaluable, whereas: 'If you talk, it's just words that go right above somebody.'

The move to a new institution with a very different culture and environment to school can be a very positive experience for young people. One parent, for example, reported how 'the freedom and openness of the campus [are] allowing [my son] to gain confidence in himself'. Another parent said:

> *The big step from school to college has been successful* […]. *He's gone from being picked up in a bus every morning, being taken to school, having no responsibility* […]. *He now travels independently, he manages his money* […]. *So life is very different today than it was a year ago at school.*

Similarly, many of the young people we spoke with, both those in the final years of school (years 11-13) and those currently accessing college programmes, talked about FE offering them a greater level of independence. They particularly value the opportunity to maintain contact with their friends, as well as access a wider social network.

However, a change of learning environment for post-compulsory education also introduces new challenges for some young people and their families, as one parent reflected: 'It was an incredibly anxious time for me as his mother.' Some parents struggled with the idea that a full-time college placement typically provides only three days of structured activity per week: 'That presents difficulties […]. He's going to be on his own [at home] all day long.' Young people also described the challenges of a college life and the need for greater support in order to fully integrate:

> *I wanted somebody to help out, like an older student* [to help me]. *I wanted somebody to help me learn to socialise. I got no help with that. All I got was a weekly meeting to see how I was getting on.*
>
> Young person with an Autistic Spectrum Disorder (ASD)

Some interviewees were disappointed with the level of challenge offered by FE programmes. A few professionals raised concerns that although young people may have successfully transferred to college, college staff are not necessarily building on previous education and learning experiences (and/or are failing to identify suitable progression routes). One interviewee described colleges as being inclined to 'play it safe, because of retention and achievement success rates'. Similarly, some of the parents we spoke to felt that staff do not always encourage or enable their children to achieve their potential, and they question the meaningfulness of certain activities:

> *They do colouring, this is youths at 20!* [They're] *just keeping them busy because they do not know what to do with these children* […]. *I said: 'Why don't you teach him some English, teach him to read?' and I was told it was a really good idea.*

Parents also described struggling to ensure their child has sufficient opportunities to develop the basic skills needed to progress to higher-level college courses:

> *The Director of Courses said* [our son] *wasn't able to do an employment skills course next year, because he wasn't academically qualified to participate* […]. *He could be, if* [they] *stopped trying to teach him to cook for one day a week!*

Though some parents spoke very positively about the adults working with their children, others (with sons and daughters currently in FE) expressed concern about the training and qualifications of some staff. A few suggested that staff are not adequately prepared for the challenges of working with young people with learning disabilities:

> *In my experience,* [my son's] *teachers have been untrained. They're not trained sufficiently to teach youths with special needs. Having said that, there are a number of very good teachers, who are not allowed, within the confines of their organisation, to develop children.*

3.4 Information, advice and guidance for post-compulsory education and/or training

Interviewees across the six areas felt there is sometimes a shortage of IAG for young people and their families in relation to education and training opportunities. To some extent, this could be due to the limited range of opportunities available. It was suggested that in the majority of cases specialist Connexions staff only have the capacity to support the most vulnerable young people (typically those with learning disabilities) through the initial transition into post-compulsory education. Capacity is expected to become more of an issue as budget cuts hit home (see also Chapter 2).

A few parents expressed the belief that their children have an unqualified right to publicly funded education through to the age of 25. However, college staff stated that the conditions of their funding regimes only allow them to offer ongoing provision where clear evidence of academic progress can be provided. Families have been shocked to find colleges stating they can no longer offer a young person a college place since the young person is unable to demonstrate any academic progress. Unsurprisingly, different interpretations of young people's entitlements as well as the apparent provision of inaccurate advice from professionals has led to tensions between parents and college staff.

A further challenge identified in terms of young people's transition to adult life is the lack of IAG to identify alternative programmes when there are problems with an initial placement or course. As one young person with an ASD explained:

> *When I left school and started college, that was hell! I didn't enjoy it because I was meant to start a course, but they didn't set that course up, but they didn't tell me* […]. *It's annoying when you leave school and start college you know, there's nothing there, there's like an in-between area.*

Interviewees were unclear about the extent to which there would be ongoing transition guidance once a young person has progressed to FE or training. Similarly, upon leaving FE at the end of a course, many young people were reported to be largely without support (other than that provided by their family) to continue their transition into adult life. One concerned parent explained the frustration of this situation: 'There's a lack of information, there's a lack of coordination, and in some respects, there's a lack of care.'

None of the six local authorities had tracking systems in place, as one professional explained: 'I don't think we are doing much about really seeing what happens once they leave college.' Interviewees suspected outcomes for many young people might be poor, with some young people becoming less skilled and equipped to cope with adult life as time went on.

4 Transition to employment

This chapter looks at the experiences of young people in the case-study local authorities, and the planning, preparation and support that is available to help them make a transition into employment.

4.1 Summary

There are three main findings relating to planning for the transition to employment.

- Many young people with SEN or LDD expressed a clear interest in working, and see employment as playing a central role in adult life.
- Adult interviewees identified a number of barriers to these young people entering employment, including: low expectations; a lack of opportunities and support to develop essential skills; and discrimination in the labour market.
- Several case-study local authorities have long-standing and successful supported-employment projects, but these are only able to accommodate small numbers of young people.

4.2 Discussions about employment

Many of the young people we spoke to expressed a clear interest in working, seeing employment as playing a central role in adult life. However, our adult interviewees identified a number of barriers to these young people entering employment. Several professionals and parents remarked that, historically, the assumption has been that young people with SEN or LDD would not go on to work, and this is key to understanding the pattern of un- or under-employment prevailing today. One local authority interviewee commented: ‘The major barrier [to employment] is that there is no expectation that this group of people will work.’

This lack of conviction could explain why transition directly from school into employment is rare in the case-study local authorities. The small sample of interviewees in this study offered no examples of young people going directly into work. The focus of statutory transition planning seems to be predominantly on transitions that are easiest to secure (for example, going into a post-compulsory education setting, which in some cases might offer work preparation programmes). This is consistent with wider trends and agendas, which are encouraging young people to stay in education for as long as possible and achieve as high a level of qualification as they can before attempting to enter the workforce. However, interviewees expressed concern that, for some young people with SEN or LDD, employment may never have been considered as an option. As one local authority interviewee suggested: ‘They have never really been asked questions about employment […]. It’s [been] assumed that they won’t ever work.’

Interviewees from several case-study local authorities reported that they are attempting to change this mind-set, and believe they are making some progress. FE providers offering work preparation and supported-employment programmes appear to have been instrumental in bringing about this change. For example, an interviewee in one local authority described how he had visited schools and met with special educational needs coordinators (SENCOs) in an attempt ‘to raise awareness and expectations’.

An initiative targeting the parents of children in special schools was also outlined in the interviews. It intends to get parents thinking about employment in adult life ‘because parents’ expectations can be quite low [too], they never think their son or daughter can work, so it’s just putting the seed in’. Offering a contrasting experience, a couple of local authority interviewees remarked that whilst some parents underestimate their child’s capabilities, others overestimate them. One explained: ‘Some parents think their child is brilliant and really can do anything.’ Another commented: ‘You’ve got to be realistic. Parents do sometimes build them up too much – and then we have to take [their dream] away, and that's sad.'

Local authority and college interviewees involved with supported-employment projects said that helping young people and their parents to develop stretching, but realistic, ambitions can be a long process. One described the approach she would typically take with young people:

> *Looking at what their interests are, and then bringing that in a little bit. So if they said they wanted to be a vet, or a veterinary nurse, you know that's unrealistic, but there are other jobs working with animals* [we can look at] *so they still have the area that they're interested in, but in a more realistic setting.*

Some of the parents we interviewed, whilst confident their child is capable of work, expressed concerns about them taking on relatively low-paid work. This could lead to the loss of valuable benefits, as one mother said:

> [My son] *is desperate for work and is very capable of work but, with the benefits system, he has to be working 16 hours a week or more after the first* [year] *or he loses all his benefits.*

4.3 Preparation for employment

Whilst the recent Green Paper (DfE, 2011) highlights the poor quality of work experience opportunities, those in our study suggested there are little or no opportunities at all for work experience whilst at school. One young person with Asperger's Syndrome expressed his frustrations about this:

> *I asked for work experience to try and gain some employability skills, I asked eight or nine times. I got one day of work experience.*

The lack of work experience was explained by a local authority interviewee:

> *The problem with some of the special schools is that they don't have extended work experience programmes.* [Parents] *don't push and then because they don't push there isn't the demand. Generally, the supply of those work experience placements is going to come from either parental contacts, or large firms.*

Several parents told us that they had been pivotal in arranging their child's work experience, one commenting: 'Work experience was only obtained through parental initiative, as our son was overlooked.'

Some local authority interviewees conceded that they need to work towards raising expectations in schools. However, others drew attention to areas of good practice; for example, one of the case-study authorities has established a nine-week work experience programme. This was initially targeted at young people in one particular special school but it is soon to be extended to young people with SEN or disabilities in other schools. In another local authority, young people with a statement can now apply for a place on a work preparation project. According to one local authority interviewee, this has been invaluable for the young people involved:

> *It gives people a real opportunity to hone their work skills, they are looked at and assessed in practice – about what eye contact they give, what clothes they wear, their grooming – all the sorts of things that are important in a meaningful job.*

Once young people move on to college, there appears to be more opportunities to develop skills for employment and to access work placements. For example, one college-based professional told us how the college provides work experience for young people:

> *They do work experience, we've got a juice bar at the college and they help out there. They've also done some work in the food hall.*

However, she went on to explain the constraints on the opportunities the college could offer:

> *It's mainly in-college, in-house, because a lot of the students are taxied or transported to and from home.*

The critical role of travel training in young people's transition to adult life is considered in Chapter 5.

Interviewees acknowledged that there is an ongoing need for work experience and preparation programmes. Some young adults may have missed out on such opportunities whilst at school, and others might not be ready to embark on such activities until further into adult life. Several local authority interviewees emphasised that their adult social care teams are taking steps to develop opportunities for the young adults they work with. For example, in one area, negotiations are underway to secure an entitlement to a 30-day work placement at the local authority for anyone with a disability; in another, the Enterprise Unit provides a setting in which young people can demonstrate and be assessed on their work readiness, through producing gift tags and cards for sale to the public. In a third local authority, the adult social care team is in the process of developing an employment strategy, expected to include the delivery of job-readiness activities for adults on short-term placements in day centres.

4.4 Support to enter employment

Many interviewees welcomed the emphasis on work in the Green Paper (DfE, 2011), but echoed its concerns regarding the support available for enabling young people to access and retain employment. The consensus was that it is not enough just to offer work preparation programmes, and more needs to be done to facilitate young people with disabilities' entry to employment. As one local authority interviewee said: 'There's masses of money out there to get people prepared for work, but there's nobody to get them into work – that's the next stage.'

Professionals identified some effective supported-employment projects, providing examples of young people with SEN or LDD who have successfully entered employment. However, interviewees emphasised that, at present, only a small number of young people are able to benefit from the supported-employment programmes. One professional explained: 'There are limited places, because of our capacity, how many we can support in a year, and how much we're funded for.' Moreover, these programmes are largely reliant on time-limited grant funding. An interviewee from one of the case-study local authorities explained:

> *We've got fingers in lots of pies. When the lottery* [money] *runs out* [...] *we're hoping that it's going to be taken over more by mainstream provision; but we'll wait and see.*

Box 1 is an example of a supported-employment project in one of the case-study local authorities.

Box 1 A supported-employment project

One of the case-study local authorities has a longstanding and successful supported-employment project, designed to secure paid work placements for people with learning disabilities.

A tailored support plan is prepared for each participant, covering job search (for example, CV writing and interview preparation) and job retention skills. A job coach is available for as long as needed (that is until the young person can function in the workplace independently).

Project staff work closely with employers to ensure that they too feel supported, and that 'the working relationship is a fruitful one for all concerned'. One of the young people we interviewed had just found work through this project. He said:

I'm on the [supported-employment project] *and they have just found me work, which I'm quite looking forward to. It's at the library* [and] *for my work experience I worked in a library before, so I thought "Maybe I could do this''.*

Of course, not all young people with SEN or LDD need the level of support offered by a full-service, supported-employment programme. For some, lighter-touch mentoring and advocacy may be more appropriate. One local authority interviewee described how, in her experience, only a small minority of hearing impaired young people get a job, and surmised how they might be better supported to secure one:

> *It's a really difficult world out there for them* [even if] *they're very bright young people.* [One thing that might help is] *mentored employment – for young people that don't need supported employment* [but] *do need mentoring into employment.*

However, in the light of cuts in public service funding, interviewees felt that in the future local authorities will find it difficult to provide even this level of support. Although, in most of the case-study local authorities, there is a body of expertise in relation to physical disabilities and sensory impairments, this is typically vested in learning support services and there is no expectation that these staff will have the capacity to embark on additional, sustained and systematic work related to employment.

Connexions have employed staff with the expertise to provide careers IAG to young people with learning disabilities, but these staff are clearly already overstretched. One local authority interviewee explained that the Connexions office in his area had already cut its services: 'It's closed to visitors and [the advisors'] workload is so vast that [they] haven't finished all the S139As.' One local authority interviewee saw the only potential resource for developing this sort of support further as being individual budgets, where these are made available to young people: 'It will be dependent on [young people] saying, "This is what I want, and I want to pay for it out of my personalised budget''.'

4.5 Extending opportunities for employment

Staff in several of the case-study local authorities acknowledged that discrimination in the labour market remains an issue for young people with SEN or LDD. As one commented: 'The hoops to jump through are so much higher if you've got a disability.' Particular issues were identified in respect of young people with learning and communication difficulties. Interviewees (both professionals and parents) believed that many employers are frightened to employ young people with SEN or LDD, with parents accusing the public sector of setting a very poor example:

> *My son's quite an able young man, he knows what he wants, he goes to these partnership board meetings* [where] *you've got all the heads of social services, the heads of health, education. But when you ask them how many people with special needs they employ, they employ hardly anybody, and that's awful.*

Some local authority interviewees also acknowledged that local authorities need to do more to provide employment opportunities, if necessary through developing practices such as 'job carving' (that is, distilling out the specific elements of a role which are within a young person's capabilities). One local authority interviewee explained that this involves: 'Taking a job and getting rid of all the bits that they won't be able to do.'

The collective view (shared by professionals, parents and young people) was that the current economic climate is introducing additional challenges. As one parent said: 'The reality is that many people are struggling to get jobs, whether they have a disability or not. [Finding work] is a challenge for all young people.' Local authority interviewees reported that even voluntary work is becoming difficult to access, with placements in charity shops becoming 'so oversubscribed with people wanting work experience [. . .]. The young people we are working with are falling further down the line'. The issue here would appear to be largely one of competition, as one local authority interviewee explained. Jobs which in times of full employment might have gone to adults with learning disabilities are now being seen as real jobs and taken up by 'people who need to feed a family'.

It also seems likely that employers may be especially wary of incurring additional operating costs (associated, for example, with adaptations to the workplace, provision for carers, and specialist insurance – all things identified by a young adult with severe physical disabilities as conditions to them accessing employment). Several local authority interviewees thought more could be done to showcase the success stories, where young people with SEN or LDD have become valued members of the workforce. However, many felt that ultimately more support and incentives for employers would be required. As one local authority interviewee put it, the need is for a stock of 'employers who are willing, or perhaps even funded, to have openings for youngsters with disabilities, who we know don't get those chances'. Notably, no mention was made by local authority interviewees of involving employers or businesses in transition strategy groups, though the supported-employment projects in operation in the case-study local authorities had, of course, developed relationships with specific local employers.

5 Transition to independent life

This chapter reports on planning and preparation for adult life more widely by looking beyond the transition to post-compulsory education and/or employment. It looks at distinct spheres of independence: finance, accommodation, social life and use of mainstream adult health services. It also considers more closely the discussions and activities that take place with a view to making independence a possibility for young people with SEN or LDD.

5.1 Summary

The main findings on planning for transition to independent life are:

- Young people's expressed ambitions are similar to those of their non-disabled peers: to have their own home, perhaps a car, and a full social life.
- Discussions about achieving independent living do not appear to be being consistently followed up by actions.
- Interviewees felt that young people are leaving (mainstream and special) schools less prepared for adult life than they should be, having had insufficient opportunities for challenges and development.

5.2 Ambitions for adult life

For young people without a disability, the movement towards greater independence is a natural and central part of the transition to adulthood, often driven by the young people themselves. As time passes, and with varying degrees of success, they take increasing control of, and responsibility for, the organisation and day-to-day direction of many different aspects of their lives. Ultimately, as one local authority interviewee said: 'Most people at 30 want to be living on their own, or with their partners, planning families, having productive activities to do, and having sufficient income.'

Professionals contributing to this research emphasised that young people with SEN or LDD have the same aspirations. Young people's comments bear this out, indicating ambitions that are in parallel with those of their non-disabled peers. Many of the young people we spoke to see employment as having an important place in adult life, but their ambitions go well beyond the sphere of work, as these quotes demonstrate:

> *I'd like to be working, have my own flat, and have my own car, and this job could help me.*
>
> 17-year-old male with an ASD

> *I'd like to have my own home, my place, to have a job in car-selling* [...] *and to have my own car.*
>
> 22-year-old male with Down's Syndrome

> *I'd like to be able to meet more people* [...] *follow through with other writing aspirations, and, at some point – with greatest respect to my parents – like to be more independent.*
>
> 24-year-old male with complex physical disabilities

Whilst acknowledging that disability does place some constraints on young people, and that on occasion ambitions are simply unrealistic (for example, young people with a serious sensory impairment wanting to drive), several local authority interviewees emphasised that they would expect and encourage the young people they worked with to seek out the same opportunities as their peers:

> *We should expect young people to want to leave home, to want to go and live in uni accommodation, or with their friends, and not be limited in where they go* [by having] *to live at home.* [We] *give the message to parents and young people: 'Let's just imagine, if you hadn't got your disability, what would you be aiming for?' Because we can usually find a way to help* [young people] *manage to do what they want to do.*

5.3 Discussions about independence in adult life

The Green Paper (DfE, 2011) states that discussions about independent living, in its fullest sense, should 'become a standard and early part of the transition process' p.91. Whilst, in many of the case-study local authorities, the primary focus of statutory transition planning appears to be on the transition from one educational setting to another (see Chapter 2), some efforts are being made to widen the focus of transition meetings and to take a more holistic look at the trajectory of young people's lives. In addition, as noted in section 5.2, individuals working closely with young people throughout the course of their childhood are encouraging them in a more ad hoc way to articulate and think through their hopes, dreams and ambitions for adult life.

Local authority interviewees recognised the need to systematise discussions about independent living, embed them in the statutory planning process, and, as already discussed, provide access to transition planning support to young people without statements of SEN. However, they pointed out that there is already some good work going on. For example, one drew attention to the 'My Future, My Choice' document prepared by young people attending a special school in his area:

> *It's a booklet that asks all the questions about what they want when they progress into adulthood, and some of it's about their dreams, but we have to capture that so* […] *it's a reflection on their whole life, not just their school life.*

5.4 Progressing plans and ambitions for independence

Whilst discussions about independent living are taking place in the case-study areas, they do not appear to be being consistently accompanied by actions to move young people towards greater independence. Some efforts are being made to support young people's wider development, but they appear to be largely contingent on the work of committed individuals. Should these key individuals leave, work could quite quickly come to a stop in the absence of clear organisational accountability. In some case-study local authorities, this appears to have been a result of weaknesses in the planning process, with one local authority officer reporting:

> *Historically the plans haven't really gone anywhere to be honest* […]. *A lot of the transition plans didn't have an action plan, it didn't say who would do what, and when, within what timescale.*

This interviewee went on to say that work is underway to make the transition planning meetings more fruitful. A key change is the expectation that all transition plans should include a three-year action plan to move the young person forward.

A range of other explanations were offered for the lack of follow-up activity. Interviewees, both professionals and parents, drew attention to a range of barriers to effective planning and preparation for young people's wider adult life. For example, they highlighted the many areas of uncertainty which planning needed to take account of, warning that young people's capacity and needs, as well as the funding and opportunities to which they might have access, could change dramatically within a couple of years.

In addition, statements made by professionals and, indeed, some young people, suggest that some parents have been very protective, and are averse to exposing their child to new risks associated with greater independence. Whether a product of anxiety or low expectations, interviewees felt this protectionist outlook might be deterring some people from engaging in serious activity to promote the highest possible levels of independence.

5.5 Developing essential skills: laying the foundations for adult life

Schools are seen as key in laying the foundations for young people's successful transition to an independent adult life. Local authority interviewees stressed that 'what happens in schools influences what responsibilities [adult social care] have in the future'. Several interviewees argued that the foundations for independence in adult life need to be laid early, and a few suggested that young people leave school less prepared for adult life than they could and should be. One interviewee took this further, describing young people as 'disabled by the system'.

Both mainstream and special schools have their critics. For example, in relation to young people with less profound needs, typically attending mainstream schools, one professional argued that there is often a failure to achieve the right balance between challenge and support. He explained the impact of this:

> *Sometimes, if you have a mainstream school, and you have a disability, you end up with an LSA* [learning support assistant], *and that actually slightly handicaps your independence* [and] *gives the message that you need to be looked after.*

Other professionals, and several parents, expressed similar concerns about the experiences of young people educated in special schools. Some parents, however, and several professionals, had more positive perspectives on special education. They drew attention to independent-living facilities developed with resources accessed through Aiming High (a service improvement programme jointly delivered by the DfE and DoH), and the activities built around these facilities. They see this (non-statutory) work as valuable, but also, in the context of cuts to public funding, very vulnerable to closure.

Interviewees made a number of suggestions about what could be done in the future to help young people arrive at adulthood 'in the best possible state'. These included developing life skills in a community setting through programmes involving a range of services and professionals, and working with parents to help them promote their child's independence. Interviewees of all types (young people, parents and professionals) acknowledged that dependence could result from providing support to young people beyond the point where it is needed. As such, the movement towards independence would necessarily involve the tapering off of certain forms of support, such as door-to-door transport as described in Box 2. However, local authority staff were acutely aware that any withdrawal of support could be perceived negatively, and such proposals would need to be introduced with great care.

Box 2: Independent travel training

Both professionals and parents spoke very positively of the impact on young people's lives of independent travel training, describing it as opening up access to a wide range of services and opportunities. It also decreases young adults' expenditure since, in some local authorities, those attending day centres have to use their disability living allowance to pay for transport to and from centres.

One parent told us how frightened she had been when her son made his first fully independent journey, but she now wondered whether, with training and discreet support, he might actually have been able to travel to secondary school using public transport rather than taxis. Professionals, too, see value in offering travel training earlier in young people's lives.

An interviewee from one of our case-study local authorities said it can be very hard to create realistic and meaningful opportunities for independent travel in rural authorities with poor transport infrastructure. However, this interviewee did agree that efforts should be made to do this whenever possible, as they were doing in her local authority.

5.6 Financial independence

As they move into adulthood, most young people gain greater financial independence. One parent described how the responsibility for managing his educational maintenance allowance (EMA) had offered a new and useful challenge for her son:

> *He now manages his* [EMA] *money – he doesn't always do great with his money, but show me a 16-year-old boy who does!* […] *That's a learning curve, because even something like having some money to go and buy some lunch, he's never done that before. Sometimes he's come home and he's just had a packet of crisps and a can of coke – we've discussed that and he's learning.*

However, in other instances, young people's increasing financial independence can introduce more significant challenges. Families with a child with a disability may have had access to, and come to rely upon, a wide range of benefits and budget allocations. Where caring responsibilities have limited parents' access to well paid and secure employment, these payments can become a key part of the overall family income. The transfer of these payments to the young person themselves at (or before) 18 years of age can present a considerable concern. Professionals told us how families are not always prepared for this change, and it has to be discussed with considerable sensitivity.

Many of the parents we spoke to, in particular where their child had learning disabilities, were more obviously concerned about their son or daughter's readiness to take on financial responsibilities. They emphasised the need to recognise the vulnerability and limitations of these young people and to provide appropriate support. One parent of a young adult with learning disabilities commented:

> *I'm very much for empowerment, but it has got to be honouring the fact that intellectually they may be like a 12-year-old and they're not able to make huge decisions.*

This parent had serious doubts as to whether all Department for Work and Pensions (DWP) staff charged with assessing young people's capacity to take responsibility for their money had the skills and knowledge to make such a judgement. Other parents' comments suggest doubts about benefit assessors' knowledge and understanding of disability are fairly widespread:

> *You wouldn't believe it, I was asked: 'And how long has your son had Down's Syndrome?' And you have to laugh, because I tell you, sometimes you want to* [cry]. *These are people that are assessing if your son, your daughter, is entitled to benefits!*

Another concern was the complexity of the benefits system. One professional said:

> *The DLA* [disability living allowance] *form, for me, it takes about five hours to complete – and I do a lot of them! Families haven't got that level* [of knowledge]. *It's really hard.*

A parent told us how even specialist professionals struggle to make sense of the system and, in the case of her son, this meant:

> *He missed out on 18 months of money that he was entitled to, because the local benefits agency didn't know* [what his entitlements were].

Parents were also worried that college staff without a full understanding of the benefits system might encourage their children to make decisions, such as doing part-time work, which could cause them to lose essential financial support.

There were some reservations amongst both professionals and parents about the types of personal budget currently in existence. Parents portrayed them as complex and time-consuming to employ and, as discussed in Chapter 2, being of no value unless there is a service available to purchase which, in their experience, is not always the case.

Professionals questioned the description of these budgets as personal, emphasising that they could only truly be considered personal if a young person has the opportunity and capacity to manage the budget.

One professional drew attention to the particular vulnerability of young people with personal care needs and said it is critical that they receive appropriate training:

> *If you're trying to manage a budget to pay the person who's going to be your carer, it's another level of responsibility.*

The message is clear: families need access to good information, support and oversight in order for the system to work effectively for them.

5.7 Moving into adult accommodation

Moving out of the family home is perhaps the most significant transition young people make. It is accepted that without major adaptations to accommodation, and a comprehensive support and personal care package, it is unlikely to be possible for every young person with a disability to live independently. However, interviewees felt that, with changes in culture and expectations, it should be a realistic aspiration for many young people with SEN or LDD.

Local authority interviewees said that typically families are extremely anxious about, and sometimes resistant to, the idea of their son or daughter moving out of the family home. So, for example, one described parents' concerns about their physically disabled child leaving home:

> *All parents go through that angst about their child going off to university, but it is more difficult when your child is in a wheelchair, and has got a deteriorating condition, and there are personal care issues.*

Similarly, a young person, with a learning disability who had moved out of home into supported accommodation, told us how her parents worried: 'They're concerned about me now, about me moving out […] but I wanted to move on.' Some young people are able to sympathise with their parents, and had their own concerns about how their parents would manage without them. As one young man with a learning disability explained:

> *I worry about my parents, twenty years on* […]. *I helped my mum and dad loads of times when I used to live with them* […]. *They worry about me moving on, and I worry about my parents being really old.*

Professionals described what they have done to alleviate families' concerns whilst preparing young people for independence. This included sharing information on other families' experiences and using technology to develop, monitor and evidence young people's skills. There are gadgets that can remind a person of appointments and how to get to them, and tracking devices which allow parents to check where their child is. Staff in the case-study local authorities described a number of different levels of support they can provide, from preparatory work in the family home with young people and their parents though to supported accommodation and a lighter-touch floating community support service. One local authority interviewee explained the benefits of such a service:

> *That encourages carers to feel safe, because they know the member of staff will go in and help the individual to prepare meals, to safely close the windows and make sure they've got the door locked when they're going to bed. It teaches those skills that they need to live safely.*

However, as only young people with the most extreme needs receive ongoing social work support as an adult, there is limited help available to the majority of young people to plan for progressively greater independence. The parents of a young person with moderate learning disabilities described how they had carried out their own research and made arrangements for him to try living more independently:

> *Again nobody told us* [what was out there]. *It was a case of finding out, looking on the internet, and ringing up people* […]. *You can't go to one particular place for any help. Nobody really knows.*

Some examples were given by local authority interviewees of work underway with housing providers to agree short-term tenancy models in order to extend the range of provision and offer young people independent-living tasters. In one local authority, information about young people's housing aspirations is shared with colleagues in the housing department to help them develop a picture of future housing needs. The local authority had also developed partnerships with housing providers, enabling them to influence accommodation being built and ensure it can accommodate a range of physical needs. However, looking across the six case-study local authorities as a whole, we found little evidence of housing teams or providers being strongly linked into current transition planning structures and processes. They do not, for example, appear to be represented on transition panels or strategy groups. If planning for independent living is to lead to action, it is important to see explicit linkage to the housing agenda, and close work with housing partners.

5.8 Development of an adult social life

The development of positive adult relationships and a good social life is considered by all categories of interviewee to be a key component of a fulfilling adult life. However, many comments were made which suggest that, to date, this has not always been taken into account when planning support for independent living.

Interviewees drew attention to the various ways in which disability can exacerbate the impact of other changes in people's lives as they approach adulthood and, in general, make it harder for people to develop and sustain social relationships. For example, some young people who, because of their disabilities, are educated in specialist provision outside their local community enter adulthood at a disadvantage. They have had limited opportunities to develop friendships in their neighbourhood. Changes within the family, in particular siblings leaving home, can make a particularly significant difference to these young people's lives. As one parent whose (non-disabled) daughter is about to leave home commented: 'One of the vital pieces of [my son's] support network is going to be gone.'

One local authority interviewee remarked that 'disability is terribly isolating' and several other interviewees (local authority staff, parents and young people themselves) drew attention to the many and varied barriers to accessing social networks and opportunities through regular channels. A parent, with a son with Down's Syndrome, commented: 'It's very difficult for them to make friends – he can't get on the phone and just say "do you fancy coming round?"' Another parent, with a son with an ASD said: 'Our kids are quirky and they'd be eaten alive if they tried to go to a normal youth club or a pub, and just sit around talking about daleks.'

For young people with a physical disability, the barriers to socialising tend to be quite different, but equally significant: social activity may require immense amounts of planning, covering transport needs, wheelchair access, and suitable toilet and changing facilities. One such young person told us:

> *Since leaving college in 2006, I have found it very difficult to find a place to interact socially with both physically disabled and able-bodied people who are around my age and in the local area* […]. *It can feel somewhat isolating that there currently seem to be no suitable social venues* […] *other than pubs, which can sometimes make disabled people feel out of place* […]. *All of this is important, because physically disabled people should still be able to feel mentally stimulated and part of the community.*

Consequently, adult life can be a lonely experience for young people not in education or employment, and whose access to specialist clubs often ends at or before the age of 25. Several professionals (from different case-study areas) expressed concern that this left some groups of young people very vulnerable to negative influences. One cited an example of a young person with an ASD ending up in the criminal justice system. Meanwhile, the parent of one severely brain-damaged girl expressed frustration at the narrowness of her daughter's life: 'The only place she goes is my house, the college, and my mum's.' Another explained that although her daughter, who had a severe developmental delay, was entitled to direct payments to support personal assistant (PA) time, this did not give her the opportunities she needed to get out of the house and mix with her peers:

> *Through direct payments, there's also the option for someone to come to your house to look after them for a couple of hours a week, but again, that isn't what these youngsters need.*

Professionals in the case-study local authorities suggested that young people with SEN or LDD have social needs which often go unmet. One interviewee commented: 'Young people need to access simple things to make their life better […]. They need to be able to get out of the house, to access facilities and have leisure time.' There was evidence that some voluntary and community sector organisations, often parent led, have made efforts to fill the gap in opportunities for young adults. However, as one parent put it, 'it's a drop in the ocean really'. The sad thing for these parents is that they could see how a very modest investment would have a major impact on their sons' and daughters' quality of life. Box 3 describes how some local authorities have taken account of the need for a social life.

Box 3 Local authorities' efforts to create opportunities for social interaction

Action is being taken in several case-study areas to try and take social interaction into account when planning for adult life. Examples of good practice include factoring into planning the relationships young people developed at school and looking at ways of enabling them to sustain these, for example, by sharing PA time, and going to the same college as a friend.

One interviewee from a local authority said:

We were slow to recognise, but now we know, that lots of young people have built up very good relationships across the years with other young people with learning disabilities in their peer group. But historically, once those young people left school, that was the end of those relationships. [Now] *families are saying who their child's best friends are, and where they are going to college, and* [asking] *can their child go there as well.*

Where young people have been educated out of authority, it is proposed that transition reviews include recommendations on how young people can be helped to reintegrate into the local community.

5.9 Transition to mainstream adult health services

While health service personnel were not interviewed as part of this study, the views of other professionals, young people and parents, corroborate the findings of earlier research (DoH, 2010; Lamont *et al.*, 2009) which suggests the transition to adult health services is difficult and disjointed. One local authority interviewee said:

> *When a young person is in children's services, they've got a paediatrician, and all their health needs met. When they come into adult services, their consultants change, their physio*[therapist] *changes, their SaLT* [Speech and Language Therapist] *changes, all their health needs are met by different departments, and they don't get the consistency they* [had] *in children's services.*

A statement in the Green Paper says general practitioners (GPs) will 'maintain' a link into adult life (DfE, 2011). However, the comments from a range of interviewees suggest that GPs, who become the gatekeeper to services at 18, may have little or no knowledge of young people or their medical history before this point (where young people have been accessing health services through a designated paediatrician, or their school). One parent, whose daughter had been educated entirely in a special school, told us how worrying this transition was for her:

> *While they're in school, they can still see the school paediatrician and the school nurse* [but] *at 18-19 they then go into the community for that side of their care* […]. *I've been asking about how that will all work, and just get told: 'Find yourself a good GP'.*

A young person with an ASD described how unhappy he had been with the service provided by his GP, who appeared to have little or no understanding of ASDs: 'He said that it wasn't a lifelong condition […]. His attitude was that one day I'd wake up and it [will] have gone.' A professional from the same local authority area confirmed that there was a shortage of GPs with expertise in learning disabilities, and said that they would like to see a GP practice within the local area develop such a specialism.

In addition to concerns about expertise, there was an awareness that as public resources became scarcer, service providers are likely to become more stringent about their eligibility criteria. One local authority interviewee warned that a possible consequence was that young people with a dual diagnosis (for example, a learning disability and a mental health problem) 'might fall through the gaps'. Another local authority interviewee commented:

> *My concern is that all sections have gone into themselves, and* [that] *everybody is protecting their little section and not really looking at the needs of young people.*

Proposed changes in NHS structures and commissioning processes are expected to introduce further challenges, such as requiring the development of new relationships.

Local authority interviewees with experience of working with health personnel were able to identify a few positive developments. For example, some local authorities are using their transition panels to try to ensure that young people get the support they need in areas of particular concern such as in relation to mental health. Interviewees also drew attention to a number of new practices, believed to be proving successful, such as:

- the compilation of health passports with a brief medical history that a young person can present to a new GP or other medical professionals
- the co-location of health and social care staff
- the employment of designated coordinators and caseworkers to oversee this transition to adult health services.

6 Developing new approaches to transition

Across the six local authorities, there have been a number of developments in recent years to support the smooth transition of young people to adult life and services. The impact of this work may not yet be fully apparent.

6.1 Summary

Key developments identified in the research which could have a positive impact on the transition to adult life for young people with SEN or LDD are:

- creation and development of transition strategies
- establishment of multi-agency transition panels and/or transition teams
- employment of transition champions and key workers
- implementation of person-centred planning approaches
- efforts to work more effectively with parents and schools throughout transition.

Local authorities have been developing strategies and protocols for the transition of young people with additional needs into adulthood. Such documents set out a local authority's vision for improving young people's experience of this transition and inform the development of provision. Transition strategies typically detail the expectations, roles and responsibilities of key agencies supporting children and young people through the transition to adulthood. They also commonly provide a framework for practitioners and agencies to work together.

Interviewees also described how their local authorities have established multi-agency transition panels and/or transition teams to develop and enhance transition planning and provision. Such panels and teams are typically responsible for identifying and monitoring young people during this transition, and resolving more complex situations. In one case-study area, for example, the multi-agency transition panel is working to develop information-sharing protocols among partner agencies to help establish how many young people locally are approaching transition and what their aspirations and support needs are. The panel's longer-term goal is to use this information to identify any gaps in support and provision, and to inform the commissioning of services.

Some of the case-study local authorities employ transition champions to promote the transition agenda and to influence change across the local authority. Transition key workers, as recommended in the Green Paper (DfE, 2011), are also providing direct support to young people (aged 14-25) and, as noted by one local authority interviewee, acting as 'a bridge between the world of a child and the world of an adult'. These professionals are working closely with all agencies involved with a young person: schools, social care and health services.

There was recognition amongst local authority staff of the increasing need to involve young people in the choices and decisions made about their future. All six local authorities are, in principle, committed to person-centred transition planning, though they are at different stages of embedding this approach. A proportion of both professionals and parents identified challenges associated with this approach, some of which will require ongoing work. The time required for person-centred planning was highlighted as one such issue (meetings take longer and often involve preparatory work with young people and their families). How the approach should be employed in respect of young people with the highest level of need should be clarified.

Local authorities are involved in a wide range of work with schools and families to develop and enhance transition planning. This includes increasing parents and carers' involvement in the transition planning process and overcoming parents' fears and anxieties as their child progresses towards adulthood. An interviewee from one case-study local authority, for example, found that the key to working with 'risk-averse' parents is to plan for a series of 'bite-size' risks. In another local authority, work developed through Aiming High has given young people opportunities to take carefully managed risk and, through doing so, demonstrated their capabilities to their parents. As one local authority interviewee said:

> *We are being much more challenging of parents. For example, as part of Aiming High, we did an awful lot of stuff about non-traditional, non-containment-based support for children and their families, which was very much about making sure that young people had choice, an ability to take risks, and an ability to enjoy themselves – and* [the outcome was] *parents actually being overwhelmed by how capable their young people are.*

Work is also underway (and being planned) with schools to develop the skills and practices of staff and to widen the curriculum to better support and prepare young people for adult life. Social care staff in several areas described how they are taking steps to smooth the transition of young people through joint work with schools and children's services.

7 Conclusion and implications

This study set out to shed light on how young people with SEN or LDD have been prepared for adult life and adult health services, and where the process of planning for this transition might be improved. It looked in particular at how young people's ambitions for their education, employment and living independently have been developed, and at the steps taken to equip young people to realise these ambitions. In many respects, the findings of the study complement and reinforce those of earlier research (see, for example, Sloper *et al.*, 2010, 2011). For many young people with SEN or LDD and their families, the transition to adult life is difficult, and outcomes in adult life remain uncertain.

The historical context of this particular study is significant. It took place shortly after a change of government and against a backdrop of a rapidly shifting policy landscape. Local authority departments (both children's services and adult social care) were facing substantial cuts to their budgets, and there was widespread concern about the ability to maintain and extend existing levels of services. The SEN and disability Green Paper (DfE, 2011), has also fuelled the debate about the effective provision of services in this particular area.

The research drew on the experiences of a relatively small number of people in a particular group of local authorities. Some of the professionals, parents and young people interviewed identified historic weaknesses in transition arrangements. However, it is possible that the experiences of young people currently in the earliest states of transition may be better, as, in many cases, the parents and young people interviewed were reflecting on the situation several years ago. As noted in Chapter 6, in several of the case-study local authorities, work has recently been undertaken to improve and make systematic the support provided to young people. The impact of this activity, however, may only be evident in years to come.

The findings of our research suggest that planning and preparation work is focusing on young people with the most extreme needs. Those young people without a statement of SEN and/or a high level of social care needs appear to have had little (or no) transition support. Planning and preparation activity has traditionally focused primarily on specific, early transitions from school to college (at 16, 18 or 19) or (for the few young people who meet the threshold for ongoing services) from children's services to adult social care. Even with this narrow focus, professionals reported struggling to fulfil their obligations in terms of transition planning. There is limited capacity and, in some service areas, a high turnover of staff.

Interviewees recognised that the foundations for progression and independence need to be laid relatively early on in young people's lives (that is before they leave school). There appears to be limited support available for young people to achieve practical independence and increase their capacity to access universal services. Interviewees' comments suggested that low expectations have discouraged many professionals and parents from initiating work to develop wider or longer-term ambitions.

The concerns expressed in the Green Paper (DfE, 2011) about integrated planning and support, access to information, and high quality education and training have resonance for many of our interviewees. Young people and their families are finding the lack of information, support and appropriate opportunities frustrating. They expressed disappointment in the range and quality of post-compulsory education opportunities currently available, arguing for more and different offerings, including access to ongoing support in adult life to maintain skills after the conclusion of formal education.

Many interviewees welcomed the Green Paper's emphasis on preparing and supporting young people to enter the world of work. Young people expressed a keenness to gain employment and to lead relatively normal and productive lives. However, whilst supporting this aspiration, many professionals and parents drew attention to the barriers facing young people, emphasising the additional challenges created by the current economic climate. Whilst several of the case-study local authorities have longstanding and successful supported-employment projects, these are only able to accommodate and place small numbers of young people. There is considerable uncertainty about their capacity to expand

Interviewees from all groups have concerns about the extent to which young people's wider needs, such as support to maintain or develop a social life, are being taken into account in transition planning. They stressed the isolating nature of a disability and the importance of positive social relationships, making a strong case for greater consideration of and support for this aspect of life.

In terms of wider independence, professionals drew attention to the tension between this goal and the emphasis in the Green Paper on parental choice. They stressed that a key feature of the transition to adult life is the increasing importance of young people's choices, which might be at odds with those of their parents.

Interviewees emphasised that transition is a continuum, not a series of events marked by the handover from one service or provision to another. Whilst they acknowledged the commitment of individual professionals, the experiences of the young people and parents we spoke to suggest there are multiple gaps in the support. Many parents felt the prospects for their children in adult life are far less good than they could (and should) be.

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Appendix: Research methods

The research team contacted local authorities by email with details of the research and asked them to register their interest in participating. Given this method of recruitment, in particular the element of self-selection, the local authorities which participated may not be typical. Agreement was reached to include six local authorities and key contacts in these areas were asked to identify a range of colleagues who might be well placed to contribute. These professionals were then approached by the research team and agreement sought to interview them (either face to face or over the telephone).

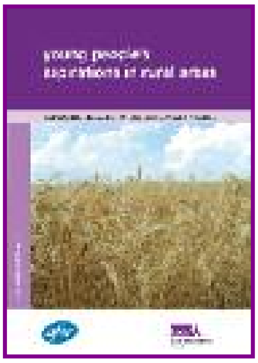
Local authority contacts and their colleagues in special schools and/or colleges identified young people and parents eligible for involvement in the research and made initial contact with them on our behalf. Local contacts were asked to provide all interested young people, parents and carers with an information sheet. This document included the aims and purpose of the study; the subject areas to be covered and methods to be used; ethical principles underpinning the research (informed consent, anonymity and confidentiality); and the research team's contact details. In some cases, staff read and explained the information sheet to potential participants. Under the provisions of the Mental Capacity Act 2005, interviews could only be conducted with young people with the capacity to decide that they wanted to be involved in the research. As such, we asked that young people were invited to opt in (not just allowed to opt out).

Further school, parental and young person approvals were needed before the interviews took place. All interviewees were reminded by the interviewer of the research purpose and procedures at the start of the interview, and of their right to withdraw at any stage. With permission from interviewees, sessions were audio-recorded. Verbatim notes were analysed by the three researchers who conducted the interviews; these notes provide the basis for this report. In line with the NFER's Code of Practice, all information was treated as confidential. Data from all participants has been anonymised and no individual or local authority is identified in this report.

This research was commissioned by the Local Government Group (LGG), through its Local Government Education and Children's Services Research Programme (LGECSRP). As such, the project was scrutinised by the LGECSRP Board, which comprises representatives from various members of the LG Group, including the Association of Directors of Children's Services (ADCS). As the ADCS is represented on the LGECSRP Board, it does not require its projects to have separate approval from the ADCS Research Group. The research was submitted to and agreed by research governance committees in the local authorities that requested this.

Recently published reports

The Local Government Education and Children's Services Research Programme is carried out by the NFER. The research projects cover topics and perspectives that are of special interest to local authorities. All the reports are published and disseminated by the NFER, with separate executive summaries. The summaries, and more information about this series, are available free of charge at www.nfer.ac.uk/research/local-government-association/



Young people's aspirations in rural areas

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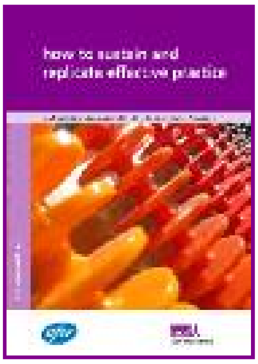

How to sustain and replicate effective practice

This report examines how effective practice examples that have been through the Centre for Excellence and Outcomes' (C4EO) validation process have been, or could be, replicated and sustained. A set of online guidelines was produced as part of this research.

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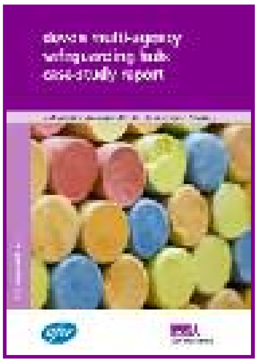

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The transition to adulthood for young people with special educational needs (SEN) and learners with learning difficulties and disabilities (LLDD), can be difficult and is not always entirely successful. The 2011 Green Paper on special educational needs and disability makes wide ranging proposals to improve services and outcomes.

This report explores how young people with SEN or LLDD are prepared for adult life, and where the process of planning for this transition might be improved. The report covers:

- Planning for young people's futures
- Transition to post-compulsory education and/or training
- Transition to employment
- Transition to independent life
- Developing new approaches to supporting transition
- Conclusion and implications.

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