Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

Bryony Beresford, Nicola Moran, Tricia Sloper, Linda Cusworth, Wendy Mitchell, Gemma Spiers, Kath Weston and Jeni Beecham

THE UNIVERSITY *of* York

THE QUEEN'S ANNIVERSARY PRIZES 2009

spru | Social Policy Research Unit

Contents

Separate Volume

Appendix A: Interview schedule for researching potential research sites

Appendix B: Staff recruitment materials
    B1   Staff covering letter email
    B2   Summary of the study
    B2   Staff information sheet
    B4   Staff consent form

List of Tables and Figures

Figures

Tables

Acknowledgements

A note about the research team

Professor Patricia Sloper was awarded the grant by the Department of Health to conduct this study and was Principal Investigator for the early stages of the project and during the data collection periods for Stages 2 and 3. Following Professor Sloper's retirement in 2011, Professor Bryony Beresford assumed the role of Principal Investigator for the remainder of the project.

Dr Nicola Moran was lead researcher on the project and also led on the interviews with practitioners and the management of the surveys of young people and parents. Dr Wendy Mitchell led on the qualitative interviews with young people with High Functioning Autism and Asperger's syndrome. Gemma Spiers and Katherine Weston led on the qualitative interviews with parents. Dr Linda Cusworth was responsible for data management and the analysis the surveys of young people and parents. Professor Jeni Beecham led on the costs work.

Executive Summary

Introduction

Improving outcomes for adults with autism is a key objective for the government. This is because research had shown that many people with autistic spectrum conditions (ASC) are not realising their full potential in adulthood and are failing to achieve the so-called markers of adulthood such as employment, independent living, fulfilling social lives and 'adult' relationships.

In order to improve the outcomes of adults with autism, it is essential that we understand, and evaluate, transition planning processes and current systems and services for supporting young people and young adults with ASC. At the same time is it essential that we also understand the lives of individuals and their families as they experience this life stage. This research sought to develop and extend the evidence base on these issues.

The study therefore focused specifically on young people with ASC on the cusp of leaving school and in the early post-school/college years. This is a period of significant change, and for that reason, presents particular challenges for young people with ASC which are over and above the challenges of transition experienced by other groups of young people. There have been concerns that young people with a diagnosis of autism but with no learning difficulties (that is, those with 'high functioning autism' (HFA) or Asperger's syndrome (AS)) whilst not eligible for support from adult social care, do have significant support needs to enable them to successfully transition into adulthood.

Study aims

Key aims of the study were:
- To investigate the roles of multi-agency transition services in relation to young people with ASC, and the arrangements that were in place for planning transitions for young people with and without learning disabilities.
- To explore young people's and parents' experiences of planning for transition and making the transition from children's to adults' services.
- To explore the costs and outcomes for young people of the transition process.

Study design and methods
The project was located in five research sites. These were identified as localities which had established multi-agency transition planning processes and systems in place and which had actively developed ASC specific services. A mixed methods approach was adopted including:
- interviews with managers and practitioners in the five research sites working in transition services or services which support young people and young adults with ASC, including both statutory and non-statutory agencies and organisations;
- a survey of young people with ASC and parents: both those who were on the cusp of leaving school (defined as 'pre-transition') and those who had recently left school and moved into adult services/adulthood (defined as 'post-transition');
- interviews with young adults (18 – 24 years) with High Functioning Autism (HFA) and Asperger's syndrome;

- interviews with parents/carers of young people with autistic spectrum conditions (aged 16 – 24 years); and
- an analysis of the costs of providing transition support in each of the research sites.

The survey of parents and young people yielded very low responses rates and was extremely variable between research sites. This severely compromised the way the data could be analysed and hence the achievement of some research objectives. Specifically, we could not explore and compare families' 'post-transition' outcomes against the different models of transition planning and support in place in the research sites. In addition, not all research sites provided adequate financial data. This lack of data, coupled with the low response to the family survey, significantly restricted the work we could do on costs.

Key findings
The transition pathways and planning for leaving school
- Some research sites had systems and structures in place which sought to ensure all young people with a diagnosis of ASC were receiving some sort of support during transition. However, in other sites it was evident that young people with HFA and AS were not eligible for support from transition teams and thus were vulnerable to planning and preparing for leaving school with no ASC-specific input or support.
- Experiences of planning for leaving school were mixed – both for those families who had experienced transition planning within statutory SEN/transition planning processes and those who had not.
- The lack of post-school options and, for those ineligible for adult social care, the lack of support was the issue of greatest concern to parents and practitioners.
- Parents and practitioners noted that level of cognitive ability *per se*, did not necessarily act as an indicator of the degree to which a young person was able or willing to engage in planning around leaving school and taking responsibility for moving towards adulthood. They also noted that, for young people with ASC, involvement in planning could be stressful and challenging in itself.

Experiences of further education
- The accounts of college life of many of the young people we interviewed revealed it to be a positive experience. However, the evidence gathered from parents and practitioners suggested that a successful college career was not the experience for all young people with ASC.
- The greatest area of concern was with regard to suspensions, expulsions and/or simply dropping out of college. These were typically viewed by parents and practitioners as outcomes of colleges failing to properly support young people with ASC and manage any challenging behaviours. This was particularly felt to be an issue in mainstream college settings.
- Young people who left college prematurely were identified as a highly vulnerable group. The circumstances of their departure precluded any advice or planning around next steps, and if ineligible for support from adult social care, they were often invisible to statutory services.

Planning for leaving college
- Young people and their families lacked advice and support as they anticipated leaving further education.

- The perceived role of Connexions[1] at this stage in a young person's life appeared to be very variable across the research sites.

The lack of post-education options
- The lack of post-school/post-college options was an issue for young people with ASC.
- The absence of any meaningful daytime occupation was an enormous worry for parents. The accounts of some of the young people with HFA and AS who we interviewed corroborated parents' views of the negative impact of this lack of occupation on well-being.

Experiences of employment for young people and young adults with HFA and AS
- Interviewees agreed that a lack of appropriate employment opportunities, and insufficient support to gain and maintain employment, were key barriers to paid work.
- Policies and practice with respect to supporting young people with ASC into employment appeared to be specific to localities. Transition teams did not appear to view employment as an outcome in which they actively engaged. The perceived (and actual) role of Connexions varied considerably between sites.
- There were examples of positive practice from ASC-specific services supporting young people into work. However, there was also evidence to suggest there may be lack of understanding of ASC among Job Centre and Job Centre Plus staff.

Support for young adults with HFA and AS
- Community mental health teams and, in some places, specialist 'Asperger's teams', were identified as the first port of call for young adults with HFA or AS who were struggling with the transition to adulthood. All these services provided multi-disciplinary, but time-limited, support.
- The other main providers of support for young adults with HFA and AS were third sector organisations, all of which were autism specific. Some of these outreach services were very positively endorsed by parents and young people. However, knowledge of and access to such support was extremely variable.

Moving from the family home and independent living
- The consistent view of interviewees was that, for many young people with ASC, moving into an independent living situation was not appropriate or feasible in the early years of adulthood. However, there was agreement that 'work' to support and enable the young person to achieve this was required.
- Parents reported particularly struggling with knowing how best to support their adult sons and daughters to acquire independent living skills. This was a key area of unmet need for young people with HFA and AS who were not eligible for adult social care.

The role of parents
- A recurrent theme emerging from the interviews was that parents appeared to be very involved in supporting and, in cases, 'managing' their son or daughter's life. The accounts of the young adults we interviewed suggest that high levels of parental

---

[1] In 2011 changes to statutory guidance removed the expectation that local authorities should provide a universal careers services. This has resulted in the withdrawal or changes in local Connexions services. At the time of conducting this research there was a Connexions service in each of the research sites.

involvement in their lives were not, typically, unwanted. However, this was not a role parents typically wanted to assume.

Implications for policy and practice
Transition planning, strategies and processes
- Young people ineligible for support from children's services and without a SEN, including young people with HFA and Asperger's syndrome, are at risk of being invisible to strategic groups and commissioners of adult statutory services. Undergoing transition in the absence of appropriate support can affect young people's outcomes in adulthood and thus needs to be addressed.
- Transition planning practices, for example person-centred planning, need to take account and be responsive to ASC-specific issues which may interfere with transition planning, for example, social anxiety, aversion to change. Practitioners need to be knowledgeable and skilled in working with young people with ASC, including HFA and AS.

The move from further education
Support and advice in planning for the move from further education into employment or other settings was largely absent and needs to be addressed.

Continuity of mental health support at a time of change
The loss of, or interruption in, mental health support at a time of, potentially, considerable change in other areas of a young person's life, appears counter-intuitive. Work to identify service models which ensure continuity of mental health support (and thus also removing the need to develop new therapeutic relationships) over late teenage and early adulthood is recommended.

Services and support for young adults
This and other research call for 'low intensity', early intervention/preventative holistic support for young people with HFA and AS, and believe that this can be cost effective (National Audit Office, 2009). Crucially, any study of effectiveness needs to take a cross-agency view on costs and cost-effectiveness.

The lack of meaningful daytime activities for young adults with ASC placed considerable organisational, time and financial burdens on parents as they sought to 'create' a meaningful life for their child. Some third sector organisations were providing day services and peer support opportunities for those with ASC, particularly those with HFA or AS. Whilst some might baulk at specialist, non-inclusive provision, some of the young people we interviewed were very clear that they preferred spending time in such settings which they saw as 'normalising' them. It is important that these are investigated and evaluated.

Overall, experiences of employment were disappointingly low and, where achieved, there was a sense of fragility. Access to specialist employment support did not appear adequate, and experiences of mainstream job support by young people with HFA and AS suggested a lack of expertise and understanding of HFA and AS among frontline staff. Voluntary work placements in settings where ASC was understood and accommodated were consistently viewed very positively by the young people interviewed. Further consideration of the strategic and planned use of such placements, and their impact on longer-term outcomes, may be productive.

Chapter 1
Introduction

The research described in this report compliments an earlier project commissioned by the Department on Health on transition to adult services for disabled young people and those with complex health needs (Sloper et al., 2010) (referred to subsequently as the 'Disability and complex health needs transition project'). Whilst young people with autistic spectrum conditions, and particularly those with learning difficulties, were included in that project, the Department of Health was keen to commission a further project specifically looking into transitions for young people with autistic spectrum conditions. The Department of Health wanted this new project to cover young people across the entire autistic spectrum including those with high functioning autism and Asperger's syndrome. In order to facilitate comparisons of research findings, the research design, methods and research instruments used in the Sloper et al. (2010) study were adopted, with some adaptations, for this new study.

1.1   Terminology and abbreviations

We use the term **autistic spectrum conditions (ASC)** when referring to the entire autistic spectrum. We explicitly make it clear when distinguishing between those with **ASC and learning difficulties** and those with higher levels of cognitive ability and functioning using the diagnostic terms used for this end of the spectrum, namely: **high functioning autism (HFA)** and **Asperger's syndrome (AS)**.

Throughout this report, we use the term **'transition team'** to refer to the statutory team tasked with transition planning for young disabled people. The term **'transition service'** is used to describe the work undertaken by the transition team, including transition planning and support into adulthood. Finally, we use the term **'transition support'** is used to describe support to young people/young adults with ASC during the transition period (~14-25 years) that is provided by statutory and non-statutory services, agencies and organisations other than the transition team

1.2   Introduction

There is considerable evidence from research that for most young people with disabilities the process of transition from child to adult services is problematic. Whilst transition is often discussed in terms of transfer of responsibility from children's to adult services in health, social care and education, it is important to recognise that for the young person, transition to adulthood also encompasses a range of different processes. These include for example, leaving home, entering further education and employment, and taking more responsibility for health, nutrition and finances. It is clear therefore that supporting transition to adulthood for disabled young people requires an ongoing multi-agency approach which can address these different aspects of the young person's life. The

problems in provision of appropriate services to support transition and in achieving positive outcomes for young people have been acknowledged in government policy and guidance (for example, *Valuing People,* DH, 2001; *the National Service Framework for Children, Young People and Maternity Services,* DH/DfES, 2004; *Better Services for People with an Autistic Spectrum Disorder,* DH, 2006a; *Aiming High for Disabled Children,* HM Treasury/DfES, 2007; and *Transition: Moving on Well,* DH, 2008. Recent policy developments, such as personalisation and the Transition Support Programme, and the growth of multi-agency working may lead to improvements in this situation.

There is some evidence that young people with autistic spectrum conditions (ASC) have not had the range of support needed for them to achieve positive transitions, and there have been particular gaps in services for young people with high functioning autism (HFA) or Asperger's syndrome (AS). At present little is known about the life experiences and views of young adults with an ASC and their families about the transition process, the services they receive and their unmet needs. It is recognised that transition to adulthood, and in particular leaving full-time education, is a critical time that profoundly affects adult outcomes and life opportunities and experiences for young people with an ASC and their families.

The rationale behind the current study
Concerns regarding the transition experiences and outcomes for young people with autistic spectrum conditions prompted the Department of Health to commission this study looking at support during transition and in early adulthood for young people with autistic spectrum conditions, with a particular focus on those with HFA and AS. This study followed on from an earlier study, funded by the Department of Health, on models of multi-agency transition services for disabled young people and those with complex needs ((Sloper et al., 2010). That piece of work investigated multi-agency co-ordinated transition services located in five local authorities. It became evident that transition teams worked primarily with young people with learning, and/or complex, disabilities, as this group met the eligibility criteria for the transition service and adult social care. Support was available to those with ASC and learning disabilities, but typically not to those with HFA or AS. Currently, there is little research which explores transition for young people with ASC to identify the components of good practice that are associated with more positive experiences for young people and their parents. This study addresses those issues in order to inform standards of good practice in services for young people with ASC and their families at transition.

1.3   What are autistic spectrum conditions?

Autistic Spectrum Conditions (ASC) include a wide range of related developmental disorders, from classic autism including severe learning disabilities, to high functioning autism and Asperger's syndrome. ASC begin in adulthood and last throughout adulthood; there is no cure, but treatments including specialist education and behavioural programmes can improve symptoms. The autistic spectrum covers a wide range of symptoms, these are commonly grouped into three categories known as the 'triad of impairment': impaired language and communication skills (including language delay and an inability to initiate or take part in conversations), difficulties with social interaction (including lack of

understanding or awareness of the emotions of others), and unusual patterns of thought and physical behaviours (including repetitive movements and set routines of behaviour) (NHS, 2012).

Although there is wide variation in the progress that individuals with an ASC make, autistic spectrum conditions are lifelong conditions and many individuals with an ASC have significant continuing need in adulthood and throughout life.

1.4   Current evidence on transition

Transition from adolescence to adulthood has been identified as a key period for promoting independent and successful functioning in adult life for people with disabilities (Beresford, 2004).

Effective transition services
Reviews of research on transition (Forbes et al., 2002; Beresford, 2004) have found moderate evidence in support of a number of features of services as benefiting transition. In relation to service structures, these included: transitional workers and transitional teams; transitional services such as adolescent health services; formal intra- and inter-agency liaison and agreements; frameworks for fostering accessibility of services. Service process components included: a systematic approach to managing the transition process, including holistic assessment, care planning and review and active involvement of young people and their families; and case management approaches. The National Service Framework (DH/DfES, 2004) identified the need for age-appropriate services for young people as they grow into adulthood (Standard 4) and recommended that local agencies should set up a multi-agency transition group to take responsibility for overseeing arrangements for transition for disabled young people (Standard 8). More recently, Sloper et al. (2010) identified having a transition worker and having a written transition plan as factors contributing to good outcomes after transition to adult services.

Problems with transition
However, research points to a number of problems in achieving a coordinated approach to transition. These include: lack of multi-agency working; lack of an holistic approach; lack of specialist transition services and workers; lack of information for young people and parents; lack of user-involvement in the planning process; insufficient attention paid to the concerns/priorities of the young person; and lack of appropriate service/provision onto which the young person can transfer (Cope, 2003; Dean, 2003; Forbes et al., 2002; Heslop et al., 2002; Morris, 1999, 2002; Fiorentino et al., 1998; O'Sullivan, 1998; Pownceby et al., 1997; Sloper et al., 2010).

Underlying these challenges to co-ordination are shortfalls in the provision of adolescent and adult services, including paucity of post-school provision (Dee and Byers, 2003) and shortages of accessible housing and supported employment (Morris, 1999, 2002). A 'poor transition' is likely to lead to reduced support and unmet needs which may have prolonged and cumulative consequences for the young people's education attainment, health and welfare. Other factors linked to poor transitions for disabled young people include: poor

staff attendance at meetings (Bhaumik et al., 2011); lack of clarity among services about responsibility for service provision (Bhaumik et al., 2011); untimely addressing of key issues (Heslop et al., 2002); poor coordination between agencies (Morris, 2002; Heslop et al., 2002); lack of information about planning, and options (Morris, 2002; Heslop et al., 2002; Bhaumik et al., 2011; Martin et al., 2011); and limited capacity of transition workers and high staff turnover (Martin et al., 2011). Furthermore, not all young people who are supposed to have a transition plan actually receive one (Heslop et al., 2002). A lack of planning causes uncertainty and stress for families (e.g. Heslop et al., 2002).

1.5   Transition planning for young people with ASC

Existing research has often focused on young people with learning disabilities. There is little research on the transition experiences of young people with ASC and their families, or on the specific practices of transition services for such young people (Charman and Clare, 2004). Studies focusing on learning disability may include some young people with ASC, and the problems noted above will clearly impact on those young people.

However, ASC covers a wide spectrum of abilities, and it is estimated that the number of children with Asperger's syndrome, who have IQs in the normal or above normal range, is approximately equal to the number of children with 'classic autism' (Baird et al., 2006). Average or above IQs may mask high levels of vulnerability and need (Barnard et al., 2001). These young people require a range of support to enable them to make a transition to greater independence (VanBergeijk et al., 2008), but evidence suggests that they have not had this support. Barnard et al. (2001) found that adults with HFA or Asperger's syndrome were not being offered social care services, and that most adults with medium or higher functioning autism were falling through 'the gap between mental health and learning disability services' (p.6).

Young people with ASC face additional difficulties in coping with multiple changes or transitions (Madders, 2010) due to difficulties envisaging and planning for the future (Reid, 2007) and the impact of changes to their routine and structure of their day (Reid, 2007). Reports have noted that successful transition for young people with ASC 'requires thorough preparation and implementation' and requires adequate resourcing (Hendricks and Wehman, 2009, p.83).

Most individuals, including those with ASC, spend a far greater proportion of their lifetime outside of the education system than inside it, thus transition from school to some form of meaningful employment, (semi-) independent living and a place within the community is key to maximising outcomes and quality of life (Hendricks and Wehman, 2009, p.84). However, a recent survey conducted by the National Autistic Society in England (2007) found that only half of autistic young people in the sample had received a transition plan during their education. Further, many parents reported dissatisfaction with the transition planning process; one in three parents felt that Connexions' knowledge of autism was poor; and there was reported to be a lack of support for young people with ASC in post 16 education (Reid, 2007).

It is clear that the increasing numbers of young people with ASC coming through to transition need a multi-agency approach that brings together both children's and adults' services in education, social care and health, including mental health. However, even where multi-agency services exist, young people with ASC may continue to face additional problems, including:

- Eligibility criteria for multi-agency transition services and for adult social care services frequently being based on learning disability. Young people with ASC who do not have a learning disability or have mild/moderate learning disability may not be deemed eligible for these services.

- Some authorities have a number of children with ASC placed in costly out of area residential placements. Previous research on young people with learning disability suggests that the transitions of disabled young people leaving residential school placements can be even more problematic than the transitions of disabled young people living with their families and attending local schools (for example, Audit Commission, 2007; Heslop et al., 2007; Beresford and Cavet, 2009).

- Lack of suitable adult services – there is perceived by staff to be better provision in children's services (for example, for short breaks) and such provision is not available in adult services.

- Conflict/confusion between adult learning disability and mental health teams about who will take on young people with ASC.

- Greater numbers of young people with ASC thought to be coming into youth offending teams.

Young people with ASC who do not meet criteria for multi-agency transition services will be supported by Connexions (DfEE, 2000) but work by Grove and Giraud-Saunders (2002, 2003) suggests that while the role of the Connexions PA is well placed to address problems of coordination of services, there are difficulties due to PAs' lack of specific skills and expertise in disability and insufficiency in the number of PAs.

A recent study of transition amongst young people with ASC in Northern Ireland (McConkey, 2010) found a lack of transition and post-education support for this group of young people and recommended: improved transition support in school; increased post-school provision for the increasing population diagnosed with ASC, including further education, careers advice, and training for employment; increased support for social inclusion; better advice and support for families (including better coordination among existing services); improvements to certain health and social care services; and better training to 'equip primary care staff such as GPs, school nurses, social workers to offer prompt and appropriate support to the young person and the family as well as to teachers and pastoral care staff within schools' (p.31).

A multi-agency approach to supporting transition and the needs of young adults with ASC is essential. Any transition poses challenges to young people with ASC. This is accentuated in cases where appropriate services for adults with autism do not exist. However, even where appropriate adult services do exist, 'access will depend partly on an effective transition process, with joint planning and information sharing between health, social care, education and employment services' (National Audit Office, 2009, p.16).

1.6   Mental health transitions for young people with ASC

Research suggests that young people with mental health problems tend to suffer poor transitions into adult mental health services, if indeed they are eligible for adult mental health services. Transition from education into training, employment, day services, (semi-) independent living and so on is a time of significant worry, stress and anxiety for young people with disabilities, particularly those with ASC (Kaehne, 2011, p.10). However, at this time of need, mental health transitions are relatively poor and indeed stricter eligibility criteria for adult mental health services may mean that young people in transition are left without any mental health support, unless they fall into crisis (Kaehne, 2011). Where a young person was deemed ineligible for adult mental health support, CAMHS may instead make a referral to adult social care, but their strict eligibility criteria could similarly mean that a young person is not eligible for support.

A study undertaken by the National Autistic Society (2010) found that most Child and Adolescent Mental Health Service (CAMHS) teams 'did not routinely plan for transition to adult services, and lacked any kind of formal protocol for dealing with transition. Those who did take steps for a smooth transition to adulthood often found it very hard to get adult mental health services to buy into the process, as they would not plan support for anyone who was not presently eligible for their service' (p.20). Similarly, a study by Kaehne (2011) found that, in Wales, mental health services had not been given the opportunity to be involved in transition protocols and pathways produced by education and social care and had instead drafted their own transition paths and protocols for transfer from CAMHS to AMHS which were not integrated into wider transition pathways. Kaehne concluded 'at the time of need young people may face fragmented mental health services, an adult service that may not favour a preventative approach or, worse, a considerable service gap where CAMHS does not work with young people above the age of 16' (2011, p.15).

1.7   Transition into and out of further education for young people with ASC

Recent research with parents of disabled young people (those with learning disabilities and/or physical disabilities) found that further education is the default post-school destination for those with low to moderate needs (Martin et al., 2011). However, there are concerns that college courses are not always well suited to the needs of the young person, and concerns that college typically only provides three days of structured activity per week (Martin et al., 2011). While young people with HFA and AS may have the intellectual abilities to succeed at college, research shows that many 'are, in effect, barred from such education by the barriers they face in accessing college and/or in coping with college life' (Chown and Beavan, 2011, p.11). Chown and Beavan suggest that further research is needed to establish the prevalence of young people with ASC in college, and investigate the barriers to gaining access to college, plus in-college barriers to achievement (p.11).

Hudson (2006) describes the transition from school to college as the *visible transition*, but the transition from college to post college options the *invisible transition*, due to a lack of guidance and clarity about who should be doing what and when. Hudson argues that this is

6

due to a lack of post college options which, for many young people, has resulted in their remaining at college, often repeating the same course and not advancing in skill or ability.

1.8   Outcomes for young adults with ASC

Studies of young adults with ASC suggest that very few are in paid employment, or have friends or intimate relationships (Rosenblatt, 2008; Reid, 2007; Howlin et al., 2004; Howlin, 2000). Over the past decade, several groups have reported on adult outcome in cohorts of individuals with an ASC. A recent report on adults with autism in the UK (Brugha et al., 2009) highlighted the high levels of social isolation experienced by these individuals: few were married, many were on benefits and/or living in social housing, and most were under-supported by social, educational, welfare and health services. Howlin et al. (2004) reported on a UK cohort of adults with autism at a mean age of 29 years and found that only a minority had achieved relatively high levels of independence: one third had some form of employment, only three adults (from 68) lived independently (with support from parents) and more than one third lived at home; and only one in five were reported by parents to have friendships characterised by selectivity and initiating social contact. Social isolation and dependence levels remain high. Another study of young adults with ASC found the lowest quality of life ratings being most common in adults who were not in further or higher education, (supported and unsupported) employment or a day care activity centre (Billstedt et al., 2011). Taylor and Seltzer (2011) reported on employment/day activities in a USA cohort of adults with ASC at a mean age of 23 years and found that those of average IQ were significantly less likely to be engaged in any regular day time activity than those with learning disabilities. Further analysis of the cohort showed that symptom levels decreased from childhood through adolescence; that is, that social and communicative abilities increased and problematic behaviours diminished. However, once the cohort had left full-time education these improvements slowed in individuals who did not have learning disabilities and in adults from families with lower income, suggesting that lack of structure/routine and less availability of family resource negatively impacted on adult outcomes (Taylor and Seltzer, 2010).

Employment
Research by the National Autistic Society showed that only 15 per cent of adults with ASC were in full-time paid employment (Reid, 2007, p.6). However, the NAS' own employment service, *Prospects*, which provided work preparation, job finding and employment support for individuals with ASC, and assistance with recruitment, training and the retention of staff with ASC for employers, was able to secure employment for 67 per cent of its clients. This represented a cost saving to the Government of almost half a million pounds in less than three years (Reid, 2007, p.6; referring to Alcock and Howlin, 2003). Thus, with adequate support, employment can be a successful option for young people and adults with ASC. In 2010 the Department of Health published *Valuing Employment Now* (HM Government, 2009), a government strategy to increase employment rates for people with learning disabilities, including those with ASC and learning disabilities. Valuing Employment Now encouraged the development of qualifications in supported employment and accreditation for job coaching. However, this policy does not include those with HFA or AS.

Independent living

Research suggests that 49 per cent of adults with ASC live at home with their parents, and 70 per cent of parents feel that their autistic child would not be able to live independently (without support) (Barnard et al., 2001). Difficulties include coping with unstructured time, and the lack of practical independent living skills such as cooking, shopping, and money management. The NAS report that the social and independent living aspects of being at college or university can hamper the retention and academic achievement of young people and young adults with HFA and AS (Reid, 2007, p.5).

Improved outcomes?

A Canadian study found that outcomes for adults with ASC were slightly more positive (in relation to friendships, activities, and employment) compared to studies of previous cohorts. This was assumed to be because of better identification of children with ASC and more services for children with ASC which led to increased aspirations and possibly increased abilities (Eaves and Ho, 2008, p.746). Improved outcomes for adults with ASC could be expected if greater transition support was available to this group and if supported living, supported employment, and other services were available post-education to this group.

1.9 The costs and benefits of providing specialist adult services for people with HFA and AS

Recent work to estimate the costs of ASC (Knapp et al., 2007) estimated that the costs of supporting young people aged 12-17 with ASC and learning disabilities were £62,500 (2005-2006 prices) if they were living in residential or foster placements and just over half that (£36,400) if they lived with their parents. For high functioning autistic young people aged 12-17 years who were living with their families the support costs were £21,000 per year. These totals exclude informal care. Knapp et al. report that obtaining the data to make these estimates was difficult. They drew on relatively easily available information on prevalence and level of functioning, but much of the data of use of education and other services and supports had to be derived from data collated across many smaller studies. The team are currently trying to update these estimates but have found very little additional data for the UK.[2]

A review of interventions for children with ASC found 22 studies identifying costs or cost-effectiveness, but that together these papers constituted a very limited evidence base about the economic pay-offs from intervention, despite the fact that many treatments are widely practiced. However, there were some indications that effective interventions could help reduce the need for intensive support in both childhood and adulthood (Romeo et al., forthcoming).

A report by the National Audit Office (2009) demonstrated that potentially huge savings could be made if specialist multi-disciplinary services were commissioned for adults with HFA and AS. The cost-benefit analysis focused solely on England. The costs contained in the

---

[2] http://blogs.lse.ac.uk/healthandsocialcare/, 9th April 2012.

economic modelling consisted of costs to the NHS (inpatient care, crisis resolution, NHS accommodation and treatment costs); costs to local government (social services costs, employment support, housing, adult education, day services); costs to central government (primarily employment support); and costs to private individuals (accommodation, family expenses, carers' lost earnings). The research found that if as little as four per cent of the adult population with HFA and AS were identified, the provision of a specialist service would be cost neutral in terms of public expenditure but would result in additional earnings and reduced expenses for individuals. A higher identification rate of six per cent of the adult population with HFA and AS could lead to savings of £38 million per year; a realistic identification rate of eight per cent of adults with HFA and AS could lead to savings of £67 million per year; and an identification rate of 14 per cent (currently achieved by a well established Asperger's team in one part of the country) could result in a total saving to the public purse of £159 million per year (National Audit Office, 2009, p.49). Thus providing specialist services to support adults with HFA and AS could yield considerable benefits to public expenditure, in addition to significant benefits to the adults with HFA/AS and their families.

1.10   The prevalence of ASC

It is estimated that approximately one per cent of children and young people have an autistic spectrum condition (ASC) (Baird et al., 2006); and that there are half a million people with an ASC in England, including approximately 400,000 adults (National Audit Office, 2009, p.4). The diagnosed population of young people with ASC has increased over recent years; this may be as a result of advances in diagnosis, monitoring and awareness of autism rather than an increase in the actual prevalence or incidence of ASC (National Audit Office, 2009, p.16; McConkey, 2010). The overwhelming majority of managers and practitioners interviewed for this study (see Chapter 2) also reported a perceived increase in the number of young people being diagnosed with an ASC in recent years; and reported that this had impacted upon existing services. We briefly report below practitioners views on the impact of these increases.

The impact on services of an increasing diagnosed ASC population
Managers and practitioners from transition teams, children's services, education, CAMHS, Connexions[3], adult social care, adult mental health services and non-statutory services reported that the increasing number of young people diagnosed with ASC was putting pressure on them and their services. It was hoped that commissioners would take the increasing ASC population into account when planning for transition services and adult services, and create more in-county provision to reduce the number of high-cost out-of-care placements. Nurses with a remit for transition also noted the increased strain on the schools and on the school/transition nurses. One referred to the high degree of unmet needs amongst young people in mainstream schools. There were numerous accounts of significant increases in referral rates. For example, an autism specific community advisory

---

[3] In 2011 changes to statutory guidance removed the expectation that local authorities should provide a universal careers services. This has resulted in the withdrawal or changes in local Connexions services.   At the time of conducting this research there was a Connexions service in each of the research sites.

team funded by children's services in one site reported that the diagnosed population with ASC had increased from 120 children in the 1990s to over a thousand in 2010; while a specialist Asperger's team located in adult mental health services reported that referrals had increased from 11 per month to 30 per month over just a few years.

As a result of the increasing ASC population, there were reports of colleges amending their timetables to minimise the number of young people with ASC in any one lesson; increases in the number of teachers and support staff in schools and colleges; more specialist provisions for young people with ASC, including within mainstream schools; plans to recruit/create specialist posts for ASC workers within adult services; the creation of a specialist autism outreach service; increasing numbers of psychologists and support staff working with people with ASC, particularly those with HFA or AS; and the emergence of new non-statutory services aimed particularly at young people with HFA and AS, including support groups, outreach services, information help lines, and activity days.

However, concerns were raised that adult services, colleges and supported employment services in particular were not geared up for young people with ASC and were struggling to accommodate a rising population. Further, there were concerns that not enough frontline staff were trained in autism awareness and were adequately equipped to support a young person with ASC.

1.11   The policy context

Growing evidence regarding poor transition planning and outcomes for disabled young people has meant that improving transitions to adult services and adulthood for disabled young people is a government priority, as illustrated in policies such as the *National Service Framework for Children, Young People and Maternity Services* (DH/DfES, 2004), *A Transition Guide for all Services* (DCSF/DH, 2007), *Transition: Moving on Well* (DH, 2008), and the *Aiming High for Disabled Children Transition Support Programme* (HM Treasury and DfES, 2007).

Since this research has been carried out there have further developments in policy for disabled children and young people. The Special Educational Needs and Disability (SEND) Green Paper set out how the Department for Education is seeking to improve the support provided to, and outcomes for, disabled children and young people (0-25 years) and those with Special Education Needs (SEN), and their families. There are three key elements to the proposed reforms: (i) a single assessment process for education, health and social care; (ii) this assessment leading to a multi-agency 'Education, Health and Care Plan'; and (iii) enabling families to have greater choice and control in the services and support they use through increased access to and use of personal budgets. To support the implementation of the proposals contained within the Green Paper, the department has commissioned a two year Preparing for Adulthood Programme to support statutory services to facilitate the move to adulthood for disabled young people. A Pathfinder Programme was also instigated in late 2011 in order to test the green paper's proposals. It will be important to monitor the findings from the evaluation of this programme in terms of learning around ASC and transition.

The problems faced by adults with ASC have also been noted in policy. The gap in services and disparities over eligibility criteria between adult learning disability services and adult mental health services has been described as 'unacceptable and contrary to the intention of government policy' (DH, 2006a). Guidance issued to Directors of Adult Social Services (DH, 2006b) required a named manager to be responsible for a number of client groups, including ASC. However, Rosenblatt (2008) found that only 39 per cent of authorities had implemented this. In recent years ASC has become a priority area for national government, local social care and mental health services and charitable organisations. This is reflected in the National Audit Office report (2009), the Autism Act (HMSO, 2009), the Department of Health's Strategy for Adults with Autism (DH, 2010a), and the forthcoming publication of National Institute for Clinical Excellence (NICE) guidelines on services for adults with an ASC (due 2012).

Perceptions of the impact of recent policy
Managers and practitioners who were interviewed for this study reported their perceptions of the impact, if any, that recent government policy around transition and autism had had in practice. We report findings regarding this here as they provide useful contextual information for the main findings section of the report.

Aiming High for Disabled Children
'Aiming High for Disabled Children' (AHDC) launched by the Labour government in 2007 (HM Treasury/DfES, 2007) aimed to improve outcomes for disabled children through increasing their access to services and support, and empowering them in making decisions and shaping their own futures; ensuring that services and support were both timely and responsive; and through improving the quality and capacity of disabled children's services. It also led to the setting up of the Transition Support Programme which provided support to transition services across local authorities. AHDC was jointly delivered by the Department for Health and the Department for Education.

Managers and practitioners interviewed for this study praised AHDC for financing a number of programmes and initiatives across the research sites. However, it is important to note that, on the whole, these were not ASC specific. Concerns were raised about what would happen to some of those programmes and initiatives – and the young people and families they supported – once Aiming High monies were gone.

The Autism Act and the Strategy for Adults with Autism
The Autism Act (HMSO, 2009) was the first ever disability-specific law in England. The Act required the Government to produce a strategy for adults with autism, and required the Department of Health to produce statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism. The Strategy for Adults with Autism (DH, 2010a), published in March 2010, set out what the government would do to ensure adults with autism received the help they needed, and offered guidance to local councils and health services in providing services for adults with autism. The focus of the strategy's first year delivery plan was:

> *Increasing awareness and understanding of autism among frontline professionals;*
> *developing a clear, consistent pathway for diagnosis in every area, which is followed by*
> *the offer of a personalised needs assessment; improving access for adults with autism to*

the services and support they need to live independently within the community; helping adults with autism into work; and enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities" (Department of Health, 2010b, p.6).

When we conducted our interviewees with practitioners in the latter half of 2010 a small number of adult services managers across each of the research sites reported not yet having read the Act, Strategy or guidance, and not yet having considered any possible implications of the Act. A small minority of interviewees questioned whether it was necessary to have an Act of Parliament for one condition. One interviewee argued that it could have been more productive to strengthen the powers contained in the Disability Discrimination Act or the Special Educational Needs Act so that people with other conditions could also be better supported. Another interviewee commented that the Autism Act reflected the economic power of people with high functioning autism and Asperger's syndrome and of families with autistic members in comparison to those with other disabilities. However, a further interviewee noted that the Act had made autism 'flavour of the month' and hoped that this would prioritise funding and boost services for people on the spectrum in the way that Valuing People had supported those with learning disabilities.

Some managers reported that the Autism Act and Strategy for Adults with Autism had already had some impact. Thus, the Act had opened up dialogue about: the needs and (lack of) services and support for adults with autism; the need for autism specific services; the need for transition planning for young people on the autistic spectrum and clear transition pathway from children's services through to adult services; the need to know the population of adults with ASC in their borders and to commission services accordingly; and the need for some form of support for adults with ASC who do not meet FACS criteria, possibly the establishment of a 'vulnerable adults' team.

The majority of managers reported that the Act had led or was leading to the establishment of a multi-agency steering group focusing on how agencies needed to work together to meet the various elements of the Act. This had forced services to better understand one another's remits, roles and responsibilities; undertake more and better joint-working; and work to develop a transition pathway from children's services to adult services for young people with ASC. Interviewees in one site reported having identified a lead commissioner for people on the spectrum, while an interviewee in a voluntary sector organisation reported using the Act to put pressure on commissioners in adult learning disability services and adult mental health services to fill the gap that those on the autistic spectrum often fell into. A few managers were optimistic that funding for autism awareness training packages could improve services for those with ASC; however, practitioners were less optimistic as the training was not compulsory. Interviewees also welcomed the fact that the Act would ensure diagnostic services were available in all areas. However, there were some concerns that this could lead to a significant increase in the diagnosis of adults with autism and thus increase demand on already scarce and over-stretched resources.

1.12   The purpose and focus of the current study

Building on the existing limited research evidence outlined above, the specific aims of this study were:

- To investigate the roles of multi-agency transition services in relation to young people with ASC, and the arrangements that were in place for coordinating services for young people with and without learning disabilities.
- To explore young people's and parents' experiences of planning for transition and making the transition from children's to adults' services.
- To explore the costs and outcomes for young people of the transition process.
- To identify aspects of good practice in this area of work – what works, how does it work?

Key research questions addressed were:

- What differences are there in support for young people with ASC who have and do not have learning disabilities?
- Are there differences in experiences and/or outcomes between different groups of young people with ASC?
- What is the extent of young people's active involvement in transition planning?
- To what extent do services meet young people's and their parents' aspirations for adult life?
- What appears to be working well and why? Where are the gaps? What do these mean for young people? What can this tell us about policy?
- What skills do professionals need to support young people with ASC, and to promote their involvement in transition planning?
- What mechanisms need to be in place in different contexts of the young person's life (e.g. school, college, family, community) to support young people with ASC to achieve positive transitions?
- What are the costs of supporting young people with ASC through transition? Are the costs different for those who have and do not have learning disabilities?

The project was located in five research sites. These were identified as localities which had established multi-agency transition planning processes and systems in place and which had actively developed ASC specific services.

A mixed methods approach was adopted to address the research objectives and research questions:

- Qualitative interviews with managers and practitioners in the five research sites: transition workers/teams, transition service managers/coordinators, and mangers and practitioners in relevant services, including schools and colleges, CAMHS and adult mental health services, children's and adult social care, Connexions, and statutory and non-statutory autism-specific organisations.
- A survey of families in each of the five research sites of young people on the autistic spectrum and their families who were 'in transition': both those who were on the cusp

of leaving school (defined as 'pre-transition') or who had recently left school and moved into adult services/adulthood (defined as 'post-transition').

- Qualitative interviews with a sub-sample of post-transition young people with high functioning autism and Asperger's syndrome and parents/carers of young people with autistic spectrum conditions to explore perceptions of the process and outcomes of the transition support services they had received.

- An analysis of the costs of providing transition support in each of the research sites.

Chapter 2
Methods

2.1   Introduction

This study followed on from an earlier study, funded by the Department of Health, on models of multi-agency transition services for disabled young people and those with complex needs (Sloper et al., 2010). This piece of work investigated multi-agency, co-ordination transition services located in five local authorities. It became evident that the main group of young people whom the transition services worked with were young people with learning, and/or complex, disabilities, as this group met the eligibility criteria for the transition service and adult social care. However, concerns regarding the transition experiences and outcomes for young people with autistic spectrum conditions prompted the Department of Health to commission a further, linked, study looking at support during transition and in early adulthood for young people with autistic spectrum conditions, and taking a particular focus on those with high functioning autism (HFA) and Asperger's syndrome (AS). In order to allow comparison of research findings between the two studies, a similar research design was adopted and the same research instruments used, adapted where appropriate to reflect or explore ASC-specific issues.

This research was conducted in four sequential stages.
- Stage One: identification and recruitment of five research sites.
- Stage Two: interviews with managers and practitioners involved with supporting young people with autistic spectrum conditions, including those with learning disabilities and those with HFA and AS, through the period of transition from leaving school and/or during early adulthood.
- Stage Three: a survey of young people with ASC and their parents across the research sites, both those on the cusp of leaving school (defined as pre-transition) and those who had recently left school (defined as post-transition).
- Stage Four: semi-structured interviews with a sub-sample of young people and their parents who had taken part in the family survey.

Alongside these stages data was collected which would allow the costs of the transition pathways to be estimated. Each site provided their income and expenditure accounts for the transition team (or Asperger's team in the site that did not have a generic transition team) for the period 2009-10. This data included the amount and sources of income obtained, and the expenses incurred by the team, including expenditure on services/ support for young people in transition, salary costs for the transition team, and on-costs such as heating, lighting, rent of office space, etc. Data collected in Stages 2 and 3 also formed part of the costs dataset.

This chapter reports on the research methods and data analysis techniques utilised at each stage in the research.

2.2   Stage 1: selecting the case study sites

Key contacts based in the transition services that participated in the previous study were contacted and asked about the extent of any provision for young people with ASC, particularly those with high functioning autism and Asperger's syndrome, in transition and in early adulthood. Three of the five sites responded positively – they reported special provisions for young people on the autistic spectrum, including those with HFA and AS, and were keen to take part in further research. Those three sites became sites A-C in the current study. The two remaining sites from the previous study reported very little support for young people with HFA or AS and/or they were not willing to participate in further research, thus they were excluded from participation in the new study. Two additional sites were thus sought.

The research team explored provisions for young people with HFA and AS in transition and in early adulthood in numerous local authorities across England. These were identified by contacts within the Transition Support Programme, suggestions from the National Autistic Society, internet searches, and transition guidance documents highlighting examples of good practice. Six local authorities were identified through this process and contact made with these sites. Telephone and email contact with lead officers was used to test the suitability of these sites. Two sites clearly emerged as being suitable for recruitment to the study and became research sites D and E.

The research sites
Site A: an outer London borough with a population of 263,464, of which 25 per cent were in the 0-19 age range. It is one of the most culturally diverse areas in the UK, with 71 per cent of its residents from black and minority ethnic groups (2001 Census, see Office for National Statistics 2004). The area has a high transient population and is ranked within the most deprived third of all counties within England (Communities and Local Government, 2008).

Site B: a large rural county with a population of 498,093. Twenty-four per cent of the total population were aged 19 years or under and just fewer than three per cent were from black or minority ethnic groups (2001 census, see Office for National Statistics 2004). Although there were significant areas of both rural and urban deprivation, the county overall had lower levels of deprivation than the national average (Communities and Local Government, 2008).

Site C: primarily a rural county with a population of 668,553. Of the total population, twenty-four per cent were aged 19 or under and just over six per cent were from black or minority ethnic groups (2001 Census, see Office for National Statistics 2004). There was considerable variation in economic prosperity across the county, with deprivation in some areas above, and in others significantly below, the national average. This area ranked within the least deprived third of all counties within England, and was the least deprived of all the research sites (Communities and Local Government, 2008).

Site D: a mixed urban and rural county with a population of 629,676, of which twenty-six per cent were aged 19 or under and just over eight per cent were from black or minority ethnic groups (2001 Census, see Office for National Statistics 2004). This area ranked within the

16

least deprived third of all counties within England (Communities and Local Government, 2008).

Site E: a small rural coastal county with a population of 157,979 (2001 census). Twenty-seven per cent of the total population were aged 19 years or under, and just over two per cent were from black or minority ethnic groups (2001 census, see Office for National Statistics 2004). This area ranked within the most deprived third of all counties within England and was the most deprived of all the research sites (Communities and Local Government, 2008).

2.3 Stage 2: interviews with managers and practitioners

Throughout this report, the term 'manager' refers to those with lead and/or strategic responsibilities, and the term 'practitioner' refers to those undertaking practical day-to-day work with young people and families.

As sites were recruited to the study, set-up interviews were arranged with lead officers in the site, including the transition lead and the managers of any autism specific services (see Appendix A). At those interviews, an overview of the support and services for young people with ASC, with and without learning disabilities, during transition and in early adulthood was presented. Having provided this overview, lead officers were asked which agencies were involved in supporting young people with ASC and were also asked for the names of any key practitioners involved in working with this group. Names and contact details were provided and the researcher then emailed each potential participant with a covering letter requesting their participation in an interview, a summary of the study, a project information sheet explaining more about the study and what their involvement in an interview would entail, should they choose to take part, and a consent form (see Appendix B). Snowballing was also used to identify additional practitioners, services, and agencies offering support to young people with ASC, HFA and AS during and after transition. Across all sites, the researcher attempted to arrange interviews with transition service managers, transition workers, CAMHS consultants, Connexions managers and practitioners, and independent advocacy organisations used by the local authority. However, not all were willing to participate, including CAMHS consultants in two sites and advocacy organisations across all sites. Participation rates ranged from just 54 per cent (15/28) to 81 per cent (13/16), as depicted in Table 2.1 below.

Table 2.1   Response rates for interviews with managers and practitioners

Site	Number contacted for interview	Number interviewed N	(%)
A	16	13	(81%)
B	18	12	(67%)
C	15	10	(67%)
D	28	15	(54%)
E	26	18	(69%)

Potential interviewees who did not respond to the original contact emails were emailed again, telephoned at least twice and their contact details checked, before they were excluded from the sample on grounds of non-response. Table 2.2 below illustrates the breakdown of those who were interviewed in each site. A total of 68 interviews were conducted with a range of managers and practitioners from the transition service, children's and adults services, education, health, Connexions, and autism specific organisations.

Table 2.2   Breakdown of interviewees by site

Site/Role	A	B	C	D	E	Total
Transition service manager/lead	2	1	2	1	1	**7**
Transition service worker	1	1	-	-	1	**3**
Transition nurse	1	-	-	-	1	**2**
Connexions manager/worker	3	1	1	1	1	**7**
Education staff: special needs or transition leads in schools and colleges, autism advisory teachers, educational psychologists	2	3	3	2	4	**14**
Children's social care managers and practitioners	-	-	-	2	2	**4**
Adult social care managers and practitioners	-	-	1	2	2	**5**
CAMHS Consultants	1	2	-	-	1	**4**
Adult Mental health practitioners, Asperger's team managers	-	1	-	2	1	**4**
Youth services managers and practitioners	1	-	1	-	-	**2**
ASC specific services/organisations: statutory	-	1	-	1	1	**3**
ASC specific services/organisations: non-statutory	2	2	2	2	-	**8**
Supported employment service managers and practitioners	-	-	-	1	2	**3**
Commissioner	-	-	-	1	1	**2**
Total	**13**	**12**	**10**	**15**	**18**	**68**

Distinct semi-structured topic guides were used for managers and for practitioners; topic guides for managers focused on strategic and policy issues, whilst topic guides for practitioners asked about the day to day service and support available for young people with HFA and AS (see Appendix C).

The topic guides were adaptations of those used in the previous 'Disability and complex health needs transition project' (Sloper et al., 2010). The main piloting of the topic guides had been undertaken during that study however further refinements were made in consultation with the project's research advisory group (which included practitioners).

All interviews were conducted over the telephone and were audio recorded, with the consent of the interviewee. Two interviewees requested that the interview was not audio recorded; thus the interviewer instead took notes and created a detailed interview

summary afterwards. Telephone interviews were used as this was felt to be less of an imposition on managers and practitioners and there was the option of spreading the interview over two or three telephone calls depending on the time constraints of the interviewees. Interviews typically lasted between 60 and 90 minutes. All audio-recorded interviews were transcribed.

Data analysis
One member of the research team lead on the analysis of this dataset but there were on-going discussions with two other members of the research team. The data were analysed in two ways. First, the transcripts from each site were scrutinised and summarised in order to develop as complete an account as possible of planning processes and services for young people and young adults with ASC over the transition period. A subsequent thematic analysis was then carried out in order to explore research questions concerned with issues including: experiences of supporting young people with ASC over the transition period, factors which facilitate or impede transition planning and positive transition outcomes.

2.4   Stage 3: family survey

The purpose of the family survey was threefold:
* To create a sampling pool for the qualitative phase (see Stage 4).
* To collect data for the costs element of the research.
* To generate quantitative evidence on young people and parents experiences of planning for leaving school and child-adult servicer transfers, and levels of met and unmet need over the transition period.

The family survey was introduced to lead officers in the research sites during initial contacts and at the set-up meetings as it was essential that lead officers supported the administration and distribution of the family survey through their own agencies and/or encouraged other agencies to contribute to the dissemination of the survey.

Versions of the questionnaire
The questionnaire was the same as that used in the earlier Sloper et al (2010) study, with some adaptations and additional items to allow exploration of ASC-specific issues.

Questionnaires were developed for those defined as 'pre-transition', i.e. those on the cusp of transitioning from school into adulthood or adult services, and those defined as 'post-transition', i.e. those who had recently moved/transitioned into adult services or adulthood. Separate 'pre' and 'post' transition questionnaires were designed for the parents of young people with ASC and for the young people themselves. Three versions of each questionnaire were prepared for young people: a standard version containing the full range of questions, a shorter abbreviated version containing fewer questions and using more simplified language, and a symbol version of the questionnaire for those with more limited communication skills.

Piloting

The questionnaires had been extensively piloted in the previous 'Disability and complex health needs and transition project' (Sloper et al., 2010). Amendments and additions required to explore ASC-specific issues were developed in consultation with the project advisory group, which included the parents of young people with ASC.

Questionnaire packs

Questionnaire packs differed according to whether the recipient was pre or post transition. Pre-transition questionnaire packs were addressed to the parent(s) of the young person with ASC. These packs contained a covering letter, information sheet, parent pre-transition questionnaire, a request for information in alternative languages, summary reply slip (on which an individual would indicate if they would like to receive a copy of the study findings) and pre-paid envelope for parents; and a covering letter, information sheet and a copy of each of the three versions of the pre-transition questionnaire for young people for their son or daughter (see Appendix D). A post-transition questionnaire pack was produced for young people including a covering letter, information sheet, each of the three versions of the post-transition questionnaire, a request for information in alternative languages, summary reply slip, and pre-paid return envelope (see Appendix E). A similar questionnaire pack was produced for post-transition parents (see Appendix F). Separate packs were produced for post-transition young people, but not pre-transition young people, to indicate the adult status of post-transition young people. Questionnaires contained site identifiers numbered one to five, so that the research team could identify which research site the questionnaire had been returned from if it was returned anonymously.

Content of the questionnaires

The questionnaire replicated, as much as possible, the instrument used in the earlier 'Disability and complex health needs transition project' (Sloper et al., 2010). It covered the following topics:

- Demographic, service use and diagnostic information.
- Experiences of planning for service transfers and transition and the support received.
- Satisfaction with transition planning.
- Met and unmet needs (parent and young person).

Distribution of the questionnaires

At the stage of designing the study it was decided that, in the three sites that had taken part in the previous transition study (Sloper et al., 2010), questionnaires completed by families with a young person with ASC would be used as data for the current study[4]. Thus in those sites, distribution of the questionnaire was targeted at young people with HFA and AS. Distribution of the family survey through teams, services and agencies other than the transition team was thus necessary. Services were asked to identify young people with HFA and AS, both pre- and post-transition, as appropriate.

---

[4] A decision was subsequently made that it was not valid to use this data due period of time which had elapsed between the data collection time points of the previous and current study and possible changes in transition support which may have occurred.

In the two new sites recruited to the study, the research team wanted to target young people across the autistic spectrum, from those with ASC and learning disabilities to those with HFA and AS. Thus, questionnaires were distributed by various services including the transition team, children's social care, education, adult social care and ASC specific services. Table 2.3 below shows the breakdown of teams, services and agencies used to distribute the family survey in each research site.

Table 2.3 Breakdown of the services used to distribute the family survey in each research site

Service/Site	A	B	C	D	E	No. of sites using this service
Transition team					■	1
Asperger's team		■		■		2
Connexions	■		■	■	■	4
Children's social care					■	1
Adult social care				■		1
CAMHS		■				1
Special educational needs		■				1
Special school					■	1
Educational psychology service					■	1
College (mainstream)					■	1
Autism specific educational outreach service	■					1
Autism specific outreach service					■	1
No. of services used per site	**2**	**3**	**1**	**3**	**7**	

There were three mail-outs per site. During the first mail-out questionnaire packs were sent out to all young people with ASC and their parents, as identified by the services. Three weeks later services were asked to send out reminder letters. The reply slips at the bottom of the reminder letters stated the site identifier number, plus P (for Parent) or YP (for Young Person) and pre or post for pre- or post-transition. Two weeks after that the services posted out a further set of questionnaire packs (see Appendix G). However, to ensure that young people and parents who had responded in some way to the questionnaire were not sent reminder letters or a repeat questionnaire pack, agencies were sent the names of those who had already responded and were asked to take those people off their mailing lists for the family survey. Parents' and young people's involvement in the survey was not revealed. Instructions to the agencies read thus:

> *The questionnaires state a return date of [X]. Shortly after this date I will contact you with a list of names of those people who have responded to the survey – however, I will not tell you whether the person completed the questionnaire or told us that they did not wish to be involved. We ask that you remove these people from your original list of identified young people. Then we ask that you print address labels for the remaining people.*

21

This statement aimed to keep the participants' level of involvement with the survey confidential.

Reimbursement

Agencies were reimbursed for the costs of posting out the questionnaire packs and reminder letters. Each agency was requested to keep a record of postal costs and at the end of the distribution period to submit an invoice stating the number of packs sent out, the cost of postage per pack, and total postage costs. Post office receipts were required for those packs/letters that had been sent through a post office.

In addition to reimbursement for all postage costs associated with distributing the family survey, agencies involved in the distribution of the family survey were offered a payment of up to £100 in each site toward the cost of administering the survey. In sites where more than one agency had distributed the questionnaire packs, the £100 had to be split between the agencies involved and was split according to the numbers of questionnaires (and thus the amount of time and effort) sent out by each agency.

Challenges with the distribution of the family survey

A number of challenges were identified with the distribution of the family survey: difficulties identifying those with HFA or AS; lack of engagement; attempts to avoid duplication; delays around consent; financial complications; and mistakes on the part of the distributing agencies.

Difficulties identifying those with HFA or AS

In three of the research sites the family survey was only to be distributed to young people with HFA or AS and their parents/carers. However, in one of those sites the Connexions service reported that it could not identify that group of young people as their databases would simply say ASC and thus would include those with and those without learning disabilities. Consequently, young people with HFA or AS were identified from a list provided by the Special Educational Needs Assessment Service (SENAS) but distributed by the local Connexions service.

Lack of engagement

A small number of services approached to take part in the distribution of the family survey declined to take part or did not return telephone calls or emails. In one site, workers in a particular agency were very keen to be involved but management was non-responsive. This severely limited access to post-transition young people with HFA and AS. In the same site, one agency sent out the original questionnaire packs but then stated that they did not have time to distribute the reminder letters; the local R&D office offered to take over the role and was very helpful. In another site, post-transition questionnaire packs due to be sent out by one agency were never distributed as the care managers who had identified the young adults and their parents were reportedly moved in a reorganisation and the manager was unable to locate the contact details of those people, and the care managers were reportedly not tracked down and asked to retrieve the contact details. It transpired that the questionnaire packs had been passed on to the transition team, even though the group of young adults previously identified were unknown to that team. In the same site the transition team had passed some of their questionnaire packs to a different agency to

distribute, without the knowledge of the research team. The agency in question had not communicated with the research team and thus was not involved in the distribution of the family survey. This was problematic in that the transition team had sent the agency the wrong type of packs, the wrong number of packs, the packs had been sent to the agency too late in the year for them to be distributed, and the agency was unaware of what was required in the distribution of the survey. Consequently, the research team requested that the agency did not distribute any questionnaire packs.

Attempts to avoid duplication
In one site, nine agencies were originally involved in the distribution of the family survey. In an attempt to avoid duplication and multiple questionnaire packs being sent out to families, the transition lead asked each participating agency for the date of birth and the initials of each young person on their lists. These details were then cross-checked and where there was duplication the young person's initials and date of birth would be removed from all but one of the lists. However, one special school was not informed of duplications and thus sent packs out to all previously identified students, which would have resulted in some families receiving multiple questionnaire packs. Another special school had no unique cases and thus was no longer needed to participate in the study. Another agency was unable to fulfil its commitment to the distribution of the family survey.

Delays around consent
One agency encountered significant difficulties in the distribution of the family survey. Their regulations stated that they could not distribute any form of questionnaire unless they had pre-existing consent from each young person to contact them for research purposes. Each clinician was thus required to contact their own clients, which proved onerous and resulted in delays as some staff members were on leave. Each young person also needed to be asked for their permission for their parents to be contacted. Further, there were difficulties in tracking down the postal addresses of parents where the young person no longer lived with them.

Financial complications
An agency in one site reported that the postage costs associated with the distribution of the family survey was prohibitive (even though this money would be reimbursed) thus individual workers had been asked to personally hand out the packs during their meetings with young people. This would have slowed down the distribution process and created difficulties with sending out reminder letters and questionnaire packs thus the agency was requested again to post out the questionnaire packs; monies were found to cover this cost; and reimbursement from SPRU was speedy.

Mistakes on the part of the distributing agencies
A few mistakes were made by the distributing agencies. In one site some questionnaire packs had been posted out with insufficient postage, thus some families had had to pick their packs up from the local post office or sorting office and pay a fee for doing so. Those families who contacted the research team to inform them of this mistake were reimbursed and also given a £5 high street gift voucher by way of apology. A small number of questionnaire packs were sent to people who were outside the target age range; or to individuals who reportedly did not know of the young person; and some reminder letters

were sent out to young people and parents who reportedly had not received the original questionnaire pack and thus did not know what the reminder letter was about.

Response rates

Response rates to the family survey were very low (see Table 2.4 below) and lower than those achieved in the earlier study (Sloper et al., 2010). Appendix H provides details of the demographic and diagnostic characteristics of the survey sample.

Table 2.4   Response rates for the family survey

Site	Pre-transition parents	Pre-transition young people	Post-transition parents	Post-transition young people
A	7 (12.3)	1 (1.8%)	2 (25%)	1 (14.3%)
B	17 (13.7%)	7 (5.6%)	3 (11.5%)	2 (7.7%)
C	15 (23.8%)	8 (12.7%)	5 (31.3%)	4 (25%)
D	42 (13.4%)	29 (9.3%)	14 (29.2%)	10 (17.9%)
E	24 (9.2%)	11 (4.2%)	4 (30.8%)	3 (23.1%)
Total	12.8% (105/818)	6.8% (56/818)	25.2% (28/111)	16.9% (20/118)

Analysis of the survey responses

Data was double-entered onto SPSS and cleaned. Decisions regarding the appropriate approach to take with the analysis of the family survey data were driven by the response rate, the sample size achieved and the nature of the sample from each site. As a result no between site analyses were conducted and the analysis undertaken was restricted to descriptive statistics and simple tests of association. Where both the parent and young person had taken part in a survey we conducted some analyses to compare within-dyad reports of the young person's unmet needs.

2.5   Stage 4: family interviews

Parents and young people who had completed a questionnaire from the family survey were purposively sampled to take part in semi-structured interviews about their transition experiences. This section first reports on the interviews with parents, and then on interviews with young people. Parents were typically interviewed first.

Interviews with parents

The study design incorporated interviews with 40 parents of young people with autistic spectrum conditions. Parents were recruited from those who responded to the family survey. Only those parents who had expressed an interest in being interviewed by providing their contact details were approached. A main aim of the interviews was to learn about the support available from statutory services in the lead up to, and during, transfers between services and transition into adulthood. A decision was therefore made to limit recruitment to parents whose son or daughter was aged between 15 and 20 (at the time of completing the questionnaire) and who were, therefore, likely to have had experience of planning for an imminent or recent transfer, including leaving mainstream or special school. Additional selection criteria were also employed:

- whether or not their son/daughter had a statement of educational need (the support available to young people without a SEN was of particular interest so as many as possible were included in the study);

- the young person's ASC diagnosis as identified by parents (to include a mix of those said to be diagnosed with Autistic Spectrum Condition, Autism, Asperger's syndrome, or High Functioning Autism);

- the kind of secondary school attended by the young person (a roughly equal mix of mainstream and special schools was sought);

- the local authority area in which they lived (far more parents were identified in some areas compared with others, but attempts were made to ensure all areas were represented).

This left 67/133 parents who were eligible to be contacted about being interviewed. Letters and information sheets were sent to all 67 parents, reminding them of the study aims and explaining what taking part in an interview would entail (see Appendix I). Researchers spoke to 44 of those parents and invited them to take part in interview. This process stopped for eight parents who either chose not to take part (3), withdrew or could not be contacted again (2), or were ineligible because their child had not experienced any transfers and was not on the cusp of transfer (3). Researchers attempted to contact a further eight parents but were unable to speak to them. Letters were sent to the 23 parents who had not been contacted by telephone to explain that recruitment for the study had come to an end and that they would not be asked to participate in an interview, but they would be sent a summary of the research findings at the end of the project. Of the 67 potential participants, 36 were interviewed. One of the parents in the sample was interviewed about two autistic children, thus 36 parents discussed 37 young people. The characteristics of the sample of parent interviewees are presented in Table 2.5 below. The vast majority of interviewees (30/36) were mothers of young people with ASC, HFA or AS.

Table 2.5   Sample characteristics of parents interviewed

Characteristic	Number of parents
Mother	30
Father	1
Both parents interviewed	1
Other *(mother & grandmother interviewed)*	1
Foster parents	1
Adoptive parents	2
Total	**36**

The characteristics of the sons and daughters of the parents interviewed are illustrated in Table 2.6 below. The highest number of interviews took place in Site D which also had the highest response rate in the family survey.

Of the parents interviewed, most (23/36) defined their son/daughter's diagnosis as Asperger's syndrome.

Table 2.6   Characteristics of the sons/daughters of the parents interviewed

		No. of young people whose parents were interviewed
Site	A	1
	B	9
	C	8
	D	13
	E	6
Age of young person	15	1
	16	8
	17	3
	18	10
	19	5
	20	9
	21	1
Sex of young person	Male	29
	Female	8
Parent-defined diagnosis	ASC	2
	Autism	8
	Asperger's syndrome	23
	HFA	4
SEN	SEN	30
	No SEN	7
School	Special school	12
	Mainstream school	19
	Experience of both special and mainstream	6
Total		**37**

(N.B. one parent was interviewed about 2 autistic children)

Ten parents were interviewed face-to-face and the remaining 26 were interviewed over the telephone, in accordance with their preferences. Where parents agreed to be interviewed, arrangements were made to conduct the interview at a time and place convenient to them. Interviews tended to last between an hour and an hour and a half and were digitally recorded with permission from interviewees. Recordings were transcribed. Where consent to record the interview was not given, contemporaneous notes were taken by the interviewer. Written consent was obtained in all cases and parents were invited to ask questions about the research prior to interviews commencing (see Appendix J).

A semi-structured topic guide (see Appendix J) was used in all interviews to direct discussion around the following themes:

- particular difficulties experienced by the young person, especially in moving towards adulthood;
- parents' experiences and views of planning for their child leaving school, of transfers from children's to adults' social care or health care services, and of any support received from non-statutory services regarding transition;
- the impact of impending or recent changes on the young person and the parents;
- their son's or daughter's hopes and aspirations and the extent to which these had been achieved;
- the young person's current needs and the provision of support to meet them;
- parents' overall views about what works well or does not work well regarding support for transition and suggestions for improvements.

Brief details of the household composition were also taken at the interview (see Appendix J).

Leaflets outlining local and national sources of support for young people with ASC and their families were provided to parents as appropriate at the end of interviews (see Appendix J).

Piloting the topic guide

Researchers piloted the topic guide with two parents of young people with ASC. Throughout the pilot interviews the parents were asked to let the researcher know if they felt that any of the questions were unsuitable or were inappropriately worded and whether key issues or topics were not elucidated by the questions contained in the topic guide. Further, data from the interviews underwent a preliminary analysis to check whether the questions yielded information that would help to answer the research questions. Minor changes were made to the topic guide as a result of the piloting.

Data analysis

Thematic analysis of the interview data was conducted. Key processes of thematic analysis are: data immersion; identification of themes; data reduction; data display; and analytical writing, conclusion drawing and verifying (Miles and Huberman, 1994). Framework (Lewis and Ritchie, 2003) is a very well-established analytical method which uses a thematic approach to classify and interpret qualitative research data and was used in this study.

First, the interview transcripts were read and re-read by members of the research team. The team had in mind the research questions when immersing themselves in the data. The output of this process of immersion and team discussions was a set of themes, or topics,

which the team felt would most effectively organise and represent the data. The themes were derived from the research questions though emergent topics (identified during data immersion) were incorporated into the thematic framework as sub-themes/topics.

A chart for each theme was then created. Columns were used to divide each chart into sub-themes/topics. Data from each participant was entered into the cells on a single row. This data took the form of summaries and, sometimes, direct quotes. Reading of the charts enabled within and between case analyses. Each chart entry was referenced back to the transcript by noting the transcript page number alongside each summary or quote.

The material contained in each chart was subject to further scrutiny and discussion before detailed analytical notes reporting the findings, and drawing conclusions, from the data contained in each chart and written.

Interviews with young people
The research design also included interviews with a sample of 20 young people with high functioning autism or Asperger's syndrome who were on the cusp of leaving school (at 16 or 18 years: pre-transition) or who were young adults (19-21[5] years). Young people were recruited from those who responded to the family survey and indicated that they would be willing to participate in further research. None of the young people from Site A indicated that they were willing to participate further and so the sample was drawn from four of the five research sites. Twenty-six young people (out of the total sampling pool of seventy-six) fulfilled the above inclusion criteria and were thus eligible to participate in the interview phase.

Age appropriate but simply written letters and information sheets were sent to all 26 young people, reminding them of the study and explaining what taking part in an interview would entail (see Appendix K). Amongst the potential pool of 26 young people, six young people declined the offer to participate. Amongst the 20 young people willing to be interviewed it emerged that two respondents did not have HFA or Asperger's syndrome, thus these two young people were also excluded. The sample characteristics of the 18 young people ultimately selected for interview are depicted in Table 2.7 below, along with brief details of their school transfer and any subsequent transfers or their current situation.

The researcher rang each young person to arrange a convenient interview time; most of the young people chose to make these arrangements themselves, however some preferred their parents to talk to the researcher and make these arrangements. The young person's preference often related to their comfort with talking on the telephone. Each of the 18 young people was interviewed face-to-face in their own home by a single researcher. Written consent was obtained at the start of each interview (see Appendix L). Two sets of flexible topic guides were developed based on pre- and post- school transfer experiences. The pre-school transfer topic guide was used with young people who were preparing to make the transfer from school (this was predominately the younger young people in the sample, i.e. those under 17 years) and the post-school transfer topic guide was used with

---

[5] This age range was lower than that used for the family survey due to concerns about young people's ability to recall leaving school experiences in detail if too long a period of time had elapsed.

the young people who had left school (see Appendix L). Interviews focused upon young people's transfer experiences, in particular, post-school/college transfers (including leaving school planning, support and feelings and after school/college support and feelings), transfers from children's to adult services (including discussion of any service changes, and any planning and support, young people's feelings were also explored), and steps towards greater adult independence (specific areas where steps had been taken, how they had been taken, and any support received). Future aspirations for adult life were also discussed.

Recognising that the terms HFA and Asperger's syndrome can be broad and that young people's level of understanding and communication can vary within these definitions; a simple version of both the pre and post-school transfer topic guides was also developed. The simple versions of each topic guide were based on the same themes and issues as the standard pre and post-school transfer topic guides but used more closed, direct questions and contained fewer questions (see Appendix L). In addition, four charts were developed which the young people or researcher could, if the young people chose to do so, complete during the interview. These charts focused on background information, school/college transfers, service transfers and steps towards independence. The charts employed age-appropriate clip art symbols to aid explanation and interest (see Appendix L). The topic guides and charts were piloted with two young people with HFA/Asperger's syndrome. The main finding from the piloting suggested that, in contrast to parents, young people may be unlikely to provide a detailed chronology of transition planning and service transfers and that this part of the interview schedule could become burdensome and distract from the main topics under discussion. The topic guides were subsequently amended in response to this.

The young people interviewed for this study were all verbal and all interviews were audio recorded, with the consent of the young person. Interviews lasted between an hour and one and a half hours. Young people were asked if they would like to use the charts, two young people chose to use them. Both the young people completed the charts themselves and reported their decision to use the charts based on their enjoyment of writing. Whilst completing the charts, the young people verbally explained their responses to the researcher. Of all 18 interviewees, half (nine) chose to be interviewed with another person present, for eight of the young people this was a parent and for one young person, it was a carer. All nine of the young people choosing to have another person present initially appeared anxious and the presence of a parent was wanted for reassurance. Some of the young people were also concerned that they would not be able to remember specific details; especially service details or dates and so looked to parents to confirm the accuracy of any specific service details.

Data analysis
The interviews were transcribed and a single researcher analysed the data by developing a summary of each young person's interview based on a list of key themes and issues developed by the members of the research team (WM and BB) on the basis of close reading and re-reading of the interview transcripts and with the project's research questions in mind. After a list of themes and issues was agreed, the researcher began summarising each interview. The researcher and co-researcher subsequently met during this process of summarising, once again, to check consistency with regard to the use of the list of themes

and issues. Once a summary profile had been developed for each young person, the summaries were then used as the basis for comparisons between the young people and the authorities.

Table 2.7   Sample characteristics of young people with HFA or AS interviewed for the study

Identity code*	Authority code	Gender	Age at interview	School attended	School transfer	Subsequent transfer(s)/current situation
Andrew	2	Male	25	Special	18 years – specialist residential college, 3 year animal based course	21 years plus – seeking paid employment, currently doing part-time voluntary work
Stuart	3	Male	16	Special	16 years – local mainstream college, 2 year special foundation learning course	Soon to enter final year
Ian	3	Male	20	Mainstream	16 years – local mainstream college, 2 year catering course	18 years – did not complete higher level catering course, currently on sickness benefits
Sophie	3	Female	18	Mainstream	16 years – local mainstream college, 2 year animal based course	18 years – higher level animal based course
Bob	4	Male	18	Mainstream	16 years – local mainstream college, 2 year graphic design course	18 years – planning art degree course at local university
Ben	4	Male	19	Mainstream	16 years – local mainstream college – 3 year science course	19 years – preparing to seek paid employment after summer vacation
Steven	4	Male	20	Special	16 years – local mainstream college, series of special IT/science based courses	Soon to enter final year
Tracy	4	Female	18	Special and mainstream	16 years – local mainstream college, 2 year animal based course	18 years – planning further college animal based course
Karl	4	Male	18	Mainstream	16 years – local mainstream college, 1 year vocational studies course	17 years – car mechanics course at college but did not complete, currently seeking paid employment
Emily	4	Female	18	Mainstream	16 years – local mainstream college, 2 year social studies based course	Left before completing course, succession of part-time vocational courses, currently seeking paid employment and doing part-time voluntary work
Edward	4	Male	16	Mainstream	Preparing for A' Levels at local 6th form	N/A
Charley	4	Male	20	Mainstream	16 years – local mainstream college, 2 year media course	18 years – further media college course. 20 years – planning media degree course at local university
Simon	4	Male	23	Mainstream	16 years – job in local factory	Succession of manual jobs and vocational courses. Currently seeing paid employment and doing part-time voluntary work

Identity code*	Authority code	Gender	Age at interview	School attended	School transfer	Subsequent transfer(s)/current situation
Greg	5	Male	20	Mainstream	16 years – special residential college, 3 year education and independence based course	19 years – media course at local college, about to enter final year
Katy	5	Female	19	Mainstream – SEN unit	16 years – local mainstream college, 2 year special general education course	18 years – special foundation in education course, about to enter final year
Matthew	5	Male	16	Mainstream	15 years – local mainstream college, science A' Levels (transferred year early)	N/A
Sam	5	Male	15	Mainstream – currently in exclusion unit	Planning for car mechanics course at local mainstream college	N/A
Adam	5	Male	16	Mainstream – was in exclusion unit	16 years – just started media course at local mainstream college	N/A

* All names have been changed to pseudonyms

2.6   The costs work

Procedures and methods
The interviews with managers and staff in each of the sites included questions about the staffing arrangements for the transition teams and workload (or time spent) on children with ASC within those teams. The different models available in each site meant that questions were adapted to elicit the data for the way transition occurred in each site. In addition we asked for a copy of the recent income and expenditure accounts for that team. Teams were requested to provide as detailed as information as possible including:

- practitioners' roles, grades/bands, % f.t.e.
- administrative support costs: grade/band, % f.t.e.
- staff travel
- premises
- consumables
- training
- supplies and services purchased for clients
- caseload
- sources of funding.

The cost estimation approach underlying this research takes the basic principles inherent in economics and applies them to the specific field of social care services. Our approach in the costs work is to apply principles of *long-run marginal opportunity costs* (Beecham and Knapp, 2001)*.* As transition services are intended as an important component of child and adult services so the cost of expanding the service is an appropriate measure. Thus, *short-run marginal costs*, which include only the day-to-day costs of running the service, will underestimate the costs of providing *more* of the service. Our approach is to include these revenue (recurrent) costs as well as the overheads that accrue to the managing agency. Thus the full costs of providing the service are accounted for rather than the costs of squeezing just one or two more children into an existing service configuration. Costs are presented at 2010-2011 prices.

Data on the level of contact that families had with the transition teams are taken from the Family Survey. The response rate for this survey has been discussed earlier so we use these data to *illustrate* contact levels rather than to *identify* the cost implications. In case families do not identify transition support by the title 'transition (support) worker', in the Discussion section we have looked more widely at the families' utilisation rates for other professional and services.

Chapter 3
Transition Pathways across the Autistic Spectrum

3.1   Introduction

Models of transition planning and support for young people with ASC differed quite significantly between the five research sites. This chapter provides an overview of the models. It begins by describing the differential transition pathways for young people with ASC and learning disabilities, young people with high functioning autism, and young people with Asperger's syndrome in each of the research sites as described by the managers and practitioners we interviewed. The descriptions are illustrated by flowcharts of the transition pathways in each site. While the transition pathways appear relatively clear, parents and young people are unlikely to be aware of the pathways and may or may not have experienced their transition as the models suggest. Thus, following the description of each model, we report the views and transition experiences of parents of young people on the autistic spectrum. Did the families interviewed for the study experience the transition pathways in the way that the models suggest? There follows an overview of the costs of the different models. The chapter concludes with a brief discussion.

Terminology

Throughout this and following chapters, we use the term 'transition team' to refer to the statutory team tasked with transition planning for young disabled people; the term 'transition service' is used to describe the work undertaken by the transition team, including transition planning and support into adulthood; and the term 'transition support' is used to describe support to young people/ young adults with ASC during the transition period (~14-25 years) that is provided by statutory and non-statutory services, agencies and organisations other than the transition team.

3.2   Site specific transition pathways

This section sets out the models of transition planning and support for young people on the autistic spectrum from across each of the five research sites. The transition pathways and descriptions of the models have been pieced together from interviews with managers and practitioners in the research sites. Following the description of each model/transition pathway, parents' perceptions of their son/daughter's transition experiences are reported.

Across each of the five research sites, transition pathways effectively began with the work undertaken in transition tracking meetings. In those meetings, practitioners from the different agencies involved (typically children's services, adult services and the transition

team) shared information about young people within the transition cohort and known to services; provided updates on what was happening for each young person; determined what work still needed to be undertaken by different agencies and who was going to undertake which pieces of work; and then managers from adult services tried to decide which was the most appropriate adult team to take over the case if the young person was eligible for support from adult services. In one site (B) all young people with ASC, including those with HFA and AS, were identified, even if they did not meet eligibility criteria for adult services, so that all agencies were aware of the young people in case they later became eligible for support; and so that gaps in services could be identified. In another site (D) there were separate operational planning groups for those young people known to social care and those not known to social care (typically identified by Connexions) who may nonetheless be eligible for adult health and social care support, including those with HFA and AS.

Site A
The transition team
In Site A the transition team sat within children's services and was the social care team for all young people aged 14-18. The team consisted of: a transition service manager, three transition social workers and two transition key workers (who were not qualified social workers but who undertook much of the low-level transition planning and support with young people); a school nurse working with young people of transition age, a Connexions personal advisor and a trainee educational psychologist formed part of a broader 'virtual' transition team. The team worked on transition alongside their generic social work.

The transition service
The transition pathway in Site A is illustrated in Figure 3.1 below. Only those young people with a statement of special educational need were eligible for support from the transition team. This included those with an ASC and learning disabilities and those with ASC and another health condition. Transition support was not available to young people without a statement, for example those with ASC and no/mild learning disabilities or those with a diagnosis of Asperger's syndrome and no other health problem. Those who were eligible for the transition service were assessed by a transition worker and had a health action plan produced by the transition nurse; the two were combined to produce a transition plan. At age 17.5 young people were referred to adult services. If the young person met the criteria for adult services, i.e. if they had an IQ below 70, they were eligible for lifelong support from the community team for people with learning disabilities. Between the ages of 18 and 19, the young person's case would be co-worked by social workers from the transition team and adult services; the young person would transfer to the adult learning disability team at age 18 but children's services would continue to fund the care package until the young person reached age 19. The pathway benefited from having a designated social worker, senior social worker and nurse working on transition cases in the adult learning disability team. If the young person did not meet the eligibility criteria for adult services (if they had an IQ above 70) then the transition team could continue to work with them until age 19 to help them move toward independence, for example by helping them to understand when and how to access support services, and signposting the young person to other services.

Figure 3.1   Transition pathway in Site A
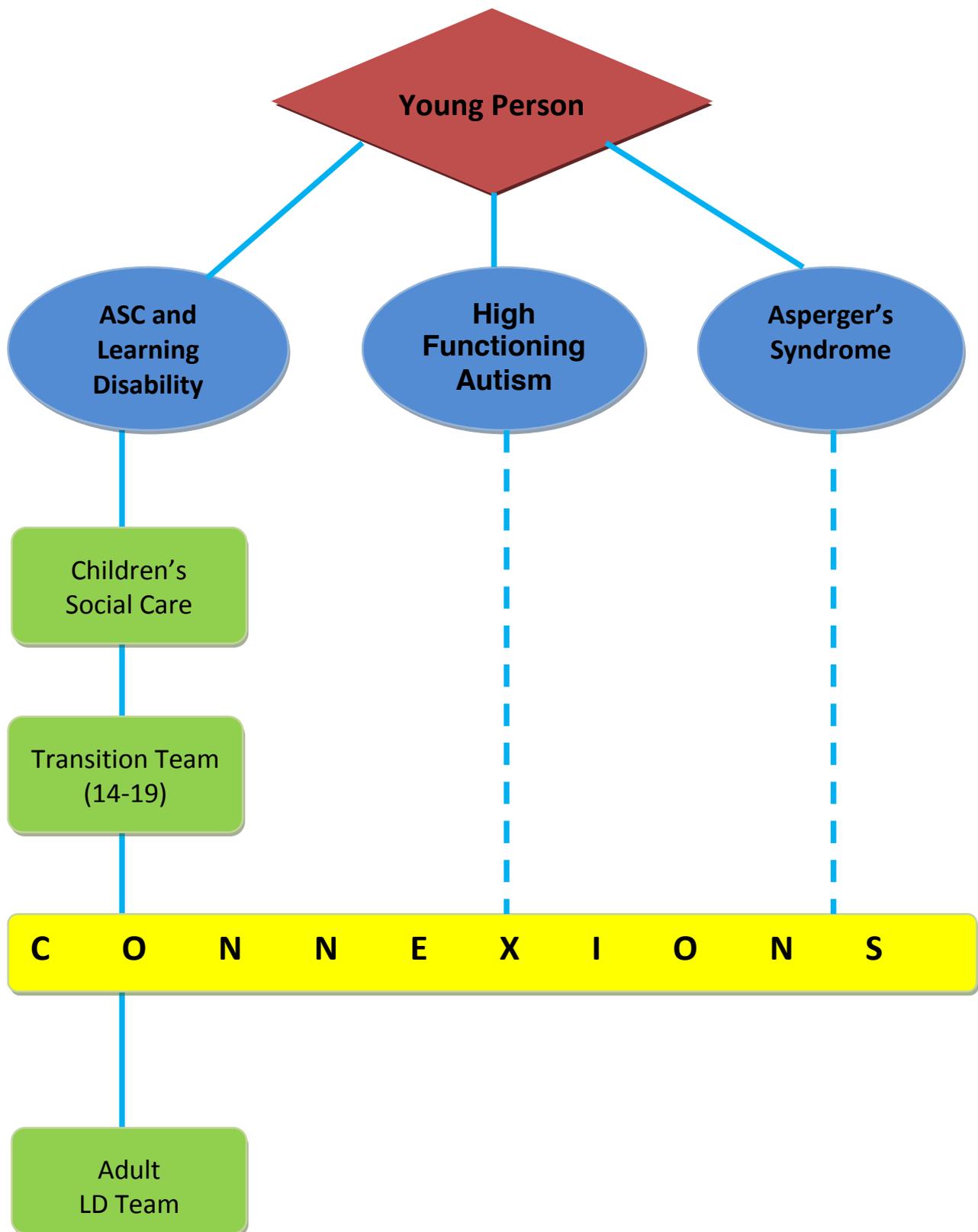
Those not eligible for support from the transition team (those without a statement, including those with Asperger's syndrome) and those not eligible for support from adult services would be entitled to support from Connexions until age 19. Some local autism specific services also provided support during the transition period and in (early) adulthood (see chapter 5 for further details).

The data on costs and service use
Overview
Transitions for children with ASC and learning disabilities or additional health needs, are supported within the LA-funded children's social care transition service (14-19 years). Use of adult services is dependent on meeting FACS criteria in the adult community support (LD) team and most services are geared towards high dependency children. Young people not meeting the criteria for adult services are signposted to Connexions (who become the lead agency), Supporting People (housing), and welfare benefits. They may receive a specialist assessment and short-term treatment from CAMHS, or from the voluntary sector organisations, but few provide services around transition. We have no information on the likely cost of these services.

Costing transition support
The manager of the disabled children's service reported that about one third of the integrated disabled children's team costs should be ascribed to transition activities; £117,600 per annum. This excludes the costs of the various services children receive (such as residential schools, direct payments, consultant fees and the like) which are not directly related to transition support.

Unfortunately we have no workload measures for the number of children in transition who are being supported within this budget, nor do we know the number of ASC children within that total. One social worker reported a caseload of 16, of whom two young people have HFA and eight have ASC and learning disabilities. One Connexions PA who is linked to a special school reported spending 25 per cent of their time on ASC. Another, who is a specialist learning disability PA, has a caseload of 150 including 15 young people with HFA and 40 with ASC and learning disabilities. The caseload includes 30 young people with ASC who are in transition.

Family contact with their transition worker
None of the seven families completing the 'pre-transition' Family Survey had a copy of their transition plan. Two, both with autism and learning disabilities, had seen their transition worker in the last three months (weekly or fortnightly) and both felt that the level of contact was sufficient. Just two families responded to the 'post-transition' Family Survey neither of whom said they had a copy of the transition plan. One parent reported that transition support was provided by a teacher and that they felt they had enough support.

Reflections on families' experiences of the transition pathways and processes
Only one parent from Site A was interviewed. It was not felt appropriate to present the reflections from just one case, thus parent perceptions are not reported for this site.

Site B

The transition team

In Site B the transition team consisted of four transition workers (one in each part of the county) based in community learning disability teams in adult services. These transition workers supported young people with an identified learning disability and an IQ below 70, including those with ASC and learning disabilities. Eligibility was not limited to young people with a statement of special educational need as additional funding for schools was not linked to statements in this county and many students were categorised as being on 'School Action' or 'School Action Plus' funding. There was also one transition worker supporting young people with physical disabilities and/or sensory impairments across the county. Transition workers were previously employed by Connexions and were not all qualified social workers. The transition workers were line-managed by the community learning disability team manager in their area, and were responsible to the county-wide transition service manager.

The transition service

The transition pathway in Site B is illustrated in Figure 3.2 below. Transition workers worked with the young person, their family, school and other relevant/involved professionals to plan the young person's transition into adult services. Transition workers attended annual reviews from when the young person was aged 14. By the time the young person was 17.5 years old, the transition worker would have undertaken a full community care assessment and, if the young person was eligible for adult services, would have developed a care plan, identified a package of care, costed the package, and taken it to a funding panel for approval. If the case was particularly complex, the young person would instead be allocated a qualified adult social worker. Once the young person turned 18 the children's social worker handed over to the transition worker. A transition worker would work with a young person until they were settled into adult services, for example when they had left college/ education, were settled into a day time occupation or employment, and their housing situation was stable. Once the young person was settled, or when they turned 25 years old (whichever occurred first), s/he would no longer receive support from the transition worker and would instead have their case open to review by social workers from the adult learning disability team.

Figure 3.2   Transition pathway in Site B
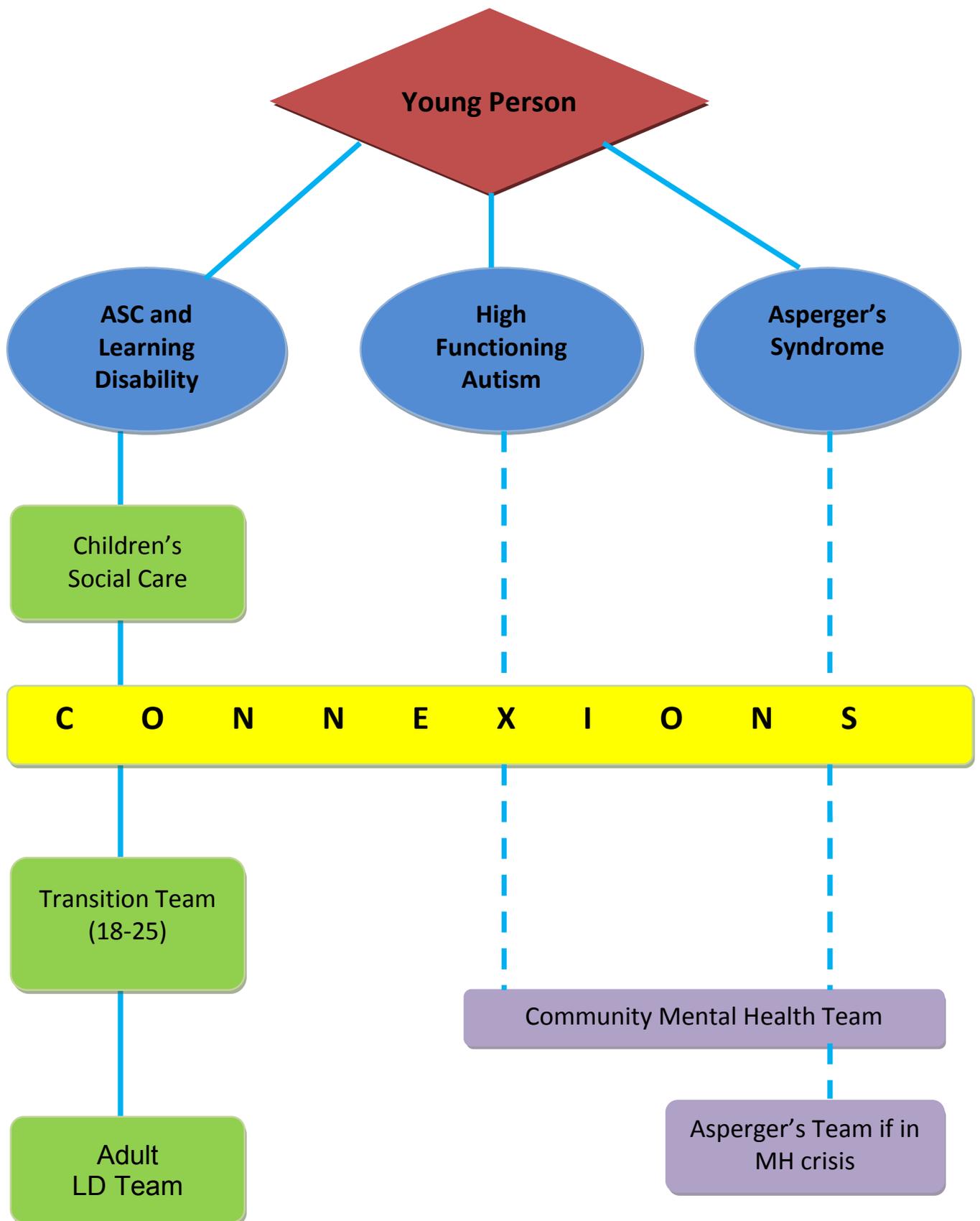
Young people without an identified learning disability were not eligible for support from the transition team, and were only eligible for support from generic Connexions PAs until age 19. However, young people with HFA or AS would still be identified at area transition meetings at age 14 and referred either to adult mental health teams at age 17, where those with AS may be picked up by the Asperger's team if in mental health crisis, or to adult social care if the young person had ongoing support needs. The Asperger's team, predominantly made up of psychologists, social workers and occupational therapists, was jointly funded by the PCT and adult social care and was based within adult mental health services. It offered intensive short-term pieces of work to those in crisis. The team could assist with independent living skills, access to supported housing and employment and support to maintain tenancies or work placements. They could also advise employers, housing associations or other services about the support needs of each individual with AS. Decisions about referral routes were made at the area transition tracking meetings. Eligible young people would transfer to an adult social worker or mental health worker at age 18, and would not encounter a transition worker. Young people with HFA or AS who did not meet eligibility criteria for adult services could be signposted to mainstream services or voluntary organisations by children's social care or by Connexions.

The data on costs and service use
Overview
Transition support in this site is mainly provided by a transitions personal assistant working in each of the four areas and linked to the local learning disability teams in adult services. Young people with an IQ of over 70 would not get transition support from these teams. Connexions provides the mainstay of transition support for those ineligible for social care or with an IQ of over 70, such as many young people with HFA/AS.

Costing transition support
No data on expenditure or costs was forthcoming for this site; however, the service is reported to be unchanged since our interviews in 2007-2008 (Sloper et al., 2010). At that time we estimated the costs from the staffing data using nationally applicable unit costs. At today's prices, this would total £207,300. One transitions personal assistant estimated that about a third of her current caseload (n=60) had ASC.

Family contact with their transition worker
Seventeen families responded to the 'pre-transition' survey, six of whom had a copy of their transition plan and six had seen their transition worker over the previous three months. Usually they had just one contact but felt this was about the right amount. These were also the families who received telephone calls from their transition worker. Four of the young people had an additional health problem (learning disabilities or epilepsy) and two had Asperger's syndrome. Three parents responded to the 'post-transition' Family Survey, none of whom had a written transition plan. One parent could identify a single person, a key worker, who had provided transition support throughout.

Reflections on families' experiences of the transition pathways and processes
Of the nine young people represented by the parent interviews in Site B, six had diagnoses of Asperger's syndrome. Thus, according to the model of provision in this site, six were eligible for support from Connexions only. This appeared to be reflected in parents'

accounts of transition, as none of this group had support from the transition team. One parent was aware of a transition team and had made efforts to access the transition service, but failed. However, this appeared to be because of rather poor coordination between services rather than because of eligibility.

Most of the six young people with Asperger's syndrome (though not all) had contact with Connexions, but input appeared to have been very limited in some cases. Just one of the young people with Asperger's syndrome went on to receive any adult social care: this appeared to have been the result of much effort on the parent's part. The Asperger's team was referred to by only one parent as a potential source of support for the young person, but access to this team had been denied on the grounds that the young person was not deemed eligible for support.

The three remaining young people represented in the parent sample had diagnoses of Autism; whilst it is not clear if these young people had an additional learning disability, all had had contact with a transition worker. The input from the transition worker varied across the three. One parent felt that their role and input was unclear, and did not find the support helpful. For the other two young people, the transition worker was involved in either preparing respite care in adult services or making preparations for leaving school, such as setting up assessments for employment, leisure and independent living options. Only in the latter case were views of this support positive. One of the three young people with Autism went on to receive full-time adult social care support.

In the majority of parents' accounts there was a sense that the input and support from statutory services in planning the transition from school had been limited. Later outcomes appeared to be more positive, but this appeared to be because parents had fought hard to get provision. Some parents in this site referred to a voluntary sector organisation for people with support needs (not ASC specific) as an option for their child in terms of securing some form of daytime occupation after college, and for accessing employment support and independent living skills.

Site C
The transition team
In Site C the transition team was the children's services social care team for all young people aged 14-18/19. The team consisted of one senior social worker, two social workers, a family support practitioner, and a transition behaviour support nurse. Linked to the transition team were two occupational therapists based in children's services.

The transition service
The transition pathway in Site C is illustrated in Figure 3.3 below. The transition service was available to young people aged 14-18/19 who had learning disabilities and a statement of special educational need, including those with ASC and learning disabilities. In advance of the young person reaching age 18 a transition worker would undertake the Fair Access to Care Services assessment for eligibility for adult services; undertake the needs assessment; set up the adult service package; gain approval for funding; and review the package six weeks later, before handing over to adult services when the young person turned 18/19.

Social workers in adult services were available to joint work with transition workers around the adult services assessment or getting through the funding panel, if need be.

Eligibility criteria for the transition team were reportedly stricter than the criteria for accessing adult services; thus some young people could be eligible for adult services even if they were not eligible for support from the transition team. This was justified on the grounds that whilst young people were in full-time education the school was heavily involved in keeping an eye on them, safeguarding them, and keeping them occupied in meaningful daytime activities.

Figure 3.3   Transition pathway in Site C
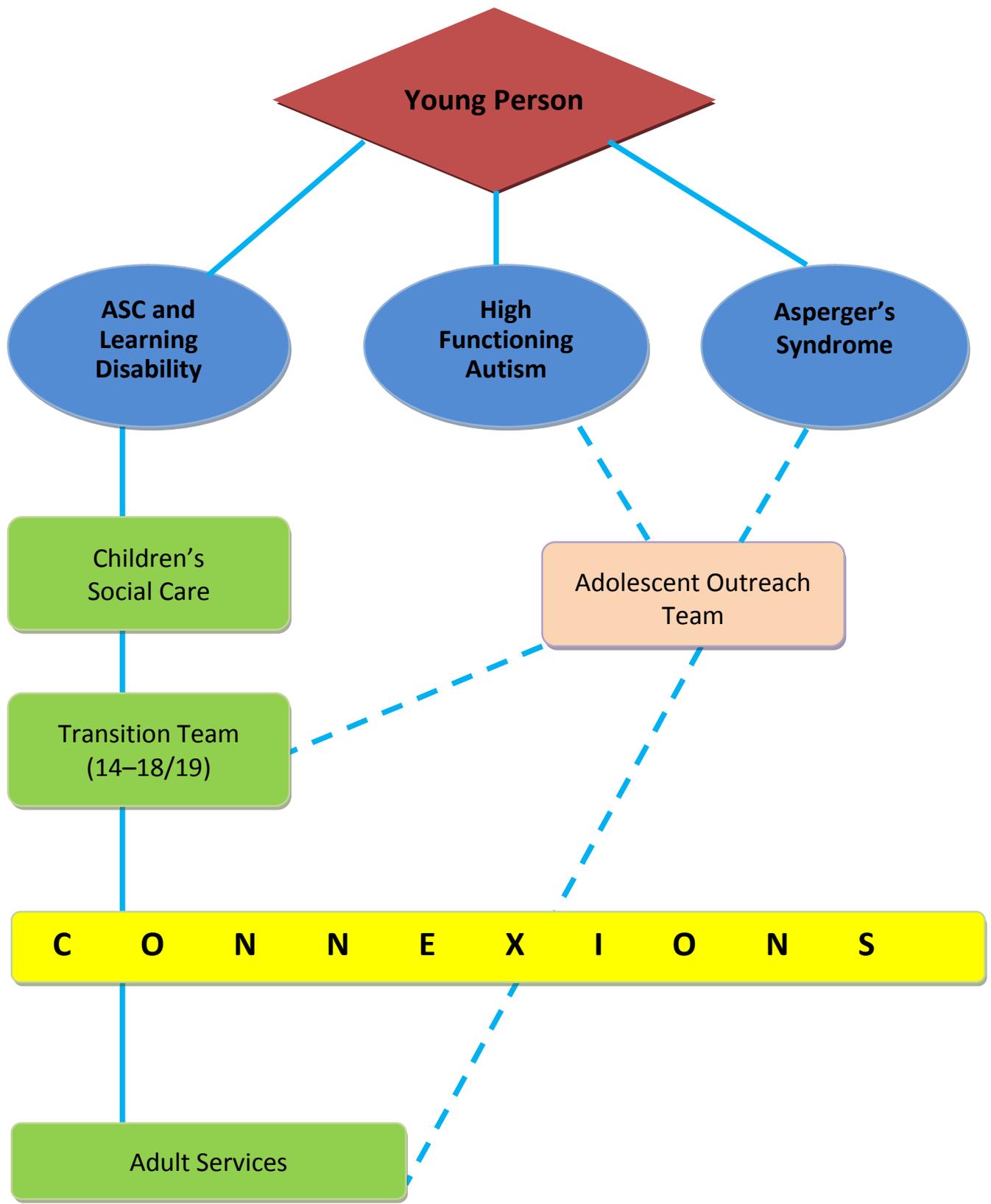
Young people with HFA or AS were not eligible for support from the transition team unless they also had other serious health problems. Those whose communication and/or behavioural problems were impacting upon their functioning and daily lives would be supported by the Adolescent Outreach Team (AOT); however, increasingly a transition worker was undertaking a joint visit with the social worker from the AOT and offering additional advice, support and information around transition-specific issues to the young person and their family. This reportedly also proved beneficial to social workers from the AOT who perhaps lacked the detailed knowledge and expertise around transition, and around what services and support were available for young people in transition. The AOT worked closely with the local Connexions service; many of the young people on its caseload reportedly had HFA or AS. The team ran holiday schemes and provided specialised targeted services. The AOT predominantly worked with young people from mainstream schools, while the transition team focused on young people from special schools.

There were no autism specific transition services in this site; however a senior Connexions PA had a particularly keen interest in supporting young people with ASC and offered additional support and signposting to any young person on the spectrum up to the age of 25.

The data on costs and service use
Overview

The transition team, funded from the LA children's social services locality budget, holds around 90 cases, 70 of whom receive social work support and 20 receiving support from an occupational therapist. Commonly these young people have a Statement of Special Educational Needs (SEN) and are attending special educational needs' schools; the team would only accept young people with ASC if they have an accompanying learning disability. The team aims to develop a settled package before the transfer to adult services. The team consists of a part-time senior social worker and two social workers and a family support worker. There is a six-month period of joint working with adult services; some children are transferred straight from children's services and others are supported by the transition team.

The social care threshold for adult services is that they should have severe, substantial and permanent disabilities (FACS critical); this can include ASC with LD. For those not meeting these criteria or who do not have a learning disability the main support is through Connexions. There is one Connexions PA who is very committed to working with ASC children, often providing a wider range of support than education, and up to age 25. He has a caseload 260-350 of whom around 35 per cent have ASC, mostly with a learning disability. A Pathfinder grant was used to set up a 'virtual' college which had about 50 learners last year. There is also an adolescent outreach team; a job training and employment opportunities scheme; a web-based directory of activities, about a quarter of which are suitable for young people with ASC; two educational psychologists with a particular responsibility for ASC; and a Community Resources Unit.

The costs of transition support
Expenditure data were sent for 2009-10 but excluded overheads which are dealt with centrally. We have added these and uprated the data to 2011-2011 prices (Curtis, 2011, p.155). The total cost for the team is £204,293, of which staffing accounts for 66 per cent. On average the annual cost of providing transition support is £2,270 per child but we do not have sufficient data to separate the cost of transition for young people with ASC from other children supported by the transition team.

Family contact with their transition worker
There were 16 respondents to the 'pre-transition' Family Survey of whom six had a written transition plan. Seven families had one person they could identify as their transition support worker. None of the families had contact with their transition worker in the last three months, except for the one family who identified a teacher (the others were Connexions PAs) who they could see 'on request'. Five parents responded to the 'post-transition' Family Survey. The two for whom there had been a written transition plan both had a single person to provide transition support (a Connexions PA and a social worker/key worker), one of whom would have liked to have more transition support.

Reflections on families' experiences of the transition pathways and processes
Only two of the young people represented in the interview sample were potentially eligible for support from the transition team. However, neither had received ongoing support from children's social services, nor support from the transition team, because the parents had refused help from social care after finding their advice unhelpful and/or because an offer of help from social services had not subsequently led to the actual provision of support. At the time of the interview however, the parents had been encouraged to seek support from adult social care and were about to meet with adult social workers to discuss possible future support.

Another young person's difficult behaviour throughout school and college might have made them eligible for support from the Adolescent Outreach Team, but the parent's account suggested that their application for support from this service had not been accepted. This family felt they had been poorly served by statutory services during their child's transition due to their limited contact with social care. However, recent contact with Jobcentre Plus and a supported employment service was reportedly more positive.

Young people with high functioning autism or Asperger's syndrome who had had contact with children's social services had done so for a short time only, or had been in touch for reasons other than their autism, or had been assessed as ineligible for ongoing support. Contact with Connexions PAs was experienced by all the young people reportedly diagnosed with Asperger's syndrome or high functioning autism, but parents' reports of the experience of using this service were mixed. None of these young people appeared to have been put forward for assessment for adult social care and thus were not in receipt of any adult services.

Site D

Site D did not have a transition team. Instead it had a transition coordinator who oversaw strategic plans around transition; two social workers within adult services who took the majority of young people with learning disabilities, including those with ASC and learning disabilities, transitioning from children's services; and an Asperger's team located in adult mental health services that offered time-limited support around transition for those with high functioning autism or Asperger's syndrome. The Transition Coordinator held a strategic post joint-funded by children's services and adult services; the remit covered 14 to 25 year olds and as such the post was based in adult services. The transition coordinator was tasked with setting up and running multi-agency forums on transition; working with colleagues across agencies to develop multi-agency protocols and pathways for young people transitioning from children's services into adult services; informing agencies about new policies; attempting to identify gaps in services for young people with a range of disabilities, including those with ASC; and following-up action points to ensure that multi-agency working was occurring around transition.

The transition service

The transition pathway in Site D is illustrated in Figure 3.4 below. Site D had a different model for accessing social care support. Children and their families in need of some support would first be directed to universal services, including the Connexions service, where they may receive information, advice and signposting to mainstream services or activities; if further support was required, the family could be referred for targeted services for which they would not require a social worker or a social care assessment. If needs still were not met then a young person could be referred for specialist services, including the Disabled Children's Service, for which they would require a multi-agency assessment of need and be allocated a social worker. The Disabled Children's Service was open to any young person aged 0-18 who had accessed universal and targeted services and had a disability that impacted upon their functioning. This rather broad definition thus potentially included young people anywhere on the autistic spectrum; however, to be eligible a young person needed to have a statement of special educational need.

Figure 3.4   Transition pathway in Site D
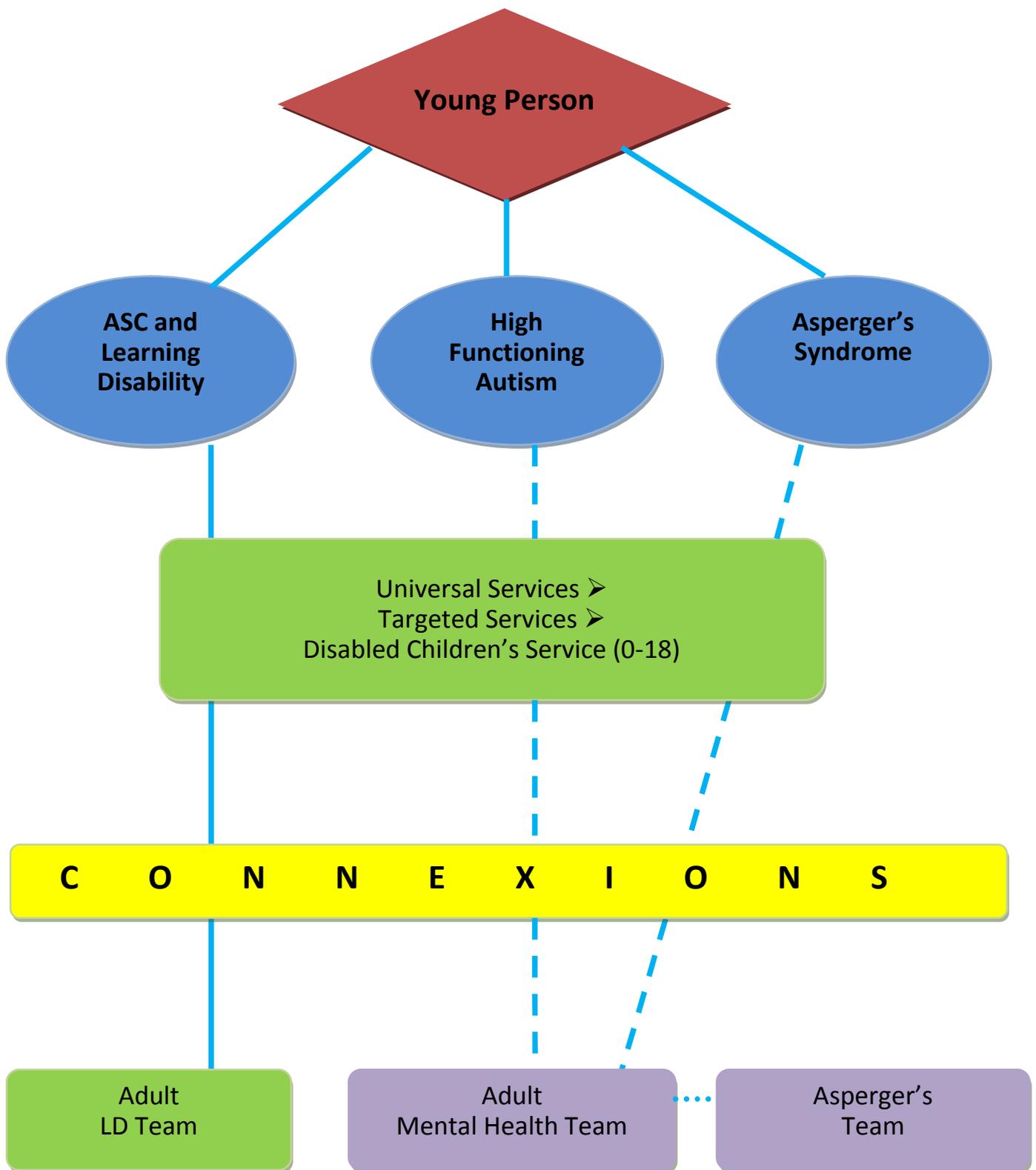
The Disabled Children's Service referred young people with ASC and learning disabilities and an IQ below 70 to particular social workers within adult learning disability services who focused on young people moving into the service and thus who had most experience of transition issues. The referral was made around the time of the young person's 17th birthday and adult learning disability services had six weeks to appoint a worker, typically one of the social workers with most experience of transition. Adult services took over on the young person's 18th birthday and worked with the young person up to age 25 or when the young person was settled into adult life. Those with ASC and an IQ above 70 were open to being diagnosed with Asperger's syndrome and were referred to the Asperger's team via adult mental health services. Thus, theoretically, all young people with any form of ASC in need of support should have had access to support in both children's services and adult services. The Asperger's team became involved in the year prior to the young person leaving school (thus at age 15 or 17) and assisted with transitional issues, such as help with accessing college, employment, independent living and social skills. However, support was short-term. In addition, young people with HFA or AS who required ongoing support could be referred to a commissioning team within adult mental health services which could commission support around, for example, supported housing and could arrange direct payments for the young adult to support their life in the community (see Chapter 5).

Data on costs and service use
Overview
There is one jointly-funded (strategic) post in social services to look across agencies and develop pathways. There is no transition team, although both children's and adult social care teams do lots of work in this area and meetings about individual children are often held before they are transferred to adult services. In-house planning meetings identify three years of transitions, about 30 cases per year for children's learning disability team. The disabled children's team has 9.0 wte qualified and unqualified social workers, each with a caseload of 20-25 children. The adult social care team includes two dedicated transition case managers, one of whom has a caseload of 39 people, about a third of whom have ASC.

There are approximately 1000 children and young people with ASC in the county; few with AS receive any social care although some are linked to CAMHS or AMHS. If young people do not meet criteria for receiving support from the children's learning disability team then there is little by way of help except through Supporting People (housing) and the National Autistic Society. There appears to be a parallel transition system in special schools, where there is also some outreach and teaching support.

Costs data
There is a 'transition liaison team' in Site D for people with ADHD and Asperger's Tourette syndromes which is linked to adult mental health services. The team supports adults of any age, starting from their last year in school and is staffed mainly by psychologists (4.5 wte) supported by nurses and clerical staff. The manager estimates they have 300-400 cases open at any one time although most referrals are for diagnosis and assessment – about 70 per cent of the 30 referrals each month. They can offer only very limited support post-assessment, currently about eight sessions.

Total costs for this team are £736,900 at 2010-2011 prices. If we assume there are 350 open cases, the average annual cost per person 'on the books' is about £2,100 per annum. About half of the team's work is with young people with ASC; £368,450

Although the team did not supply information on how young people are supported during transition we can estimate a cost for a diagnostic assessment and for a follow-up course of eight sessions. An expert diagnostic assessment will take around 6 hours from a team of a nurse (3 hours), junior doctor (2 hours) and a consultant psychiatrist (Murphy et al., 2011). The costs for this assessment can then be estimated as £380. From the information on the team's staffing and costs, we can also estimate the unit cost for a 'team member hour' of £86.50. Using this figure, the six-hour assessment process would cost £520; the eight follow-up sessions would cost £690.

Family contact with their transition worker
The Family Survey questionnaires were sent to families by the transition liaison team. Nineteen of the 42 families responding to the 'pre-transition' Family Survey could identify a single person as a transition worker, commonly a Connexions PA (n=12). Just eight families had a written transition plan and five families had seen their transition worker in the last three months. A quarter of the 42 families wanted more contact with the transition worker, seven felt they were receiving about the right level of support and the remainder did not answer the question. One person had a single telephone conversation with their transition worker and another reported that they could telephone their transition worker whenever necessary. Sixteen of the 42 young people had a learning disability/difficulty as well as their ASC.

Fourteen parents responded to the 'post-transition' Family Survey. For five families there had been a written transition plan, all of which had specified services. Each family could identify a single person giving them transition support and four of the five young people had received these specified services. Two other families also had an identifiable person providing transition support. However, only two of the 14 families felt the plan had been reviewed often enough. About half the families (n=6) had been satisfied or very satisfied with the transition support they received.

Reflections on families' experiences of the transition pathways and processes
In Site D all of the young people whose parents were interviewed were potentially eligible for support from the Disabled Children's Service. Although no parents named this service explicitly some families described having contact with children's social care and/or CAMHS and a number of parents talked of receiving excellent support from the universal and targeted services in the site. The one young person in Site D whose parent said they had been diagnosed with ASC and learning disabilities had received financial support from children's social care to pay for a carer but had no ongoing contact with a social worker. When the transfer to adult social care was made, the parent did not perceive help from a social worker with particular experience of transition and felt it had been necessary to make enquiries to initiate support. However, the adult social worker's suggestion of a referral to a day centre had worked well and the family had ongoing contact with adult social care about direct payments.

For those young people in Site D who were not diagnosed with learning disabilities, experience of transitional support from statutory services varied. Some parents explained that their son or daughter had been referred or signposted (either from children's social care or CAMHS) to the Asperger's team in adult mental health services. However, not all parents who knew about the Asperger's team had received support from it for their child due to issues around making contact or proving eligibility. One young person who was told they were not eligible was referred instead to a local voluntary sector organisation. Some parents were unhappy that their child was moved to a 'mental health' team for support for a disability. One parent had successfully challenged this decision such that the young person had recently been relocated in the Adult Learning Disability Service despite appearing to have an IQ over 70 (the cut off for young people being referred to the adult learning disability team). Experiences of the Asperger's team were mixed, with some positive accounts of receiving counselling and some disappointment expressed that appointments had not been more focused on transitional support and skills for independence. No parents said the Asperger's team had assisted with movements into further education or employment.

There were also families who had had no contact with social care or health care services. They had not felt a need for these services because they felt adequately supported for transition by the young person's school and by Connexions. All the young people in Site D (except the young person with learning disabilities) had been in contact with Connexions at some stage, though not all had found their input helpful. Useful support from other non-statutory services was also described by parents who talked about receiving little or unsatisfactory help from statutory services. For one young person, transition workers from an outreach service (funded by a national autism organisation) were assembling a package of support to develop independent living skills; whilst an employment service had helped two other young people look for a job.

Site E
The transition team
The transition team in Site E consisted of a transition coordinator and two transition social workers based within the adult learning disability team and a part-time transition nurse based in the Children's Disability Service. The service was one-third funded by Adult Services and two-thirds funded by Children's Services.

The transition service
The transition pathway in Site E is illustrated in Figure 3.5 below. Support during transition was theoretically available to all young people with a statement of special educational need and/or a disability that impacted upon their life, thus potentially including all young people with an ASC. Young people in receipt of services or support from the Children's Disability Service or other children's social care team had their transition managed by that team. To be eligible for support from the Children's Disability Service a young person needed to have a profound, long-lasting disability or a moderate disability with difficulties in at least three areas of functioning. For those young people in receipt of support from the Children's Disability Service that service undertook the transition planning; made direct referrals to adult learning disability, mental health, or physical disability teams at age 17; and undertook

a period of joint working with an adult social worker if the young person would be eligible to transfer to adult services at age 18.

Those young people who were either not eligible for children's social care, or who had refused a social worker in children's services, but who had a statement and/or a disability, including those with HFA and AS, were picked up by the transition team. The transition team should therefore have picked up all those young people that would otherwise have no transition support. The rationale for this stipulation was the desire to eliminate duplication and thus unnecessary use of resources. The service was not diagnosis specific and there were no restrictions on the basis of IQ. The service could thus potentially support young people at any point on the autistic spectrum, irrespective of whether they had a statement of special educational need. The transition team worked with young people aged 14-25 who were not in receipt of support from the Children's Disability Service. Once a young person turned 18 they would see the transition worker only once a year to review their situation; where there were problems the transition worker could offer further advice, information and signposting. Transition workers could also make referrals to adult social care and adult health services, thus all young people could potentially be assessed for adult services. Young people who were eligible for adult social care or adult mental health services were transferred to adult services at age 18.

The transition team provided a low-level service offering information, advice and support around transition. They could link with or signpost young people to services such as supported employment, adult mental health services, or the area-specific autism outreach service. The transition team could also provide information about what services and support were available locally to other agencies and professionals, e.g. colleagues in children's and adults services. If this model worked as intended, no young person with ASC should have been without some transition support. However, the transition service was relatively young and had thus far focused on young people aged 14-18, thus experience of supporting young people into adult services and adulthood was not extensive at the time of interview (2010).

For those young people who were not eligible for adult services, the transition team could provide information, advice and signposting; links to mainstream provisions; and possibly some one-to-one support for example they could take a young person to a youth club or try to set up a 'buddying' scheme. Young people who were not eligible for support from children's or adult social care or from the transition team would be signposted to Connexions, supported employment schemes, the autism-specific outreach service, or the adult intensive support service.

In this site an intensive support service in adult services had become increasingly involved with assessments for adult services and looking at people's needs through transition for those with a learning disability and/or a developmental disorder, including ASC. For example, they could provide detailed input into support plans around accommodation support needs.

Figure 3.5   Transition pathway in Site E
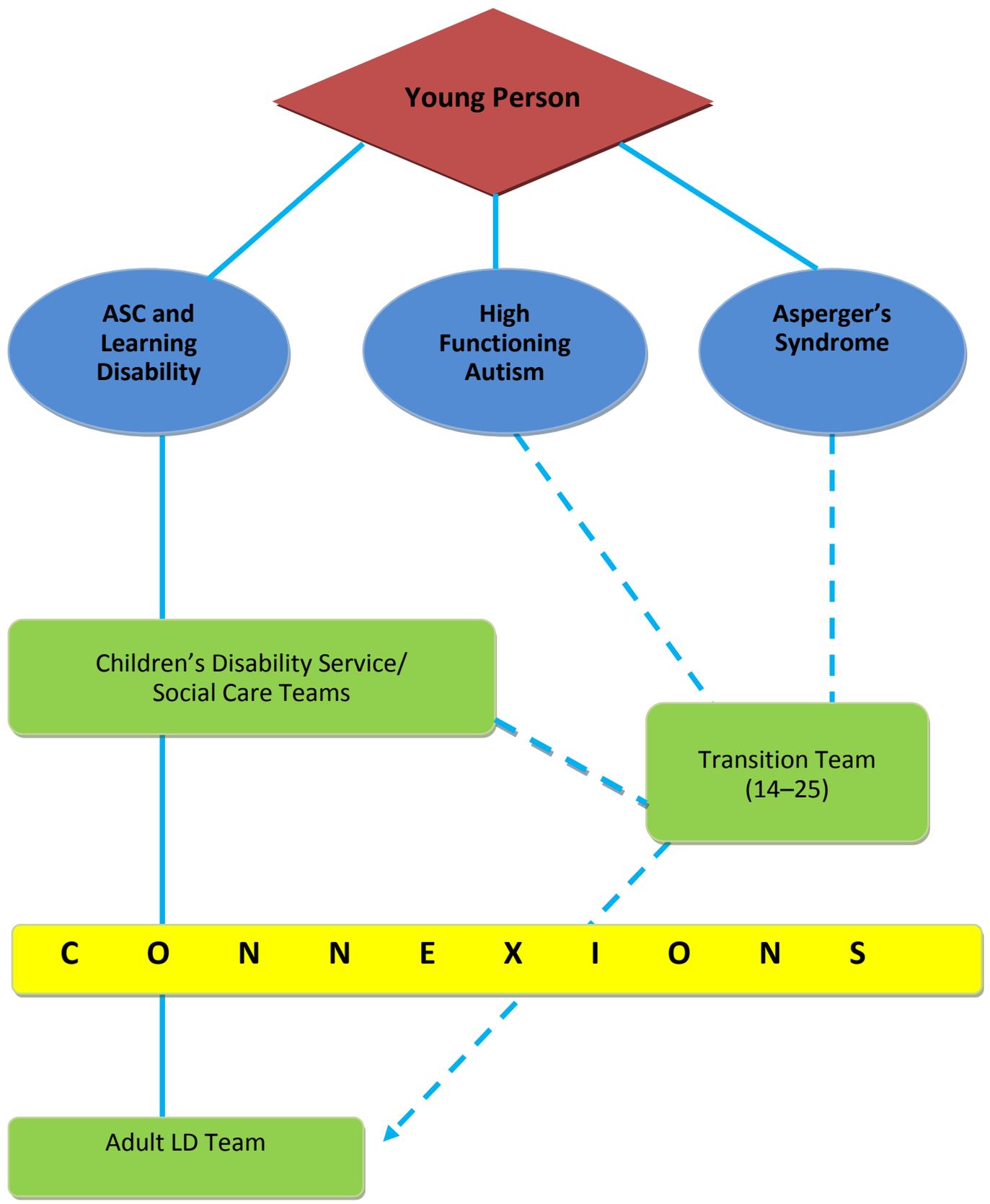
The data on costs and service use
Overview
The transition team was initially set up in children's services in January 2007, and now sits within Adult Services. The referral criteria are that the child must have a Statement of SEN and/or a disability but is not diagnosis or IQ specific. The team could theoretically support young people with HFA/AS as well as those with ASC and learning disabilities. The team aims to pass their cases to adult services at age 18, but if this is not possible then the team will support them until they are 25 years old with a lower-level information and advice service. One of the two transition workers reports that her current caseload is 86, plus some new referrals; 25 of these young people have a diagnosis of ASC, a high proportion of whom attend a SEN unit in the mainstream FE College. She contacts young people at least once a year although some get a much more intensive service. There are a range of other services available to young people with autism. There is a Developmental Disorders Team (adult mental health) which undertakes short-term therapeutic work and a consultation team, led by a clinical psychologist, that provides support in mainstream school.

Costs of transition support
Adult Services fund one third of the transition team's cost, and children's services fund two-thirds. There are two transition workers, a part-time manager and a part-time school nurse. The transition team are supporting about 180 families. At 2010-2011 prices, the total cost of this transition team is £113,800, thus the average cost per 'open case' is £630 per annum.

Family contact with their transition worker
Twenty-four families from Site E responded to the 'pre-transition' Family Survey, eight of whom had a written transition plan. Nine could identify a single person for transition support, and for five families this was a Connexions PA. Three families reported seeing their transition worker in the last three months; one family had just one visit, one saw the worker 'regularly', and the other reported they could see this person whenever they required. Six families reported seeing their transition worker at the annual reviews and one more had some telephone contact. Again, the response rate to the 'post-transition' Family Survey was low at only four families, two of whom had a written transition plan but in neither plan were services specified. Only one parent could identify a single person providing transition support (a Connexions PA) but was satisfied with the support received.

Reflections on families' experiences of the transition pathways and processes
Only one of the parents of a young person with Asperger's syndrome reported having contact with the transition team. The transition service in this site was relatively new and had thus far focused on young people aged 14-18 which may explain why other parents of young people with AS had not had contact with the team. The one family who had had contact with the transition team had received support around discussing future options for the young person, such as access to employment and independent living. The area's autism specific service had also been involved.

The majority of parents referred to having had contact with Connexions whilst their son or daughter was at school or college, but for most this input was limited. Most parents in this site reported that their child had received little help or support when planning for leaving school, and those with older young people reported struggling to find post-college options.

Some voluntary sector organisations were identified by parents as being helpful in providing young people with a meaningful daytime occupation. The autism outreach service was referred to by a small number of parents in relation to seeking further information, transport assistance and 'befriending' for the young person. In most cases (but not all), it appeared that the parent made arrangements for, and sought out, these inputs.

3.4   Summary

Each of the five research sites had a different set of transition pathways for young people with ASC, with and without learning disabilities, transitioning into adult services and/or adulthood. Within each site, there were significant differences between transition pathways for young people with ASC and learning disabilities, and young people with HFA or AS, as illustrated in the flowcharts and reproduced below for ease of reference.

Figure 3.6   Transition pathway (Site A – E)

Site A

Young Person
- ASC and Learning Disability
- High Functioning Autism
- Asperger's Syndrome

ASC and Learning Disability → Children's Social Care → Transition Team (14-19) → CONNEXIONS → Adult LD Service

Site B

Young Person
- ASC and Learning Disability
- High Functioning Autism
- Asperger's Syndrome

ASC and Learning Disability → Children's Social Care → CONNEXIONS → Transition Service (18-25) → Adult LD Service

High Functioning Autism → CONNEXIONS → Community Mental Health Team

Asperger's Syndrome → Asperger's Team if in MH crisis

Site C

Young Person
- ASC and Learning Disability
- High Functioning Autism
- Asperger's Syndrome

ASC and Learning Disability → Children's Social Care → Transition Team (14-18/19) → CONNEXIONS → Adult Services

Adolescent Outreach Team

Site D

Young Person
- ASC and Learning Disability
- High Functioning Autism
- Asperger's Syndrome

Universal Services ►
Targeted Services ►
Disabled Children's Service (0-18)

→ CONNEXIONS → Adult LD Service

Adult Mental Health Service ⋯ Asperger's Team

Site E

Young Person
- ASC and Learning Disability
- High Functioning Autism
- Asperger's Syndrome

Children's Disability Service/Social Care Teams

Transition Service (14-25)

CONNEXIONS → Adult LD Service

55

Clear transition pathways existed across all sites for young people with ASC and learning disabilities who had a statement of special educational need. Previous research has demonstrated that transition pathways are generally most advanced for young people with learning disabilities (Sloper et al., 2010), and this research confirmed that finding, including for young people with learning disabilities who also have an ASC.

Transition pathways for young people with high functioning autism or Asperger's syndrome were markedly different. Only two of the research sites (D and E) theoretically offered transition support to all young people on the spectrum, including those with high functioning autism and Asperger's syndrome. Young people with HFA or AS in the other research sites were typically not eligible for support from the transition team. Further, young people with HFA or AS were typically not eligible for adult services. Two research sites (B and D) had an Asperger's syndrome specific team or service. However, both could only provide relatively short-term support and one (B) only provided support to those with AS in mental health crisis.

Parents' accounts of their son or daughter's transition experiences did not particularly reflect the transition models and pathways described by practitioners. Most of those interviewed were the parents of young people with HFA or AS and few spoke of having received support from, or signposting to, any statutory services that existed (such as the Asperger's team) or autism specific services or organisations.

There was also no uniformity in the location of transition teams. In two sites the transition team was based in children's services (A and C); in one site the transition team was based in adult services (B); in another site the transition team spanned both children's and adult services (E); and one site did not have a physical transition team but rather had two social workers in adult services working with young people transitioning through from children's services (D). Notably, there was least support for young people with HFA and AS in the two sites (A and C) where the transition teams were located in children's services. This is explored further in proceeding chapters and discussed in detail in the concluding chapter.

[In the early part of this report we identified two aims for the costs element of this research. First using data collected during interviews with staff in the five study sites, to identify the costs of providing a transition service for children with autism spectrum conditions (ASC). Second, we abstract case study material from the Family Survey to look at the extent to which young people and their families had contact with transition team members.

Costs data
Our aim to estimate the costs of transition for young people with ASC was only partially met. While most teams could provide some information on the staffing profiles and their expenditure, this was often partial and some cost components (particularly the organisation's overheads) have been estimated based on nationally applicable data. Obtaining expenditure data for services often requires complex and protracted negotiation, and this project was no different. Sometimes the budget is held by someone other than the person being interviewed, and often the information is considered commercially sensitive or requires extra work to make it anonymous. To get data from four of the five teams stands testimony to the researchers' skills and persistence.

Teams found it much more difficult to estimate their overall workload, the numbers of young people with ASC they supported, or the amount of time they spent on transition support for young people with ASC. None of these data deficits should come as a surprise. We were interviewing people with busy front-line posts for whom supporting families should be their first task. Moreover, in teams that serve disabled children, the staff will be more likely to focus on the responding to the needs of individual young people, rather than overtly recognising and counting diagnoses.

Family contact with their transition worker
The limitations of the Family Survey data have been discussed earlier and here we use them to illustrate contact patterns with the transition workers. However, collecting use about service contacts from families is complex. While parental recall on frequency of contact matches well with data to be found in case records or billing databases over short periods it is often the case that parents do not know their support workers by the same professional titles that are used in the services. One concern, therefore, is that families were getting more support for transition than these data imply because either the parent did not identify the worker as a 'transition support worker' or because transition support was provided as part of the usual social work (or other team) role.

To try and assess the extent of this potential error we looked at the levels of contact over the previous three months with other professionals and services. We have reported these figures across the whole sample because for most sites the number of respondents is very small, see Table 3.1.

Table 3.1   Parent-reported contact with services

Service	%(n) receiving Pre-transition (n= 105)	%(n) receiving Post-transition (n=29)
GP	36% (38)	52% (15)
Hospital doctor	16% (17)	17% (5)
Child social worker	14% (15)	3% (1)
Adult social worker	4% (4)	17% (5)
Physiotherapist	5% (5)	0
Speech & language therapist	10% (10)	0
Psychologist	7% (7)	17% (5)
Psychiatrist	9% (9)	7% (2)
Community nurse	3% (3)	3% (1)
Community paediatrician	10% (10)	0
Occupational therapist	7% (7)	14% (4)
Voluntary sector worker	1% (1)	7% (2)
School nurse	13% (13)	0
Connexions worker	28% (29)	14% (4)
Inpatient stay	5% (5)	28% (8)
Short-break service	12% (13)	3% (1)

Table 3.1 shows that generally, rates of contact with these services were fairly low for both the pre- and post-transition samples. The Connexions worker was the most commonly used services pre-transition (28%), and around one in eight families saw a child/adult social worker or school nurse. These are professional groups that were most likely to undertaken transition work. GPs were seen by about a third of the sample. Post-transition, GPs and hospital inpatient stays were the most commonly used services, with other health and social care services seen by only a small proportion of respondents.[6]

---

[6] This is not a longitudinal survey following young people through the transition process so although it appears that there is a reduction in the proportion of young people in receipt of some services between pre- and post-transition, this is not a valid comparison.

Chapter 4
Staff Views on the Practice- and Service-Related Factors which Support Transition Planning for Young People with ASC

4.1 Introduction

This chapter draws together the views and accounts of staff, both managers and practitioners, on the practice- and service-related factors which support transition planning for young people with ASC. We begin with looking at practice and ways of working which are concerned with supporting the involvement of young people and parents in transition planning.

We then move on to reporting the practice- and service-related factors which staff believed affected the effectiveness of transition planning and outcomes. Finally, we report the interface between services involved in supporting young people with ASC and the criminal justice system and, particularly, how transition planning is achieved in these situations.

The source of data for this chapter is qualitative and our aim has been to identify the range of possible factors which support, or impede, transition planning for young people with ASC. Where possible we indicate the extent to which these factors appear to be confined to particular circumstances, settings or level of functioning or, alternatively, have been observed or experienced more generally.

4.2 Supporting the involvement of young people and parents in transition planning

Managers and practitioners in each of the research sites were asked about how they supported the involvement of young people and their parents in planning the transition from school to college, work or other activities. This chapter reports their responses, looking both at approaches and specific practices. Where possible, we draw out issues and experiences which were identified by our practitioner interviewees as being specific to ASC.

We begin by looking at the preliminary work that was often reportedly necessary to get the young people to a place where they could think about transition planning. Practitioners' experiences of using person-centred planning approaches is then described, followed by some descriptions of the specific methods and tools practitioners were using to identify and explore young people's aspirations. We then move on to report practitioners' experiences of involving young people in planning and decision-making processes, and the way the role of parents in that process was managed. A final findings section looks at information provision to young people and their parents. We conclude the chapter with a brief overview of the main issues raised, and highlight any key differences in the involvement of young people and parents across the autistic spectrum in transition planning.

Preparing to think about change and the future

Practitioners across all sites explained that for, many young people with ASC, thinking about life after school, change, and making plans for the future were particularly difficult activities. Interviewees noted that, even though a young person with high-functioning autism or Asperger's syndrome might be able to express themselves and their aspirations, they may still struggle to think about their future and the changes/transitions that this would entail:

> *It (leaving school) is just too random a concept as to even contemplate.[7]*
> (Autism advisory teacher)

> *Because the transition is such a scary thing, a lot of our students would deal with it by just not dealing with it.*
> (Autism advisory teacher)

Preliminary work was therefore often required to get a young person to a point where they felt able to think about their futures and participate in planning for what they would do after leaving school. Practitioners reported using DVDs and social stories to support preparing young people with ASC to begin to think about, and become involved in, planning for their future. Visits to local colleges were also used to introduce the idea of thinking about leaving school and post-school choices. However, constraints around time, capacity and resources meant that such a pre-planning stage was not always feasible for transition workers, social workers or transition nurses, etc. Staff in schools were perceived to be better positioned to undertake such preparatory work.

Planning for leaving school could also mean the introduction of new people into the young person's life. Practitioners who were not known to the young person prior to transition planning spoke of the need to get to know the young person and to work with them at their own pace. They reported that, ideally, they would take this process gradually, spending just a few minutes at a time with the young person to begin with and working up to longer periods:

> *We talk to young people when they're ready. And it might be that we just engage with them and go and have a cup of tea, walk down the seafront, go [somewhere] with them for the first month before they'll actually tell us what they want. We're totally led by them.*
> (Manager, Autism specific outreach service for adults)

However, again, this approach clearly had resource implications for practitioners and services and thus could not always be adopted.

Finally, practitioners stressed that, at the same time as starting to think about post-school destinations and activities, an equally important element of preparing for transition was ensuring the young person was acquiring the appropriate independence/life skills. Indeed, focusing on these skills was deemed critical in helping the young person ultimately achieve their longer term goals:

---

[7] Verbatim quotes are used throughout the report to illustrate a point made in the text.

It might actually be that going to the shop and buying a sandwich for the first time is what they need to be worrying about, not filling in their UCAS [University application] form yet.

(Education professional, mainstream college)

Experiences of using person-centred planning approaches

Person-centred planning (PCP) training had taken place, or was in the process of being delivered, in all sites. In most sites PCP was reportedly in use in the special schools and beginning to be rolled out into mainstream schools, although PCP had a particularly low profile in one site. Even where PCP *per se* was not being used, practices or approaches drawn from PCP were being utilised. One site had a PCP coordinator and PCP facilitators to lead the transition planning and review meetings, whilst in other sites this role was assumed by transition workers, non-transition specific social workers in children's services, Connexions Personal Advisors, or educational staff.

Person-centred approaches were seen to support transition planning and positive transition outcomes because they:

- focused on the young person's strengths and aspirations;
- supported the young person to exercise optimal choice and control in decision-making and planning;
- provided ways by which young people could share their likes, dislikes and hopes for the future;
- enabled those who know the young person best – including parents, siblings, friends, and practitioners – to share their knowledge and understanding of the young person and their wants, needs and desires, and thus contribute to the planning process;
- supported a holistic approach which demanded multi-agency planning and working.

Interviewees also believed that person-centred approaches tended to lead to more consensus and could reduce conflicts between parents and young people as all parties witnessed, and had to acknowledge, what the young person wanted. One interviewee was hopeful that in future data from the plans would be collated and used to inform commissioning.

At the same time, a few disadvantages to using person-centred approaches with some young people with ASC were identified by interviewees. These included:

- Young people (and/or their families) not understanding the reality of the context (in terms of their abilities and/or resource constraints) in which they were planning and making decisions. This could lead to unfeasible or unrealistic aspirations being expressed or, even, encouraged.
- The young person being 'overloaded' with information and the involvement of multiple practitioners.

Finding out about young people's aspirations

The wide range of abilities within autistic spectrum conditions naturally impacts on the extent to which young people are directly involved in transition planning and decision-

making. It will range from a young person assuming responsibility (with support from school, transition worker - if eligible - and family) for deciding and planning for their post-school destination, through to a practitioner using multiple informants and observation alongside direct work with the young person to ascertain the 'best' post-school destination for a young person. In the latter situations, practitioners described seeking the views and opinions of, potentially, a wide range of sources: parents, siblings, and other family members; CAMHS staff, children's social workers, transition workers, Connexions PAs, teachers, speech and language therapists, and service providers.

Encouraging young people to develop or identify their aspirations was seen as an important part of transition planning. As noted above, supporting young people to hold realistic aspirations could be a core activity of transition planning, and seemed to be something especially relevant for those with ASC. Equally, practitioners highlighted that some young people with ASC lacked confidence in their abilities and therefore needed encouraging to aspire to goals which truly fulfilled their potential.

Where the young person was able to directly participate in expressing their aspirations, practitioners used a range of tools or methods according to the capabilities and communication skills of the young person. Young people with ASC and learning disabilities were encouraged to share their aspirations through social stories, creating displays/scrap books of pictures depicting what they would like to do after they left school. Practitioners reported that some young people with HFA or AS were more forthcoming if they shared their thoughts and ideas through written notes, text messaging or emails. Some practitioners found simple film-making activities to be useful; for example, the young person filming themselves talking about, or filming examples of, things that they would like to do in the future.

Supporting young people's involvement in transition planning
There was ample evidence that practitioners worked hard to support, as much as was possible and realistic, the direct involvement of young people in transition planning.

The majority of practitioners also stated that they prioritised the aspirations of the young person in so far as these were achievable and realistic.

Concerns were, however, raised about the risk of parents'/carers' views and opinions being prioritised over the young person's best interests, especially where the young person had limited cognitive and communication abilities. Some practitioners spoke of a small minority of cases where they had concerns about parents' own needs driving decision-making about post-school options. Typically, this was centred on financial issues and the fear of losing carers' benefits for themselves and/or disability benefits for their son or daughter:

> *We have families of people with a learning disability or a disability that receive a disability allowance based on the fact that they're carers for that individual. You suddenly put that person's foot into the workplace and you're destabilising the household's guaranteed income stream.*
>
> (Manager, Supported employment service)

Managers and practitioners acknowledged the difficulty for parents to take a 'back seat' in transition planning and decision-making as they had often spent many years advocating on behalf of the young person and making decisions in what they perceived to be the best interests of their son or daughter:

> *… it's hard for parents to realise that their young people have an opportunity to make some choices; they feel protective.*
> (Transition service manager)

> *… often we have to ask parents to leave the room so we can speak to the young person alone. Sometimes it's very hard for the parents to keep quiet, but the parent is so used to talking for the young person, they don't realise that they're doing it really.*
> (Connexions worker)

Connexions PAs, in particular, spoke strongly of the need to act as an advocate for the young person in situations where parents were reluctant to relinquish control. Sometimes other professionals involved with the young person, or PCP facilitators, were used to bring a more 'objective' perspective or to 'promote' the young person's right to their views being heard and responded to:

> *PCP facilitators assist in negotiations. They're very useful when you have parents who are very rigid about what they want for their son or daughter. We're [adult services] coming from a different approach, and sometimes it's nice to have a third party come in who's a bit more, who is perceived to be a bit more impartial or objective, and they're working with that younger person. You know, they'll work with that younger person then and, and hopefully arrive at a view about what they would like, what's working and what's not working in their life and their hopes and aspirations, which hasn't been sort of tainted by us or perceived by the parents to have been tainted or influenced by us or isn't, or hopefully hasn't been too influenced by the parents.*
> (Manager, adult learning disability team)

At the same time, the practitioners we interviewed acknowledged that parents' concerns about 'letting go' could be driven by the perceived lack of support and services available to meet their young person's needs, help them achieve their aspirations, and replace the support they, as parents, currently supplied. Interviewees felt that this was a particular issue for parents of young people with high-functioning autism or Asperger's syndrome who were unlikely to be eligible for support from statutory services.

Managing difference of opinion
In situations where the aspirations of the young person differed from those of their parents, practitioners spoke of the need for discussion and negotiation to reach consensus. If the aspirations of either party were felt to be unrealistic then practitioners spoke of educating them as to why those aspirations were unrealistic and introducing alternatives. One transition worker reported that family therapy sessions were sometimes set up to help parents and young people explore their fears and their differing aspirations in attempts to reach a consensus. Similarly, an autism advisory teacher spoke of helping parents to let their child attempt new things for the sake of family cohesion 'because otherwise it's going to be your word against his and he's just going to think you're trying to ruin his life forever'.

The use of independent advocates

Practitioners reported that independent advocates were rarely involved in transition planning. One practitioner noted that the effectiveness of independent advocates could be hampered by their lack of understanding of autism and the expertise required to work with young people with ASC. A transition worker in one site stated that young people were being required to take part in an event that aimed to increase participation and inclusion for young people with special needs. As part of that initiative the transition team were seeking to train young people in self-advocacy and teach them to train other young people. This was reported to have been particularly successful for those with ASC.

Provision of information

Information about transition planning processes and post-school options was provided by transition teams and/or other agencies with some involvement in transition. The information about transition planning processes provided by transition teams and other practitioners was aimed at all young people eligible for their transition service and was thus not specific to young people with ASC. It was provided in one or more of the following ways:

- Written information: paper or web-based.
- Audio-visual information.
- Meetings and events.
- Experiential information.

These sorts of media were also used to provide families with information about post-school options. Here, however, experiential information was an additional and essential element.

Written information

Written information for young people about transition planning processes was available in all sites. One site also had a transition pack specifically written for parents. Only one site had also placed this information on their website. However, autism-specific statutory and non-statutory organisations were using the internet to share information about the services and support that they offered to young people with ASC in general and during transition. In one site (C) the local authority had set up a web-based directory of services and activities for young people aged 0-25 with any disability or long-term health condition, including those with ASC and learning disabilities, and those with HFA or AS.

Audio-visual information

Transition teams in three sites had produced a Transition DVD which sought to explain the process of transition for all young people eligible for the transition service. The DVDs highlighted the options open to young people. In some sites the DVD was partly made by and/or included young people with disabilities, including those on the autistic spectrum. One of the DVDs was intended to be a source of information for young people, their families, and practitioners; in the other two sites the DVD was targeted at young people and their families. The transition DVD in one site featured young people interviewing practitioners from different agencies – including transport, colleges, Connexions, paediatrics, adult services, and service providers – and asking what they would be entitled to and who they should contact for more information. The DVD also featured interviews

with young adults who spoke about their experiences. A copy of the DVD was provided for all year 9 students (those aged 14) who had a disability, including ASC, whether they were open to the transition service or not. The DVD, produced using monies from Aiming High, also included a section looking at health service transitions, including asking who to approach in adult health services. It was hoped that the DVD could be played in the waiting areas of GP practices.

Meetings and events
In most of the sites, statutory and/or voluntary sector services held meetings or events which served to provide parents of disabled young people with information about planning for leaving school, adult services and future options. In one site the transition team held a 'transitions' event at the local college. This included the launch of the transition DVD; a 'marketplace' where young people and their parents could meet a range of practitioners from adult services, children's services and voluntary organisations and ask questions about the services and options available, plus their eligibility for accessing such services.

Experiential information
Experiential information, achieved through visits, taster days, and short-term placements, was seen by practitioners as key to supporting the young person and/or their family to make informed decisions about post-school life. It was clear that all the sites worked hard to provide this sort of information. One interviewee gave an example of a young person who had been able to spend time at a college and speak to their potential college tutor prior to enrolling at the college. This gave the young person some confidence in the new environment and a feeling that they had started to build a rapport with the tutor.

In another example, a young person had had the opportunity to spend time visiting a supported accommodation residence, prior to making the decision to leave home and live there (semi-) independently:

> *If they're unsure they can go and visit places, go to meet people, so that they get a visual perspective on things and people can show them the type of work that they do. So they do make reasonably informed choices. But if there's any doubt we'll say 'well we will transition you, go and have tea there, go and spend the night there, and if everybody's comfortable then move in.'*
> (Adult mental health practitioner)

However, again resource issues meant that practitioners did not always have the capacity to accompany young people on such visits.

4.3   Practice- and Service-Centred Factors which Support Transition Planning

Managers' and practitioners in the research sites gave their views about what practice- and service-centred factors facilitated effective transition planning. Those factors can be grouped into five themes, see Figure 4.1.

Figure 4.1   Practitioners' and managers views' on the practice- and service-centred factors which support transition planning

- Features of the transition team
    - A designated transition team/transition workers
    - Consistency of the transition worker
    - Knowledge and understanding of ASC
    - Knowledge of available options, services and support
    - Location of the transition team in adult services
    - A well-resourced team
- Good relationships between families and professionals
- Providing opportunities for young people to access experiential information
- Joint working
    - Co-location of practitioners from different agencies
    - Good communication and information sharing
- Strategic work

Features of the transition team
A designated transition team/transition workers
The simple fact of having a transition team where designated transition workers could provide young people and their families with relevant support, information, signposting and advice was viewed as supporting transition planning and positive transition outcomes. Generic children's social workers who worked on transition alongside their other social work were not perceived to have the same capacity for detailed transition planning or the same level of expertise on transition related issues as those who worked solely on transition.

Consistency of the transition worker
A number of interviewees noted that young people with ASC typically struggle with building and maintaining social relationships. Thus, having a consistent transition worker throughout the transition period was regarded as particularly useful for this group. However, this was difficult to achieve in sites where there was a high turnover of staff.   Regular contact with the same transition worker was felt to bolster the rapport between the young person and transition worker:

> *… they [the young person and their transition worker] are in touch regularly. For the majority of young people, when they see people from the transitions team, they're really pleased to see them. They value their input in their lives.*

(Education practitioner)

Consistency of staff also supported joint working. In a site with particularly high levels of staff turnover, a manager from an autism-specific non-statutory organisation reported having only 'very poor' links with the transition team and had chosen not to work with the transition team 'due to experience of lack of consistency due to high staff turnover'.

Knowledge and understanding of ASC

Practitioners believed that transition services worked best where the transition workers had a good knowledge and understanding of autistic spectrum conditions and the issues and challenges faced by young people with ASC. This awareness helped transition workers to work at a pace more suited the individual young person and potentially avoid some of the young person's triggers.

Knowledge of available options, services and support

A good knowledge and understanding of the services, support and options available to young people on the spectrum, including those with HFA and AS, within adult services and settings was also identified as an important factor to aiding transition planning and transition outcomes. Since young people with HFA and AS were unlikely to be eligible for adult services, the ability of the transition team to be effective 'signposters' to mainstream services or to autism specific non-statutory services was necessary to ensure these young people and their families could access all available support.

Location of the transition team

In the two sites where the statutory transition support was located in children's services, there was some concern that this was not conducive to getting the best outcomes for young people in transition. Some questions whether the service would be more effective if located in adult services owing to the need to have a good working knowledge and understanding of the systems and processes in adult services in order to put together a transition plan and thus a support package that both met the young person's needs and could realistically be funded:

> *… it's a bit like having grammar schools running the UCAS system rather than universities, you know, or universities running the system rather than employers that they feed into. Any other transitions process I've ever seen, it's the receiving bit that actually says, this is what we want from the front bit rather than, than us trying to launch people into a world and say to the world, this is what we want you to be like.*
> (Manager, Children's services)

In addition, a number of practitioners drew attention to the multiple transfers young people with ASC may undergo during the transition period, for example from school into further education, further education into possible higher education or employment, from CAMHS to adult mental health; moves from the family home and so on. The nature of their condition makes these transfers and changes all the more challenging and increases the risk of poor outcomes. It was the view of some interviewees that transition teams based in children's services which ceased working with a young person once they turned 18 or 19 were only able support young people through some of these transfers and changes. Thus transition services based in adult services, or that spanned children's and adult services and supported

young people up to the age of 25 years, were felt to be better placed to plan, support, and provide continuity, across the entire transition period:

> *… you can get all the pre- stuff brilliant, but if the Adult stuff is not tied up to it then you've got a problem.*
> (Manager, Connexions service)

Well-resourced teams
Transition workers and Connexions workers in some sites complained that they did not have enough capacity to visit the families they were working with, spend enough time giving them information and working on transition planning, and did not have the time to thoroughly review cases and pick up on issues that had been raised during the transition process. These practitioners believed that more comprehensive transition planning and reviewing would only be possible with greater resourcing.

Some interviewees reported that a lack of resources (staffing, funding) had had a significant impact upon how well supported young people were at transition. For example, in sites where practitioners were over-stretched or had left their post and not been replaced, particular aspects of transition support were no longer provided (for example, supporting young people on enrolment visits to college, meeting with college tutors to explain about a young person's needs, assessing colleges for their health facilities/support).

Good relationships between families and professionals
Some practitioners reported good relationships between practitioners from various agencies and young people with ASC and their families. They believed that a good rapport that led to the development of trust and mutual understanding typically made for a smoother transition experience for all.

Providing opportunities for young people to access experiential information
The opportunity for young people to experience potential post-school options and adult services was seen as very important. Some transition workers also noted the importance of them being able to accompany the young people being accompanied on such visits.

Joint working

All the sites gave examples of joint working by practitioners which, interviewees believed, promoted effective transition planning. They included co-working between children's social workers or transition workers and adult social workers during the period prior to handover; joint visits, assessments and/or reviews between transition workers and Connexions workers; and joint visits and assessments by transition workers and educational psychologists. A Connexions manager reported that "links between Connexions and the transition team have increased the knowledge of both groups". In one site, joint meetings had been set up between practitioners from the transition team, Connexions and adult social care so that they may learn more about one another's roles and responsibilities, develop stronger working relationships, understand and share language and terminology, and work out how best they could work together and complement one another's skills and activities.

Where concerns were voiced in terms of an absence of, or commitment to, joint working, this was most likely to relate to the involvement and commitment of adult health services.

Co-location of practitioners from different agencies

The co-location of practitioners from different agencies was also seen to support multi-agency working. In one site the transition team was co-located with colleagues from education and SEN; in another the transition team was co-located with the community team for learning disabilities in adult services which was particularly useful when planning transition for those with ASC and learning disabilities. The existence of a 'virtual transition team' in one site which included a transition nurse, Connexions PA and trainee educational psychologist, in addition to the transition social workers, was regarded as beneficial for multi-agency working, but only when all posts were filled.

Good communication and information sharing

Interviewees in all the research sites provided numerous examples of situations where during the transition planning process, practitioners from different agencies had contacted each other for information or advice about a particular young person, service or for general information about what services and support were available. Indeed, good working relationships and communication and information sharing between the transition team and practitioners from other agencies were felt to be very important.

There were marked differences in attitudes toward information sharing across the sample of managers and practitioners we interviewed. This appeared to be dependent upon personality rather than research site, role or agency. Thus, whilst some reported openly sharing full information with colleagues from other involved services "because that is in the best interests of the young person", others were far more cautious. The transition service manager in one site commented that communication, networking and information sharing between agencies had improved significantly as a by-product of the transition steering group and transition sub-groups as managers and practitioners had a better understanding of the roles of staff in different agencies and knew who to contact for particular pieces of information. Information sharing was also reported to be easier where teams or agencies were co-located.

A common criticism across the research sites was the lack of compatibility between databases/computer systems which meant that data sharing was neither efficient nor cost-effective and was thus not always achieved. There was felt to be duplication of work, time and effort where different agencies were each populating their own databases, rather than all practitioners involved with a case using a single database. However, in one site, practitioners reported that Connexions had begun to share a common database with the transition workers (in children's social care) since Connexions had come back under the control of the local authority.

Incompatible databases were perceived to be particularly problematic where different systems were used in children's services and adult services. Interviewees were able to give examples of how this had led to gaps in care or inadequacies in support being provided to a young person.

Strategic work

Practitioners reported that the transition pathways and protocols that had been established by the transition steering groups had smoothed the transition process by creating clear direction around where referrals should be made; specifying which agencies could offer services to which groups of young people; and through the setting up of ASC specific transition sub-groups in some sites which had been established to discuss and propose solutions to particularly complex cases. Gaps in services were reportedly easier to identify in those sites where transition pathways had been mapped out, and managers reported working toward planning to meet the needs of future cohorts of young people coming through transition.

4.4   Youth Justice

Practitioners reported that young people on the autistic spectrum were at increased risk of entering the criminal justice system. The perceived roots of this increased vulnerability included:

- A lack of social maturity and life experience and an inability to 'read' social cues leading to making poor judgements about 'friendships';

- Mental health difficulties leading to aggressive or inappropriate behaviours

Practitioners also noted that, once in criminal justice system, problems could further develop if police and youth offending service staff did not know how to work with young people with ASC:

> *They become embedded into the criminal justice system simply because staff don't manage their needs particularly well or don't recognise their needs or do not have the skills to deal with them, and so it kind of like provokes a set of behaviours that leads to more trouble.*
>
> (Manager, service for young people with disabilities)

For these reasons, our interviews with practitioners explored how transition services worked with services within the criminal justice system.

Supporting youth offending teams to support those with ASC

Practitioners from a range of agencies/services including adult psychiatrists, Asperger's teams, adult mental health teams, and autism charities reported that staff from Youth Offending Teams (YOTs) had telephoned them to seek information and advice about young people who were thought to be on the spectrum. Specialist ASC teams had offered training on ASC and Asperger's syndrome to YOTs, the police, probation officers and other sections of the criminal justice system:

> *The people involved, including the police, might not be aware of the sensory issues for these people, their different style of communication, so locally we have offered training for the police force to help them understand those conditions…. to make them aware of how they present differently in these situations, for instance by not making eye contact*

with them doesn't mean they don't show them respect and things like that, which the police could all relate to.

(Manager, Asperger's team)

The Connexions service reported working with youth offending teams and young offenders with ASC in each of the research sites. Connexions PAs offered support to those in the youth justice system particularly those not in education, employment or training (NEET) looking at careers guidance, and advice and information around training, education and employment. A Connexions service manager in one site reported that the local authority employed a team of 'intensive PAs' who worked alongside Connexions PAs, as and where necessary, to work more intensively with vulnerable groups, including those known to youth offending teams. The intensive PAs had a Connexions qualification but their skills were to work intensively with young people with challenging behaviours. A Connexions manager in another site reported that a Connexions PA had been deployed into the youth offending service, and would seek advice from a specialist learning disability/special needs PA around autism. In another site Connexions PAs reported working closely with the youth offending service, supplying background evidence about a young person where relevant, and working with early intervention workers within the YOS. Transition service managers in two sites reported that transition workers sometimes produced a transition plan in conjunction with the young person's probation officer.

4.5   Summary

Practitioners reported a general reluctance, an anxiety, amongst young people with ASC to think about and thus plan for their future. This could make transition planning difficult. Where resources allowed, preparatory groundwork was needed to introduce the concept of change to young people with ASC to get them ready to think about leaving school, post-school options and what they wanted in their futures.

As the autistic spectrum covers a diverse group of people with an array of abilities, capabilities, and needs, transition workers and other practitioners reported using a range of tools and communication aids to help them understand and explore a young person's desires for the future and thus be able to transition plan. Tools reportedly used by practitioners included art-based activities for those with ASC and learning disabilities or those who are non-verbal, and more technological ways of communicating including email, text messaging and making short films by those with high functioning autism or Asperger's syndrome.

Practitioners identified some ASC specific issues around these young people participating in transition planning. For example, young people with ASC particularly benefitted from having the opportunity to experience situations and/or get to know new practitioners prior to a change of environment. However, resource implications meant this was not always possible. Person-centred approaches to transition planning were generally felt to be useful in helping to piece together the young person's aspirations and also in conflict resolution where the aspirations of young people and their parents differed. However, there were

some concerns that a person-centred approach may be particularly daunting for young people on the autistic spectrum owing to the greater number of practitioners typically present at person-centred meetings, and the range of options and choices that may be discussed.

Concerns were also expressed about some young people with ASC having unrealistic aspirations and expectations about their futures which needed to be delicately managed. Practitioners reported that some young people with ASC lacked in confidence and had overly low aspirations; this group needed encouragement to aspire to goals which could fulfil their potential. In contrast, other young people with ASC lacked some understanding of the constraints on their abilities and on resources and had unrealistically high aspirations which needed to be revised into something more feasible.

Practitioners sometimes expressed concerns about the extent to which some parents expected to be involved in transition planning. However, this did not emerge as an insurmountable issue and practitioners acknowledged parents' own anxieties, particularly about the lack of appropriate services and support in adult services, were often at the root of their desire to be closely involved. On occasion, however, some practitioners had encountered situations where parents were prioritising their needs over those of their son or daughter.

A number of practice- or service-centred factors were identified which, practitioners believed, supported transition planning. These included: features of the transition team (for example, ASC-specific skills and knowledge); providing opportunities for experiential information; joint-working (including co-location of practitioners from different agencies, and effective information sharing systems) and strategic work.

Chapter 5
The Transfer from School to College: The Accounts of Young People with HFA and Asperger's Syndrome

5.1   Introduction

This chapter reports young people's experiences of the transfer from school to college. We draw mainly on findings from the qualitative interviews with 18 young people with HFA and Asperger's syndrome, particularly focussing on their accounts of planning, and preparing, for leaving school, and the social impact of the transfer from school to college. It should be noted that our interviews with young people did not seek to gain a chronological account of the transition. Rather we focused on identifying processes and practice which perceived to be helpful during this period.

The findings from the qualitative data is presented in three sections:

- positive and valued support from practitioners

- parental involvement in the transfer from school to college

- the social consequences of the transfer.

As is the purpose of qualitative research, we report the range of views and experiences of young people with HFA and Asperger's syndrome we interviewed: both those which were frequently reported and those which were unique or unusual. Where experiences or views are common or consistent across the sample, or an identifiable sub-sample (for example, according to level of functioning, type of school), we report this. Equally, differences in opinion are reported (for example, practice perceived by some as helpful and others as unhelpful).

Following the section on practitioner support, we report some of the findings from the survey of young people with ASC which preceded the qualitative interviews, specifically the experiences of transition support for those young people currently undergoing planning around leaving school.

Comparing experiences across local authorities
In this chapter we do not compare the young people's experiences with regard to the different authorities from which they were recruited. This is for two reasons. First, the sample of young people recruited to interview was not evenly dispersed amongst the authorities represented in this study (see Chapter 2). Second, differences in the experiences of young people living in the same authority were frequently observed. Analysis of the interviews suggests that, for the young people who participated in the research, personal experiences, individual circumstances and the individual practitioners involved with the young person seemed to have a greater impact on young people's experiences of planning for leaving school, rather than wider authority policies or practices.

5.2   Positive and valued support from practitioners

Initiating the process
Thinking about leaving school or college was recognised as not always an easy thing to do, hence, practitioners taking an active role in leading initial discussions was welcomed. This was recognised most clearly by Bob, as he explained that he had not wanted to think about future college options whilst undertaking GCSE coursework. However, having an appointment made for him by his school to talk to the Connexions adviser, although not easy or wanted at the time had, he came to realise, been important and useful. In particular, it had helped him to focus on the future and prepare application forms on time.

Information provision
When the young people discussed information and how it had helped them to prepare for their transfer from school and/or college, some general themes were apparent. Namely, they wanted information to be clear and easy to understand: this applied to both written and verbal information:

> *He's easy to talk to and he's quite, when he speaks he speaks quite clear and he's, he's quite a slow talker but he's very calm. He listens to you …. .[8]*
> (Sam)

In contrast to Sam, Emily found the Connexions adviser she had met unhelpful because he had spoken too fast and used words she did not understand. This left Emily feeling uninformed and reticent to approach Connexions again:

> *Most of the stuff she [Connexions] said to me I couldn't understand, cos she was talking too fast for me.*
> (Emily)

The data also revealed that young people valued practitioners who gave them information in an honest and comprehensive manner, partial information was not welcomed. For example, three young people described how they felt being given limited information (in particular, not being informed of all possible college options) was both unhelpful and confusing.

Opportunities to access experiential information
During their interviews, the young people dwelt more on the verbal and experiential information they had received compared to written information.

Most of the young people (11) currently at college or planning to go to college in the near future reported having had an opportunity to visit potential college(s) or attend a 'taster day(s)' before they made their post school transfers. These were generally regarded as a positive experience and with a number of benefits. One of the most important was the opportunity to have 'real' experiences of college and being able to try out and/or talk to staff on courses they were considering. For four of the young people, having college visits

---

[8] Verbatim quotes are used to illustrate points made in the text.

helped them make what they felt were more appropriate college or course decisions. College visits enabled these young people to assess what was best for them and what they felt more comfortable with. For example, Steven came to realise that gardening was not what he wanted to do; he was more interested in the IT course at the college he visited:

> *YP: They [college] did invite us to do a taster course which was on gardening and it was nice and I enjoyed this but gardening isn't really my thing …*
>
> *Int: So you preferred to do the science*
>
> *YP: The science thing … I'm not really into physical labour*
>
> *Int: So that helped you decide having the taster day?*
>
> *YP: Yeah.*
>
> (Steven)

Katy soon recognised that [name of] College did not feel right for her at that point in time:

> *… I'd gone to [name of] College and I'd found it too crowded, too frightening at that point, I was too young for it.*
>
> (Katy)

Expert knowledge of college tutors was also recognised and regarded as helpful in the process of decision-making. For instance, Sam described how talking to tutors on the car mechanics course he was considering had helped answer questions and alleviate some of his concerns.

In addition, the opportunity to visit more than one college was also valued, as it enabled college or course comparisons. Here, the value of having timely visits was also apparent. For example, as Sophie explained, a college visit for her (which had been negative) had been organised early enough to ensure that there was still time for an alternative college visit to be arranged.

Extended or multiple visits to the same college were also typically valued by those who had had such an experience. For example, Adam believed this had really given him a chance to get to know the college and experience what college life would like. However, it was also apparent that, for most of the young people, extended college visits were not routinely offered or available as they talked predominately about 'day trips'.

Although only discussed by two young people, both Adam and Greg valued the opportunity college visits provided to meet fellow students. They found this had eased some of the anxieties they had about leaving school and moving somewhere new. This was particularly important to Greg when considering residential college:

> *Int: You had a look for three days, so you stayed down there?*
>
> *YP: I stayed down there for three days and the first day wasn't great but then I …*
>
> *Int: Why wasn't it great?*

YP: Cos I was homesick and I just didn't like it and then after the two, the other two days I got used, I got used to it, made some friends and wanted to stay there, didn't want to come out.

(Greg)

Knowledge and understanding of the young person and of ASC

The young people interviewed had mixed experiences of the working with practitioners who become involved in their lives only during transition planning. Two, inter-related, issues particularly emerged. First, these practitioners might not have any expertise in ASC, and particularly HFA and Asperger's syndrome. Second, they will not know the young person and individualised way that ASC effects or impacts on them.

Many young people implicitly reported wanting practitioners who they knew (and who knew them) actively involved in supporting them as they made plans for leaving school. For example, Ben, Karl and Steven said they had all welcomed the chance to talk to their learning support workers about future college plans and aspirations were welcomed. Both Ben and Karl contrasted the knowledge and understanding of their school's learning support staff to that of practitioners beyond school, such as Connexions advisers:

YP: She [Connexions] pretty much was calling me stupid, yeah

Int: So you didn't find that very helpful?

YP: Not at all. Basically, all my interactions with Connexions have been bad in some way or another, either bad like that or bad through they're just not very helpful at all.

(Ben)

Some young people stressed the distinction between knowledge of ASC and understanding what it is like to live with ASC. For example, Karl described feeling frustrated when practitioners said that they understood his ASC. Karl felt they did not and could not really understand due to their lack of 'real' experience of ASC. For Karl, what helped was when practitioners did not try to empathise but rather acknowledged their limited understanding and subsequently took an open mind and were willing to listen to him and learn about his ASC and his individual needs:

When it comes to the Asperger's part, no one knows anything about it until you've got it. And for people to sit there at colleges and stuff, to sit there and say, 'I understand what you're going through', yeah, you just want to turn round and smack them in the face, cos you know, they don't know. … With Dawn it was good because she would sit there and say, 'Yeah, I understand the situation, you know, to a point where you're coming from with your Asperger's but I can't understand it fully.

(Karl)

This contrasts with Sophie's experiences. She was extremely positive about the help and support she had received from her Connexions adviser when preparing to leave school and transfer to college. Sophie reported how she had found her adviser easy to talk to and understanding of her ASC needs and concerns. For Sophie, what had been particularly helpful was the opportunity to talk about both the educational and social aspects of her

transfer to college. Sophie believed this practitioner's ability to empathise and understand was down to the fact that this practitioner's own child had ASC:

> *The personal advisor … she was very understanding 'cos she had the experience. She has a son with ASD … yeah, so she understands which make a big difference to people like me.*
> (Sophie)

Support with applications

The young people said they valued practitioners' input in preparing CVs or completing college application forms; for example: providing advice on what information to include on CVs or application forms; how to present this information; or just 'giving them ideas'. Many recognised that they lacked knowledge in this area and so looked to practitioners such as, Connexions advisers or teachers to provide it:

> *She helped me with my CV …because I, I wouldn't be able to do it on my own, cos I wouldn't know what to put or I would do it wrong and the outline of it as well.*
> (Andrew)

> *They [Connexions] helped fill in the college application forms. They helped me with the interview, they just generally helped me.*
> (Ian)

> *She [Connexions] helped me do, fill out the application forms and things and understand the questions.*
> (Sophie)

> *He's a Connexions careers advisor, someone called Mike and he helps me with what I want to do and what careers to take in the future. He's, he's pretty good … he's just been, I've told him me interests and what I like to do and what ideas I have and he's been suggesting different courses and careers what I might enjoy.*
> (Sam)

A small number (two) of the young people also reported receiving advice about preparing for interviews and practising what to say during an interview. Both had found this very valuable.

Easing the early days at college
Support from college staff

As the young people discussed their initial transfers to college, it was apparent that knowing in advance that support (with learning and/or the non-academic/social aspects of college life) was in place for them was helpful and reassuring:

> *Um… when I first started the staff actually helped to get me in the groove and then after I got in the groove then they left me alone and then after that I just got, got going and*

then that's when I got my friends.
  (Greg)

Interestingly, amongst those young people who received learning support at college, none actually recalled meeting their learning support assistant before they transferred to college. However, they did not view this as an issue having caused them undue concern or stress.

A couple of the young people recalled positive practice in the way that the reduction/ withdrawal of support (both learning and social) was planned. For both the gradual withdrawal of support was accepted and viewed as not unduly stressful because college staff had involved them in support withdrawal discussions and paced withdrawal at an appropriate individual level:

> *YP: Later on in the weeks of my first year they [college learning support] came to an agreement that they'd pull away some support in some of the sessions, so just to kind of help me to be a bit more independent.*
> *Int: Was that OK with you?*
> *YP: Yeah, it was fine, it was perfectly fine … it was mostly a staff discussion, my parents weren't involved in that, in the agreement to the withdrawal of support in some sessions but it was mostly my choice …*
> (Bob)

Travel training
Transport and getting to college can also be an important part of school to college transfers. However, only one young person reported having received an identifiable programme of transport preparation and training prior to college transfer. During the summer holidays, Stuart explained that he had received home to college travel training through a bus buddy scheme (which he thought had been organised by his school). By the end of the summer holidays he reported ready to travel from home to college:

> *YP: There's this woman…. she was our Bus Buddy I knew from school and what she did is she teaches where the buses go, how you get on them, when to stop and she taught me over last summer. … and yes, it's proved quite good. … and Donna had to give me the money and she would go with me on the bus, this was at the beginning but as I got more independent she'd give, she'd part out there and she'd wait, she'd sit in her car, follow me on the bus into town. I'd stay on the bus and then I'd come home.*
> *Int: And how did that make you feel?*
> *YP: Um confident … I do it all myself now.*
> (Stuart)

The importance of reliability
A number of young people highlighted the importance of practitioners 'doing what they said they would do' during the process of planning and preparing for leaving school and moving to college.

This was demonstrated most clearly by negative experiences of four of the young people. All four reported that practitioners had promised to provide information, arrange meetings

for them or establish college links but ultimately felt that these had not been delivered, nor had they provided an explanation why they had not been delivered. This had left them feeling frustrated, uninformed and to varying degrees, expressing real anger.

Matthew in particular was very clear that he had been 'promised' more support in preparing to move to college from school than he actually received:

> *…. cos basically they promised a whole lot of interesting things and never did them. … From what I understand, it's basically they make a whole lot of promises but never follow but never followed up on them .. I mean I made it through [school transfer] but you've, you've heard all that gaps I was saying … leaving me all stressed, promising stuff that they couldn't, that they didn't even try to give. Basically it was completely, completely awful to be honest.*
> (Matthew)

Similarly, Emily and Charley described their meetings with Connexions advisers as 'one-off form filling' exercises. Attempts to access on-going support or guidance had not been successful.

Negative experiences such as these could leave the young person questioning the value of seeking or expecting future help from practitioners. In contrast, it was felt better to 'trust' more informal sources of help and support, such as parents, as they could be trusted and would not 'let you down'.

5.3   Evidence from the survey of young people on practitioner support

The 'pre-transition' sample from the young people's survey comprised respondents who were currently planning their leave from school. This therefore included young people up to school year 11 (~16 yrs) who were planning to leave school at the end of year 11 and move onto to further education at a college/leaving education altogether, and young people in school years 12 and 13 (~17-18 years) who had stayed on at their secondary school. This 'pre-transition sample' and totalled 50 young people (see Appendix H for further information about this sample).

As reported in Chapter 2, the response rates to the survey were disappointingly low. In addition, some young people with ASC will not have been able to/or willing participate in the survey (even the simple symbols-based version). Thus, the sample of young people who completed the survey cannot, in any way, be taken as representative. We are therefore choosing to present the data from the sample in a simple descriptive form with the aim of supplementing the qualitative data.

First, we looked at young people's reports of whether or not they believed 'one main person from services' was supporting them in planning for transition. A third of the sample (34%) either reported they did not know whether or not this was the case or did not respond to this question. A further step in the analysis looked at just those who responded 'yes' or

'no', of these almost two thirds (60%) believed they were being supported by a 'main person'. Small sample sizes precluded us from exploring whether or not having a statement of educational needs (SEN) and parent-reported diagnosis was associated young people's perception of transition support. Table 5.1 sets out the support being provided by the 'one main person' as reported by the young people. The question covering this topic was only included in the full version of the young people's questionnaire, and this was completed by 23 (46%) of the sample of young people.

Table 5.1 **Young people's perceptions of the ways in which the 'one, main person' was supporting the young person**

	Number of respondents reporting this support	%
They help me to think about what I want to do next (n=19)	19	100%
They give me advice and guidance (n=20)	20	100%
They ask for my ideas (n=20)	19	95%
They listen to me (n=20)	20	100%
They find things out for me (n=19)	15	79%
They talk to me about how I feel	14	74%

These responses suggest that, for the young people who completed our questionnaire and perceived that 'one, main person' was supporting them as they planned to leave school receiving appropriate kinds of support and were being listened to and participating in the planning process. A supplementary question asked if the young person would like to see this particular worker more often. Over half (53%) reported they would, with the remainder of the sample split between those who did not want to increase contact with this individual (26%) and those who were unsure (21%).

5.4 Parental involvement in the transfer from school to college

The interviews with the young people also explored the involvement of family and friends in planning the transfer from college to school. Here the young people's accounts focused, almost exclusively, on parental support. The help and support of peers was limited to the experiences of only one young person. For Sam, this was the information and advice he received from an older friend who was already attending the college he was considering.

Most of the young people recognised that their parents had played, or were playing, an important role in their school/college transfer planning and preparations. Most of the young people discussed post-school options with parents and decision-making about college was typically presented by the young people as something which had been shared with their parents. Only a minority (three) placed their parents in a relatively peripheral role. Over

half the young people (11) identified their parents, in particular mothers[9], as a key source of help and support. Amongst some of the young people it was apparent that there was a close mother/child bond and this was reflected in the fact that two of the young people frequently discussed their school leaving preparations and plans in terms of 'we'. Planning their school transfer was regarded as a joint venture for these young people. In contrast with their experiences of professional support, all the young people felt that they could rely on their parent(s) support over this period of transition.

In a couple of instances, the parental role extended to actually over-ruling the young person's preference of college course. However, in retrospect, both of these young people said they were satisfied that the decision which had been taken was the best for them:

> YP: … What my Mum did, she helped me do this foundation course. She, my Mum, chose the course for me because I need it; because if I don't do it, I'm just gonna miss out on life.
>
> YP: So was there anything you wanted to do when you left school?
>
> YP: Yeah, I wanted to carry on with my art cos I'm really good at that.
>
> WM: So were you disappointed when you didn't do art?
>
> YP: No because I soon learnt that I can do my art at home.
>
> (Stuart)

Five young people believed successful move from school to college could be <u>solely</u> attributed to the 'work' their mothers had done to achieve this transfer. All these young people clearly valued the active role that their mother's had or were still taking in their lives. To a greater or lesser degree this was because of an absence of any formal support:

> YP: Yeah, my Mum was the only one that really helped me. There was my teachers and that and I talked to them but they weren't entirely helpful, they couldn't change anything, they couldn't do anything for me. They did tell me what I needed [qualifications for college] but that's about it
>
> Int: So your Mum actually did…..
>
> YP: Actively helping me. Yeah, there was absolutely, in my entire life there has, no one's been there actively helping me to do anything, the transition to secondary school, the transition to college, nothing….
>
> (Ben)

Indeed, some anger was expressed about the lack of support over the transfer to college, and the burden (in terms of time and work) this imposes on their parents:

> Int: Who do you think was the most helpful [transferring to college]?
>
> YP: I think it was definitely Mum and Dad. But it must be pretty hard on…, I know how hard it is on my parents to have to keep chasing these people up because of bureaucracy and their stupidity.
>
> (Matthew)

---

[9] However, it should be noted four of these 11 young people lived in lone parent families headed by a mother.

> *A lot of help has to be given to the Mum's as well … it does effect everyone's life.*
> (Ben)

Roles assumed by parents

The young people described parents assuming a number of different roles as they planned for and moved to college. These included:

- driving the transfer

- information seeking

- emotional support

- addressing new support needs.

Driving the transfer

The young people frequently reported that their parents played a co-ordinating and/or administrative role in the process of managing their transfer from school to college. However, their level of knowledge of precisely what this involved varied. For example, a number of young people described their parents' input in terms of 'mum sorting it out'. Others were clearer about the specific role their parents had played. Many of the young people (16) described how their parents had led in the process of organising meetings and college visits, liaising with the college over their support needs, and sorting out travel to and from college. Some young people did not feel they could have proactively made such contacts themselves because of their social anxieties:

> *They [parents] helped with like contacts and stuff, they mostly did like the phone calls, calling the people and stuff, cos I usually have, sometimes have trouble with communication with random people.*
> (Bob)

Information seeking

Parents were recognised as playing an important role in gathering information about potential college destinations. Parents were reported to have gleaned information from a range of sources, including written college prospectuses, speaking to practitioners and using the internet. Parents' knowledge of how to search the internet was particularly valued.

As well as simply gathering information, parents were also described as playing a role in 're-providing' information in ways which were accessible and/or delivered at an appropriate time and/or setting. For example, Edward described how his mother had adopted the role of an 'information intermediary' helping him process relevant information at a time and in a manner that he felt was more useful to him. For instance, although Edward attended transfer-planning meetings with his mother, he frequently felt that he did not understand or could not (as he often felt stressed at these meetings) take on board the information that was being discussed. Hence, he valued the fact that his mother was able to later provide this information to him in a more relaxed home-based environment and also when he felt 'ready' and able to cope with it:

I went to every meeting [transition planning and discussions] with my Mum because I'm not exactly the best with memory, it fails me greatly in, in my social concerns …. So it was all, it was taken upon my Mum to take records [of the meetings] and then explain them to me more simply and at time when I was less stressed. … It was usually left to like a later day and some other times as well because of how stressed I was. … She [Mum] told me completely everything and she just made sure it was at a time when I was less stressed and it was more easy for me.
(Edward)

Addressing new support needs

Some young people described how their parents had easing their transfer to college by anticipating changes and/or support 'gaps', based on their knowledge of their child, and then seeking to address these before they started at college. This applied both to more practical support needs and supporting the development of the young person's skills and confidence prior to starting college.

Thus, for Tracy, her forthcoming move to a new college raised the issue of reduced levels of learning support. Recognising this, Tracy's parents had suggested she record lectures so that they could help her catch-up with work at home:

YP: My parents have said that it might be easier for me to take a tape recorder in and record the lessons so that when I come home my parents can help me. It will be better; otherwise I don't think I'd be able to do it really. … my Mum's going to buy me one [tape recorder] to take in so that they [parents] can help me, I think that's good.
(Tracy)

For Bob, help centred on the need to develop independent travel skills:

YP: My parents and my sister helped me figure out the bus, how, what buses I needed to take, how much it would cost and stuff.
Int: Did they come with you at first?
YP: I think my sister did, the first time and then after that I did it all on my own.

A couple of young people described how their parents had helped them think through, and practice, how they would manage new social situations which they might encounter at college:

Int: How has the sort of social aspect been at college … has anyone helped you with that at all?
YP: Um no, I've pretty much had to do it on my own.
Int: Were you scared of going to college for that aspect?
YP: Yes I was because I didn't know how to socialise at all
Int: Did you talk to anyone about it?
YP: Err, no, no one offered me any help
Int: Did you talk to your Mum about it?

YP: Yeah, yeah, she's helped me with that. She's helped me with… I ask, 'What do I say when this happens?' or 'What do I do when talking, when talking to someone about this', and she's really given, helped me with some advice on that. That's really helped. No one else helped me with it.

(Charley)

I'm rather normal socially … I can talk to people and chat, wherever we are quite normally, make some talk. … My Mum has taught me all these things, my Mum has taught me how to maintain eye contact, how to talk to someone and not talk to the wall or things like that, which I did and all that sort of stuff.

(Ben)

Emotional support

The young people generally reported they were able to talk to their parents and valued discussing any worries or concerns they had about leaving school and moving to college. This was largely due to the fact that parents, especially mothers, were felt to understand the young people's individual needs and the role that autism played in their lives. The availability of parents meant that young people could raise fears and concerns at their own pace or time:

I think my Mum was the most helpful cos the teachers don't really know, they don't really know as much as my Mum … cos they don't, they, my Mum understands me most cos she lives with me.

(Adam)

A very small minority reported that their parents did not appreciate how difficult they found new situations, including college. Here, parental support with how to manage social anxiety had not been forthcoming.

5.5   The social consequences of the transfer

When asked, just over three-quarters of the young people who had left school indicated missed some of their school friends. However, the degree of sadness expressed varied. A sense of loss was described by only a small number of the young people. For example, Sophie expressed this sadness in terms of losing continuity with her past, recognising that she was leaving peers she had grown-up with and thus felt comfortable amongst:

I do miss my old friends from school cos, … they're the ones that have seen you grow up, seen, seen you become the way you are and without them you wouldn't be the way you are.

(Sophie)

A more pragmatic perspective was adopted by others who, whilst recognising that some social contacts had been lost, believed that it was possible to stay in touch with the, typically, small group of friends who really mattered.

Keeping in touch with old friends

Only a minority of the young people had retaining face-to-face contact with old school friends: these were predominantly the young people who had fewer difficulties with social interaction. Being able to travel independently also appeared to facilitate keeping in touch; where that was the case, the young people valued, and relied on, parents for lifts.

By far the most popular and preferred way to retain contact was through virtual networks, particularly Facebook:

> *YP: I've got his [old school friend] mobile number, I've got him on Facebook*
>
> *Int: Do you use Facebook to keep in contact with people?*
>
> *YP: Yes, Facebook has benefited me in that way cos I've been able to keep up with them.*
>
> *Int: Do you think Facebook's important for you now?*
>
> *YP: I think it's important because it, it actually managed to keep you in contact with people that otherwise you'd lose contact with.*
>
> (Sophie)

A number reported that they found virtual contact less stressful than verbal or face-to-face contact. This was especially important for Ben and Charley, as they felt using the telephone was difficult and anxiety provoking for them. Although some of the young people (six) recognised that they were largely loners and often preferred to be solitary, none of them indicated that they felt wanted to be totally isolated from peers. Facebook gave them the option and opportunity keep in touch which was not stressful or demanding:

> *I prefer to use Facebook because you can just leave a message. I don't like ringing people because it's quite like, talk to me now, talk to me know.*
>
> (Ben)

Despite this, Facebook was not universally perceived as being problem free. The issue of virtual bullying was raised by two of the young people. Adam had experienced virtual bullying and, although he still used Facebook, it had made him more wary of whom he interacted with and how he presented himself. One young person feared virtual bullying and this prevented her from using Facebook.

New friendships at college

Most of the young people who were currently at, or had just left, college felt they had made some new friends whilst there. Amongst the young people attending 'special needs' courses, the friendships were typically restricted to disabled young people or others with a 'special' need. The young people enrolled on mainstream courses described a mix of disabled and non-disabled friends.

Some of the young people had clearly experienced positive social outcomes arising from the transfer from school to college. Typically, friendships with college peers were valued more highly than school peers or they had come to be viewed by these young people more as 'friends' compared to previous school peers. Two factors contributed to this: firstly, college peers were regarded as more mature in their outlook to learning; and second, they were socially more mature and accepting of disability and difference. For example, Ben highlighted that he felt more comfortable with his science course peers due to a shared interest in, and desire to, learn more about science. He also felt more relaxed with his college peers as he considered them to be generally more accepting of his ASC and special needs. This experience was juxtaposed to school peers who were viewed as immature in their disruptive attitude to learning and their lack of understanding of his ASC.

'Fitting in'

Some young people described the concerns they had had about 'fitting in' with fellow students. Indeed, as reported earlier, these concerns were sometimes usefully shared with parents who offered strategies to manage novel social situations. In contrast, four young people had taken a more independent approach, viewing their social fears as something that they themselves needed to address and deal with, as these comments illustrate:

> *Int: So did you talk to anyone about that [fitting in at college]?*
>
> *YP: No, I deal with it myself … I try and interact with them. I, most of the time it works.*
>
> *Int: Do you have any sort of strategies you do to interact?*
>
> *Int: Yeah, I just, I just look at what everyone else is doing and try to do what everyone else is doing and try to interact with them and try joining in the activities and mostly that works.*
>
> (Stuart)

> *YP: Um…getting into a new environment is pretty difficult to make, to move to, to be honest.*
>
> *Int: So what, what do you tend to do? Do you have any sort of strategies or things you do to help yourself in those situations?*
>
> *YP: In them situations I would try to put my old things [leaving school] behind me and put new things [starting college] in front … in front of me and start doing that.*
>
> *Int: Did anyone help you, teach you that or …?*
>
> *YP: No, I just thought of it myself. Just learnt myself, yeah. … I just try and put my Asperger's bits and bobs behind me.*
>
> (Greg)

In describing some of the coping strategies the young people employed to help them 'fit in' and make friends, it was apparent that the onus within these strategies was frequently on the young people themselves seeking to change. They felt that they should (or needed to be) the ones modifying their behaviour. For example, Steven commented that his Asperger's syndrome made him do 'weird things' and so felt he should address this in order to 'fit in':

> *YP: I did stand out a bit because of my Asperger's, cos I do a couple of weird things when I get excited*
>
> *Int: Did anyone help, did you talk to anyone about that?*
>
> *YP: Um, I managed to fit in on my own.*

Similarly, Tracy felt that she had a tendency to be a 'chatterbox' in social situations, especially, when seeking to make new friends. Tracy had thus come to realise that taking such an approach could be counterproductive, as other people viewed it negatively. Hence, she now tries to 'hold back' in social situations, as she explains.

> *YP: In starting college, yeah making friends basically which was the nervous part cos I don't find it easy to make friends … that was basically my fear, oh well not fear but worry, you know, just the problem I have with making friends and I do find it hard:*
>
> *Int: So have you developed any sort of strategies or things for that?*
>
> *YP: Um yeah, just, you know, not to talk about myself all the time and try and ask questions about them. … It helps because I am a chatterbox and I like go on a lot and that's what probably makes it difficult for me to make friends because they [her peers], it tends to be like – 'oh she's chattering on', you know, 'she's talking a lot and it's like getting boring'. So they kind of turn away and think I don't want to be friends with her because she's a chatterbox and she doesn't let me talk. … So it's kind of like telling myself to stop, and it's difficult.*
>
> *(Tracy)*

Experiences of bullying

This presentation of college as generally a more positive social experience was continued in the young people's reports of bullying. Bullying emerged as much less of a problem at college compared to school. Bullying at school was reported by over half of the young people (10), whereas just four reported its occurrence at college. Bullying at school was predominantly verbal and, for all, it had been a painful experience which was remembered vividly. Looking back, some of young people felt that their school had tried to address bullying whereas others felt that their school had not taken the issue seriously enough.

Two factors were identified by the young people as causing lower levels of bullying at college. First, college peers were regarded as socially more mature and accepting of disability and so, were less likely to bully those viewed as 'different' or with 'special' needs. Second, the young people also felt that colleges took bullying more seriously than schools:

> *I think if I was at sixth form, I think I would still have the same sort of problems, kind of getting bullied and stuff because, at college it was just a much more mature environment and they don't really tolerate bullying a lot …*
>
> (Bob)

The way a college responded to an episode of bullying appeared to affect how the experience impacted on the young person. A positive and direct response (in one case,

expulsion) could mean that positive outcomes were experienced from an inherently negative situation:

> *I told my parents what happened and we took it right to the college staff … they sat with me, we spoke through it and yeah, it's been done. The student who upset me is no longer in college: he's been expelled NEVER to come back. As well as making me upset, it's made me a bit more, well it's made me a lot me, how shall I say, be wary about people I should trust and who not to. … it's, it's made me a great deal more than the person I used to be… which was just, didn't know what to do, a frightened little person but now, I'm not so frightened anymore. Yeah, it's made me stronger.*
> (Stuart)

In contrast, another young person believed his reports of being bullied had not be taken seriously or acted upon. This young person felt this response accentuating his anxiety and contributed to his decision to leave college. Importantly, this young person believed a lack of understanding of his condition had contributed to the mis-management of the situation:

> *YP: I made a complaint to the college about him [the bully] but I was told to drop the allegations…*
> *Int: So how did you make the decision not to go back?*
> *YP: Just couldn't cope no more*
> *Int: is there anything you would have liked to be there for you at college?*
> *YP: I don't know, just people that understand this Asperger's, autism*
> (Ian)

5.6   Summary

This chapter has predominantly been concerned with describing the experiences of support, received from practitioners and parents, reported by young people with HFA and Asperger's syndrome's as they anticipated and transferred from school to college. We also describe these young people's accounts of the social consequence so this transfer. Descriptive data from our survey of young people is also presented.

In our analysis of the interview data on practitioner support we deliberately focused on identifying positive or 'young person endorsed practice'. Overall, the young people we interviewed welcomed the involvement of practitioners in helping them plan their move from school to college. Some acknowledged they needed help initiating or facing these sorts of decisions and practitioner involvement in this was welcomed. Moving on from school clearly generates the need for information about possible options and the young people particularly welcomed opportunities to experience post-school options: these experiences were identified by a number of interviewees as playing a critical role in decision-making. A smaller number valued the opportunity visits to potential colleges afforded, if wished, to access the knowledge and expertise of staff in those settings. It was interesting to note in some young people's accounts an acute awareness of what sort of setting would be 'right' for them.

Experiences of working with 'new', transition-specific practitioners were mixed. Two concerns were clearly expressed: that transition practitioners may not have an expertise in ASC, and that new staff will not know or understand the young person's particular needs. It was clear from some young people's accounts that they were very perceptive of the extent to which practitioners understood their condition and they disliked it when practitioners made presumptions about their specific needs and situation based on a general knowledge of ASC.

The importance of practitioners being reliable – doing what they said they would do – emerged as a strong theme in some young people's accounts. Negative experiences of practitioner support could impact on the trust placed in services.

The responses of young people who took part in our survey, and were currently planning leaving school, confirms that practitioners can be valued source of support during this period. Young people who perceived that they had 'one main person' to support them as they planned their transition from school reported receiving information and guidance and perceived that they were actively participating in transition planning. However, they were less likely to report receiving emotional support from this practitioner.

The majority of young people we interviewed described their parents as being closely involved in planning for leaving school and choosing post-school options. There was no evidence that this support was not welcomed by the young people. A sizeable minority believed that their parents (predominantly mothers) had taken the lead role in planning for their move to college. These young people were conscious of the 'work' this created for their parents and were angry at the lack of support from statutory services. An interesting insight into the role parents can play in 'coaching' or preparing their son or daughter for new social situations which they might encounter at college was provided by some of the interviewees.

The final section of this chapter shifted to look at young people's social experiences at college. It was pleasing to learn that, after possible concerns about 'fitting in', the great majority interviewees had had more positive social experiences at college compared to school. Bullying was reportedly less common and, where an opinion was offered, was perceived to be better dealt with at college compared to school. Most young people we interviewed reported making new friends at college and it seemed that these friendships were often regarded as 'better' than school friendships. This was ascribed to a more mature social environment and the increased opportunities college afforded to meet others with similar interests.

Chapter 6
Planning for Leaving School: Parents' Reports and Experiences

6.1   Introduction

This study took place in areas where multi-agency transition services were expected to be operating. As Chapter 3 has shown, transition services are not available to all young people with an ASC diagnosis. However interviews with parents were expected to highlight in some cases the involvement of multi-agency transition services in planning for young people leaving school.[10] Analysis of the data showed that there were two main ways in which preparations for leaving school were experienced by parents: (i) based in and flowing from the annual review process, and (ii) outside the annual review process. We describe parents' experiences of these two 'pathways' in detail (recording the range of experiences of these pathways and also noting patterns of consistency of experiences) and then move on to reporting parents' perceptions of their and their son or daughter's role in planning for leaving school. Finally, we supplement these qualitative accounts with data from our family survey.

6.2   Planning for leaving school within the annual SEN statement review process

Many of the parents whose child had a SEN statement reported that planning for leaving school had been discussed, and to some extent instigated, at annual SEN statement review meetings and particularly in the last one or two reviews before leaving school. It was at this stage that Connexions became involved. In the main, these parents' descriptions of preparing for their child leaving school through the annual SEN review process was similar to that experienced by families of disabled young people more generally. Parents were not aware of any adjustments being made to usual transition planning processes in light of their child's particular diagnosis. They were generally satisfied that details of the young person's diagnosis and resulting support needs were contained within the transition plan:

> So it's all there (in the transition plan) so that somebody can have a, an overview of him and what his needs are before they, they, they're dealing with him.[11]

Advice or recommendations about further education options sometimes detailed specific institutions renowned for specialist provision for autistic people.

A lack of attention to transition planning in annual reviews
An additional group of parents of young people with a SEN statement, however, either reported that annual reviews had not been a forum for discussion about what their son or daughter would do after school or that they had not had an annual review during their

---

[10] Information about the interview sample can be found in Chapter 2, Section 2.5.
[11] Verbatim quotes are used to illustrate points made in the text.

child's last year at school. Overall, there does not appear to be any differences in terms of the profile of the ASC diagnoses of the young people represented in this group compared to those parents who reported experiencing statutory transition planning processes. However, these parents were more likely to have a child who had been excluded during their final year of school and/or were attending a mainstream school. It is also possible that transition planning was included in annual review meetings but did not meet parents' expectations of what that planning would comprise.

Parents perceptions and experiences of multi-agency transition services
This study took place in areas where multi-agency transition services were expected to be operating, though as is reported in Chapter 3, not all families (typically those with HFA and AS) we interviewed would have been eligible for this sort of support.

The interviews with parents did reveal some confusion about the existence and nature of transition services and whether or not they had been in receipt of that service. For those young people not eligible to access a multi-agency transition service, it was clear that Connexions PAs, sometimes in partnership with the school, had taken the lead in supporting transition planning.

A number of parents from one of the case study sites reported that a social care practitioner with a dedicated role as transitions "adviser" or "worker" had led or been heavily involved in transition planning. These were all parents of young people already on children's social care caseloads (for example, disabled children's team).

Other parents identified Connexions PAs, either operating on their own or in combination with the school, as being their child's "transition service". Furthermore there were parents who did not perceive a "transition service" *per se* being in existence but did feel that Connexions and their child's school had worked to plan and support their child moving on from school. Included here were parents of young people with AS, HFA and AS who attended both mainstream and special schools. The great majority were not in receipt of children's social care services.

Parents of young people with SEN statements: factors affecting transition planning experiences
A range of experiences and satisfaction with statutory SEN transition planning processes was encountered in our interviews with parents. Some were positive whereas others had found the process inadequate. This could have a profound impact on parental well-being:

> *…absolutely stressed to the max, I was just crying all the time…it almost tipped me over the edge I think when I look back… and it was unnecessary.*

A range of factors appear to affect parents' experiences of planning for their child leaving school:
- having a key contact
- timely inclusion of transition planning in annual reviews
- a reliable transfer of discussion to action

- feeling informed and advised about suitable post-school options
- services working collaboratively
- schools actively preparing the young person
- the post-school options available
- school exclusion.

We describe these in more detail below, where possible drawing on positive examples and experiences.

Having a key contact

When asked if someone had acted as a key contact some parents said that the Transition Worker, a SENCO or Connexions PA had fulfilled this role. This person was perceived to have provided valuable help by, for example, coordinating support, taking opportunities to learn about the young person's aspirations, providing information and advice about post-school options, writing a transition plan, being available when approached, creating work experience and apprenticeship opportunities, ensuring that parents were adequately involved and kept informed, accompanying parents to college open evenings, and being generally reliable in keeping promises made about what they would do next.

Figure 6.1 and 6.2 summarises the experiences of two families who benefitted from a key contact (a Transitions Worker and a social worker) leading and coordinating planning around the young person leaving school.

Figure 6.1   Case study of support from a transition worker

From the age of 16 one young person's annual reviews were conducted according to the principles of person-centred planning. Instigated by the special needs school, meetings were attended by teachers, a Social Worker, a Connexions PA and a Transitions worker. The parent thought that person-centred planning had fostered multi-agency working because it had prompted more services to come together to discuss the young person's case. All attendees seemed concerned for the young person's wellbeing. The Transition worker took responsibility for conducting a holistic assessment and devising a transition plan which encompassed next steps as well as future prospects for employment, social activities and independent living.

Figure 6.2   Case study of significant support from a social worker

In one case, perceptions of the young person's behaviour had led to multiple exclusions and moves between schools. A Social Worker had played an active role with the family over several years. When it came to planning for leaving school the Social Worker had seemingly brought together Connexions, a school teacher and the parents outside of the annual review meetings to discuss options and to formulate a transition plan. When it became apparent that the young person had not obtained a place on the first choice college course the Social Worker was instrumental in helping the family to identify other suitable college courses and seek help from an employment service provider. The parent's account suggests that this Social worker was not part of a transition service. The transition team had been invited to annual reviews, but played no part in the move from school to college.

However, a key contact was not, in itself, a guarantee of a smooth transition planning process. Connexions PAs were sometimes perceived as 'no use' because workers seemed under-resourced with heavy demands on time. This was evidenced by the need to prompt PAs to follow-up requests for information and advice, or in the perception that the PA was available to all pupils in school and that no special support was offered to special needs pupils, let alone specific to young people with Autistic Spectrum Conditions. A parent of a child at a mainstream school suggested that it was easy for the SENCO to overlook individual children because of their large caseloads.

Finally, it is important to note, that some parents could not name someone as a 'key contact' and/or had not heard of, or were only vaguely aware of, 'transition support/ services'. Others had found that their transition worker or service had only appeared to be concerned with providing services, or active in planning for transfers, within social care or health care.

Timely inclusion of transition planning in annual reviews
A reason for dissatisfaction with statutory transition planning processes was that they did not align with families' planning and decision-making activities. Thus some families reported that annual review meetings had been held after they, as a family, had already decided what the young person would do next. This meant they had been unsupported in this decision-making process and that transition planning had, in a sense, taken place outside of statutory processes.

Others reported that annual review meetings had been pre-occupied with the achievement of academic goals in the final year of school or addressing the young persons' poor behaviour. Where planning for leaving school had not been discussed, parents could come away from reviews feeling very unsupported and highly anxious:

It seems to me they just say that's the end of your legal, you know, amount of time in school, goodbye.

I came away from [the meetings] worried to death what we're going to be doing with [the young person] later on. I never came away feeling confident, no.

A reliable transfer of discussion to action
Again, this theme emerged primarily from the accounts of parents with less positive experiences. They described being part of transition planning meetings where issues were discussed but apparently not taken forward or acted on. Practitioners not attending annual review meetings were identified as perpetuating a lack of action on issues.

Feeling informed and advised
Parents valued being given information and advice about post-school options and the processes involved in transition planning. Conversely, a lack of proactive information provision from services was viewed as very unhelpful and added to parents 'workload' and anxieties.

It is important to highlight that parents valued advice as well as information. Staff with a close knowledge of the child and ASC (for example, school staff) and those with an expertise with transition planning, special needs and the suitability of local options (for example, a special needs officer from the local authority, Connexions PA) were identified as sources of helpful guidance.

Parents trusted and valued advice from practitioners who knew their child well; and/or were experienced and knowledgeable in transition planning for young people with SEN; and/or who were able to make judgements about the suitability of post-school options in terms of the level and quality of autism-support. School and Connexions staff were most likely to be cited as trusted sources of information. These practitioners' cumulative knowledge of the previous experiences of ex-pupils at local educational institutions was seen as particularly helpful.

 Some parents also mentioned valuing 'post-16' or 'options' evenings held by their child's special school which had brought together representatives of colleges and residential units. 'Taster days' and opportunities for parents to meet staff (in colleges or other settings) and have the opportunity to discuss their child's particular needs were also viewed as very important sources of information and advice.

Parents who had been unsatisfied with the information and advice received often spoke about receiving only partial information. For example, they had been advised about which colleges to visit but not about which courses might be suitable for their young person.

Services working collaboratively
The sense that transition planning was, or had been a multi-agency process, did not emerge as a strong theme in parents' accounts. A common view was that, even though a number of services attended reviews, those present seemed to act separately. Some parents defined

'joined-up' working simply as being when the information provided to them was consistent across services or practitioners.

Parents were more likely to identify multi-agency working or collaboration between schools and Connexions, and when a specific issue was being tackled as opposed to transition planning *per se*. For example, collaboration between school and Connexions in organising work experience placements or visits to FE colleges. Another example was schools working in conjunction with the local authority to offer a scheme teaching pupils how to use a bus in preparation for travelling to college.

Figure 6.3 below illustrates one parent's very positive experience, which shows how the school, Connexions and college had important parts to play in the process.

Figure 6.3   Case study of support from multiple services

One parent of a young person felt "*very lucky and very supported*" by the special school, Connexions and college in planning ahead. The school curriculum concentrated on life skills and had covered topics such as personal hygiene, sex education and domestic tasks. The school had organised opportunities for the parents to learn about post-school options, taken the young person on familiarisation visits to colleges, written a transition plan, and spent time explaining to the young person what college would be like. Connexions had joined forces with the school to organise a work experience placement and to advise the parents about suitable colleges. The parents were impressed with the college's offer of 'taster' visits which were useful for gauging how the young person would cope and provided the parents with reassurance about the move.

Schools actively preparing the young person
Some parents praised the superb support their child had received from their school in preparing them for leaving school and, more generally, supporting their acquisition of the skills and experiences needed to enable them to progress towards a transition into adulthood. Both special and mainstream schools (and including an out of authority residential school) were commended in this way. The sorts of activities schools were undertaking which parents valued included: giving equal priority to the teaching of life skills as that given to academic subjects; arranging suitable work experience placements; taking pupils on familiarisation visits to local colleges; arranging for the young person to attend a mainstream school to gain extra qualifications. Some parents also highlighted the importance of implementing this sort of approach a number of years before the school leaving date.

Some parents attributed this high quality of support received to a particular special needs teacher or assistant who was said to care deeply about pupils, beyond that expected of their job.

An area where schools were sometimes criticised was when a parent believed they had failed to guide the young person's aspirations towards what the parent perceived as more 'realistic' goals.

The post-school options available

Naturally, the post-school options available coloured parents' experiences of the transition planning process. Not everyone we interviewed felt that there was more than one realistic option for their son or daughter after leaving school (as will be discussed in a later section). Sometimes parents believed the lack of (appropriate or suitable) post-school options being offered to them were due to the financial constraints under which the local authority was operating:

> *There is quite a lot of things out there, but you just get given I think what's the, the cheapest option for the county.*

Families living in rural areas emerged as most likely to report a lack of local post-school options specifically for young people with autism.

However, some parents reported that when their child was leaving school there were a number of possible options, all of which they considered to be viable post-school 'destinations' for their young person.

School exclusion

As noted earlier, parents whose children were excluded from school appeared to be more likely to report a lack of transition planning within the annual review process.

6.3   Transition planning for young people without a SEN statement

Parents of young people with ASC without a SEN statement described receiving no formal, specialised support for transition from schools:

> *… We were just left to fend for ourselves really. Unless there was things being done behind the scenes that I didn't know anything about...he was just the same as everybody else, he wasn't a child with special needs.*

There was also a view that any support that could be found was not joined-up and that no one service could provide them with comprehensive information and advice.

These parents' experiences of support from Connexions was much more variable compared to the experiences of parents of young people with SEN statements. Indeed, not all parents mentioned Connexions as being involved and there were differing opinions about the service's usefulness among those who did. Thus there were parents who described receiving significant support from Connexions during the transfer from school to college. On the other hand, there were parents who thought that whilst Connexions had offered useful information, this had either come too late or had required parents to 'chase' or prompt advisers. The support from Connexions was not necessarily visible either, as one

parent wondered if an adviser had spoken to their child in school without the parent being notified.

Information, advice and support from other services appeared to be very limited. In a case where the young person wanted to find paid work after leaving school, a visit to Jobcentre Plus led to nothing as staff said they could not help someone with an autistic spectrum condition.

6.4 Non-statutory support and planning for leaving school

When asked if non-statutory services had played any part in planning for leaving school, most of the parents in the study group identified no such involvement. Parents who did speak of such support tended to describe seeking information and advice from the National Autistic Society website, from contacts at the local Autistic Society, or from other parents.

Peer support was sought informally by some, or had been forthcoming from evening or online support groups where parents were members at the time of their child leaving school. Information and advice from other parents was thought to be important in signposting to possible sources of help or in providing reassurance about 'doing the right thing'.

As noted earlier, most of the young people represented in the interview sample were moving from school to college. For those parents of young people who were planning to move into work, specialist employment support had in some cases proved invaluable. For example, a third sector service (not ASC specific) had provided employment support by assisting a young person with job searches and applications, by explaining their needs to the employer, and by providing in-work support.

6.5 Parents' perceptions of their role in planning for leaving school

Parents' perceptions of their own role varied according to how well supported they felt by services. Thus parents who were largely positive about service support felt that their role was to make informed decisions alongside the young person, which was complemented by services, particularly in the information and advice they gave. In contrast, where parents perceived inadequacies in the support from statutory services, or that they had received no support, many felt that they had reluctantly taken the lead in making preparations.

Parents feeling informed, in control and complemented by services
Feeling supported was not at the expense of ceding all control to services. Thus parents who were pleased with the support from services felt that they had been involved in the planning process through opportunities to review transition plans and to have a say in person-centred planning meetings. They felt they had been supported to make decisions with their son or daughter drawing on the information and advice supplied to them. Parents who had a long-standing good relationship with the school said that the school had

always made them feel included in decisions and that planning for leaving school was an extension of this collaboration:

> *...I think we've always felt that, we've always been the main person (responsible for the young person's transition), we've always, as I say, we've always put our views across.*

One view was that where services understood the parent to be knowledgeable and confident, services respected parents' views. Aside from attending annual review meetings, some parents took on responsibility for conducting familiarisation visits to colleges, filling out application forms, making appointments to discuss support needs with college tutors and for choosing a college. Parents liked to be well informed, so some explained having conducted Internet research into colleges and courses or seeking advice from other parents whose children had left school. Thus there was a sense that service support complemented parents' efforts and vice versa. Some parents expressed sadness or anxiety about their child leaving behind the supportive environment of the school, but were also reassured by feeling that everything was in place for a smooth transfer.

Parents reluctantly taking a leading role
Parents who reported being unsupported or inadequately supported by services felt that they had adopted primary or sole responsibility for planning for their child leaving school. In many ways, the kinds of activities carried out by these parents mirrored the activities of parents who did feel supported – instigating meetings with colleges to discuss applications and plans for support needs, giving their child advice about which course to study and helping their son or daughter complete course application forms. However, theirs was a more intensive role because their activities were unguided. This meant, for example, that they spent a lot of time investigating a range of options for further education or paid work, or attended numerous college open days to ascertain their suitability. There was evidence that parents stumbled upon information through undirected searches on the Internet or through word of mouth. Instead, they had wanted statutory services to provide information about all available options, give instructions about where to start and who to contact, and assist parents in liaising with colleges in order to secure a place for their child.

These parents felt isolated, frustrated and that they were their child's 'key worker'. Many believed that if they had not pushed for support, or had not researched available provision, appropriate plans for next steps would not have fallen into place. Some parents felt that their role was inhibited by services providing only partial information or not taking their views into account, and felt strongly that plans for their child's future should reflect parents (and young people's) wishes rather services' definitions of what is 'right' and affordable. Some parents felt fortunate that they could rely on personal connections with special needs professionals or with fellow parents who gave advice about suitable colleges. Parents also talked about depending on their own knowledge, having worked in the educational sector, or of their abilities to be confident, articulate, determined and forward in challenging services. The planning process was also assisted where young people were set on particular post-school aspirations that seemed achievable, such as studying at college, and where there were few options to choose from.

The impact on parents of assuming the leading role

Feeling solely responsible for organising the transfer from school did not sit easily with parents. They recalled feeling concerned or 'frightened' about their child's wellbeing and future prospects, and felt inadequate to assume the role of ensuring their child would reach their full potential. Some described a keen awareness of the consequences of not planning for their child's future, or of making unwise decisions, perceiving a realistic possibility that their son or daughter would be 'in limbo', or have nothing meaningful to do after school. Not having options felt 'daunting' because there was no alternative if, for example, college did not work out. On the other hand, it took time and effort to assess a number of options and it could feel that time was running out. Some parents described the burden of responsibility having a heavy emotional and personal impact. Bouts of stress and depression or physical exhaustion, or the worsening of existing health conditions, had been experienced by some:

> *… I have never ever been so tearful, so drained, so upset, so tired, so frustrated, angry. Unable to have a life.*

> *The whole process was… even thinking about it now turns my stomach, going back to that time. It was one of the most horrendous times of our life.*

Impacts on employment were also reported, such as taking sickness absence or giving up a job partly in response to feeling unsupported. Relationships between parents had also been strained by a decision making process that was described as inducing 'internal turmoil'. However, another view was that planning for leaving school had not added to the everyday stress perceived as part of caring for an autistic child. Also, straightforward moves from school to college, where there had been few alternatives and the family knew in advance that the course application had been successful, protected some parents from stress.

6.6   The young person's involvement

Parents were asked about the extent to which their son or daughter had been involved in discussions and decision-making about leaving school. It was apparent in some cases that planning was very much driven by the parent as opposed to the young person. The severity of the young person's autism was not the sole factor affecting this. Some parents reported that their child was/had been uninterested and/or had chosen not to be actively involved in making those plans. These parents reported trying in vain to involve the young person in decision making. Parents were also more likely to assume greater decision-making responsibility where the young person did not have firm post-school aspirations.

Other parents we interviewed described how their child had been highly involved in planning for leaving school, with some taking lead responsibility for making choices and decisions. In large part these young people had diagnoses of AS or HFA. Indeed, in some families leaving school was considered an opportunity for the young person to start making their own decisions. Decision making seemed easiest for young people who had long-standing aspirations for study or work. Here, parents offered guidance but tried not to steer the young person in a particular direction:

... he's quite happy, you know, he feels that he's been in control and he's quite happy going [to the college].

... at the end of the day, it was down to [the young person] and his choice...to decide, whether he wanted to do it or not. I just said I wasn't going to force him.

Where the young person was actively involved in planning what they would do after leaving school, it was the social demands of this planning process which parents' perceived as one of the most challenging aspects for their child. Thus parents spoke about their child feeling inhibited in annual review meetings or meetings with their Connexions PA. Social anxiety also meant they forgot what they wanted to say leading to parents having to prompt them. Poorly chaired meetings, in which the young person was not introduced to those in attendance, was cited as an example of poor practice. In contrast, one parent felt the use of a visual tool, such as a white board, had enabled their child to convey their feelings.

6.7   Evidence from the parents' survey

We examined the data from the parents' survey to see whether the child having a statement of educational needs and whether or not the child was educated in mainstream or specialist settings was associated with parents' satisfaction with the transition planning processes, see Tables 6.1a (in-school sample) and Table 6.1b (post school sample).

Table 6.1a   The association between parents' satisfaction with transition support and the child's diagnosis (in-school sample)

	Satisfaction with transition support (n=27)	
	Not satisfied	*Satisfied*
Parent reported diagnosis		
HFA or Asperger's syndrome	15 (63%)	9 (37%)
Autism/ASC	23 (70%)	10 (30%)

Table 6.1b   The association between parents' satisfaction with transition support and the child's diagnosis and presence of a statement of educational needs (post-school sample)

	Satisfaction with transition support (n=27)	
	Not satisfied	*Satisfied*
Statement of Educational Needs		
Child has SEN	14 (67%)	7 (33%)
Child does not have SEN	4 (67%)	2 (33%)
Parent reported diagnosis		
HFA or Asperger's syndrome	12 (60%)	8 (40%)
Autism/ASC	6 (86%)	1 (33%)

It could be expected that the severity of the child's diagnosis and, related to that, whether or not the child had a SEN (and therefore was part of statutory transition planning processes) may impact on parents' experiences of transition planning. In terms of the parents who completed the survey, the level of satisfaction of parents in the transition support they have received does not appear to be associated with the severity of the child's diagnosis and/or the child having a statement of educational needs. Importantly, around two thirds of respondent were not satisfied with the transition support they had received.

Satisfaction with a service and the experience of unmet needs are closely related and the parents' survey explored parent's perceived needs (met and unmet) during transition, see Table 6.2.

Table 6.2   Parents' perceived transition support needs (in-school sample only) (n=70)

	Help not needed	**Getting enough help**	**Need (more) help**
Someone to talk to about child's transition (n=61)	6 (10%)	14 (23%)	41 (67%)
Someone to speak on behalf of family (n=58)	21 (36%)	8 (14%)	29 (50%)
Someone looking at parents' needs (n=57)	12 (21%)	8 (14%)	37 (65%)
Someone to provide individual support to parent (n=59)	21 (36%)	6 (10%)	32 (54%)
Someone to coordinate child's transition (n=59)	9 (15%)	11 (19%)	39 (66%)
Someone to help find suitable services	7 (12%)	8 (14%)	44 (74%)

The survey asked parents about six areas of support need. Across all these areas of need, at least a half of parents reported unmet needs. The number of unmet needs was not associated with the child's diagnosis.

Finally, we explored whether parents had found contact with agencies associated with transition planning (referred to in the questionnaire as 'transition services') affected parents' reports of the stress they had experienced, see Table 6.3.

Table 6.3 **Parents perceptions of the impact of contact with transition services on experiences of stress (n=50)**

Contact with transition services have ...	
	n (%)
Considerably reduced my stress	1 (2%)
Not had any effect on my stress	34 (68%)
Somewhat increased my stress	11 (22%)
Considerably increased my stress	4 (8%)

Overall, these findings do not paint a positive picture. For the sample of parents who completed the questionnaire, the involvement of statutory transition planning processes was not associated with higher levels of satisfaction with transition planning compared to those outside of statutory SEN review and planning processes. Thus, regardless of the level of severity of ASC, for many transition planning was an unsatisfactory process. The levels of unmet need across with regard to a number of different parental support needs are likely to be linked to these high levels of dissatisfaction. We should note here that one of the motivations to take part in a piece of research can be the opportunity to relay negative experiences and it may be the case that parents' with more positive experiences did not take part in the survey. However, the fact parents of children across the spectrum were experiencing difficulties with transition planning is important to note.

Given these earlier findings, it is not surprising that we also found that a third of parents who were in the process of planning for their child to leave school reported that contact with transition services had had negative effect on their perceived stress levels. Again, these data should be treated cautiously as the response rate to our survey was very low. In addition, we cannot be sure that parents' reports of increased stress associated with their dealings with transition services were not, to some degree, reflecting their wider concerns and anxieties regarding their child leaving school.

6.8   Summary

In this chapter we have reported parents' experiences of planning for their child to leave school. Within our sample were parents who had experienced this transition within the annual SEN review process and those who had not. For those within the SEN review process, experiences were mixed and many struggled to identify whether or not they had received support from a 'transition service' or worker.

The overall experience of transition planning for this group of parents was mixed and a number of factors were identified which supported transition planning:

- having a key contact
- timely inclusion of transition planning in annual reviews
- a reliable transfer of discussion to action

- feeling informed and advised about post-school options

- services working collaboratively

- schools actively preparing the young person

- the availability of realistic and good quality post-school options.

Equally, the absence of one or more of these factors could lead to parents finding transition planning a difficult, uncertain and stressful process. Importantly, episodes of, or permanent, school exclusion had been found to hinder transition planning.

Parents defined good transition support from services as that which had yielded realistic and satisfactory post-school options, and which supported and enabled them to make informed decisions. The role parents assumed in transition planning was, in part, driven by parents' experience of satisfaction with, and access to, transition support.

Parents who were planning for their son or daughter to leave school outside of the statutory SEN planning process appeared to be generally unsupported over this period. Connexions was typically identified as the agency providing advice and assistance but experiences of this support was very variable. Thus some parents described themselves as acting as their young person's transition worker: researching and identifying post-school options and opportunities. The wider impact of assuming this role, in terms of individual and family well-being, were acutely described by some parents.

Some parents' accounts of involving their child in planning for leaving school revealed an ambivalence, or reluctance to engage, in transition planning on the part of the young person. Parents also highlighted the social demands that involvement in transition planning can place on young people with ASC.

The data from the parents' survey confirmed the picture painted by the qualitative evidence. It also usefully highlighted parents' own needs for support during the transition planning process including emotional and information support and, for some, advocacy.

Chapter 7
Experiences of Further Education and Subsequent Transitions: Parents' Reports

7.1   Introduction

This chapter reports parents' accounts of their son or daughter's experiences in the settings or destinations in which they found themselves after leaving school. It therefore draws upon data from a sub-sample of the parents we interviewed; that is, those whose child had left mainstream or special school (n=27/36). Differences in experiences are described and, where possible, we seek to explain or identify the possible source(s) of these differences.

Post-school destinations represented in the interview sample
After leaving school, the majority of young people (n=23/27) represented in our interview sample went onto further education in a mainstream (the majority) or specialist college. One of these young people also had part-time paid employment and another was volunteering alongside their studies. Of the remaining four young people, one had entered full-time employment, two were being supported by adult social care during the day, and one young person became temporarily unoccupied after being denied a college place. These very small numbers of young people in non-college destinations means this chapter necessarily focuses on those young people who went on to college.

We begin by describing the reasons which parents reported lay behind the decision to move from school into further education. Parents' views of the support their young person received at college are then discussed. We then move on to report on the factors which emerged as supporting, or hindering, a successful time at college. The chapter concludes with looking at parents' experiences of planning 'next steps' from college and the post-college destinations and trajectories of the young people including, for a small number, the transition into employment.

7.2   Reasons for choosing college

Parents' accounts suggest that the purpose of college, and whose choice it was to attend, varied. Some parents reported that moving on to college had been driven by the young person and was part of a longer-term plan or aspiration (for example, attending university). Other parents' accounts indicated that the decisions to attend college had been driven by the need to find a short-term solution to uncertainty about what to do next and/or the lack of any other apparent options:

> *I said 'Well what, what's supposed to happen to her next?' You know 'She just sits at home, that can't be right, there must be something out there.' I said 'Do the colleges here have special needs units, do they have?'*[12]

---

[12] Verbatim quotes are used to illustrate points made in the text.

... that was really the only option given to me and there were no other options. So I was just sort of holding on to this [college] interview and hoping it would be all right.

7.3   Parents views of service support for the young person at college

Parents' accounts suggest much variability in young people's experiences of being at college. The most prominent issue for parents concerned the quality and appropriateness of the support their child had received.

Some parents described the young person being well supported in college. Examples given by parents included, one to one support, regular meetings with tutors, timetabling to support part-time employment opportunities see Figure 7.1.

Figure 7.1   A case example of good support at college

Young Person 'A' attended a 6th form college. Here, both Connexions and the special needs department were able to signpost the young person to voluntary sector services providing befriending and social support as well as employment support services. This led to a part-time job, and the college then ensured the young person had a compatible college schedule.

A key factor in parents' perceiving good support at college (both mainstream and specialist) was the skills and expertise of staff. Thus parents gave accounts of "clued in" college staff who could signpost to further support, capable staff at a specialist college who were able to teach the young person, and "open-minded staff" who could accommodate young people with different needs and abilities.

Other parents, however, felt that there had been poor or inadequate support for the young person at college, in terms of both support for social issues (for example, dealing with bullying) and support for learning. This experience was expressed mostly by parents of young people with Asperger's syndrome or HFA. Whilst some parents reported receiving a plan or agreement for the type of support their child would receive whilst in college, the evidence from the parents' accounts is that these plans are not always (fully) implemented. For example, the need for one-to-one learning support identified in transition plans but not provided. A couple of parents also highlighted a lack of planning from one academic year to the next: a contrast, perhaps, to their experiences of annual reviews whilst their child was at school.

It was not always clear from parents' accounts why colleges were unable to support the young person appropriately, though some parents identified college staff's lack understanding of, and expertise to work with, young people with ASC to be the root of the problem. Experiences of poor or inadequate support were most strongly expressed by

parents of young people with Asperger's syndrome or HFA and/or those attending mainstream FE colleges:

> …we've discussed all those sort of things that can be done, but when it comes to putting what we've discussed into practice it doesn't always happen the way it was discussed. So I think, to some extent, the impression I get is that they don't particularly understand Asperger's as well as I think they could do and should do.

7.4   The success of the young person's college career

The sample of parents (n=23) we interviewed represented ten young people still attending college and 13 who had left. Whilst five of those who had left were reported to have successfully completed their college courses, eight had not. Within this latter group were six young people who, on the basis of parents' accounts, had either been refused entry into the second year at college, or had been excluded. A further two young people had decided not to complete their college course. It is not possible to draw any conclusions from our data regarding whether the nature of the young person's autism or the type of college influenced whether or not the young people completed their FE courses.

Examining the accounts of parents whose children did or did not successfully complete college suggests that support for the young person and staff expertise may play a role in outcomes. Among those whose child had completed college, most parents talked positively about the support the young person received and the expertise and capability of college staff. One parent referred to the importance of transport support which removed the need for their child to use public transport.

Where a college had excluded or refused a second year for the young person, parents reported that the college had argued that the young person was unable to cope with college life. However, the parents believed that the real reason for their child's failure to complete their FE course(s) lay in colleges' inability to meet the needs of their child, both in terms of the support provided and the lack of expertise and understanding of ASC amongst staff. One or more parents identified additional factors which, they believed, had also contributed to their child leaving college prematurely. These included a lack of structure to the college day and an unsuitable physical environment, in terms of space and noise:

> It was a big open-plan structure with a massive staircase, lots of young people running up and down, you know, all different students of all, you know, the mainstream students … a big open refectory where everybody was mingling. Thousands of students, noise echoing. .. It just wasn't right for autism because they can't cope with a big open intimidating place.

7.5   Planning for leaving college

Some of the parents of young people still in college (n=10) described how they had started planning and preparing for their child leaving college or had made definite plans. The

options being considered or planned for included enrolling for a further year at college, employment or work placements, and residential specialist provision.

However, only a handful of parents reported having statutory support from Connexions and/or adult social care in making and implementing these plans. Two parents had had unsatisfactory experiences of accessing support from Connexions. One had found the support and advice was too generic and not 'be-spoke' to the needs of her child, the other reported that Connexions had deemed the young person too old for the service. Others reported that annual review processes which had continued in the specialist FE setting did not sufficiently incorporate planning the young person's transition from college.

A few parents had sought support and advice from other agencies including a local voluntary organisations and disability employment advisors. Many, however, described having very little or no support at all. This was a cause of concern, with one parent describing the planning as an "uphill struggle" that was "draining". There is very limited data on the support provided by colleges to families with a young person applying for higher education courses though it appears to be variable across institutions in its depth and quality.

7.6   Post-college destinations and trajectories

The destinations of the young people who had successfully completed the college courses they had enrolled on having left school included: moving on to a different FE college either alongside employment or volunteering, and entering, or intending to enter, higher education (including university, and higher education at college).

For those who had remained within the FE sector, parents' accounts indicated this was at their urging so that the young person would continue to be occupied as opposed to being a something which would support the achievement of a longer term 'career' goal. In contrast, for those parents whose child had entered/were intending to enter higher education, this appeared to be the young person's decision and part of their aspirations.

The trajectories and outcomes of the young people who did not complete college varied. Some parents' reports indicate a lack of stability and/or meaningful occupation in the young people's lives. For example, parents described how their young person had tried unsuccessfully to engage in work on a number of occasions. There was a sense that some of these young people, ineligible for adult social care support and outside of FE settings, had been 'lost to the system' with no agency taking responsibility for supporting their transition into employment. Even where statutory services continue to be involved, there are indications from parents' accounts that a premature departure from college upsets or interferes with post-college transfer planning and support processes. The lack of available options seems to compound this inadequacy:

> *I think [son] needs more of a life than he is having at the moment and he's not got that opportunity cos there's nothing that's there that they can offer him.*

However, we did also encounter an example of an autism-specific service successfully re-engaging a young person with further education, see Figure 7.2.

Figure 7.2   Case study: young person 'B'

After being excluded from college, Young Person B entered a period of being unoccupied. After the parent made contact with social services, Young Person B was referred to a autism specialist day service provided by a voluntary sector organisation. Young Person B's parent found this day centre to be very helpful, as it was tailored to the young person's needs, had staff with expertise to work with individuals with ASC, and kept regular contact with the parent. After a period of using the day centre, Young Person B was gradually reintroduced to college with the help of the day centre, before attending full-time. Young Person B is still at college, although the parent has concerns about what will happen after college and whether they will be supported in planning for this next step.

For the young people currently unoccupied, parents were concerned about the young person's mental health, their increasing social isolation (and loss of social skills) as they remained in the family home all day, the loss of academic and/or life skills acquired at school and college and the young person's increased dependence on the parent(s). One parent, for example, described her child as needing to be rehabilitated to the "outside world" after being at home and unoccupied for a long period. Indeed, overall parents were concerned that these difficulties would further hinder the chances of the young people achieving positive outcomes. Prolonged spells of inactivity at home also revealed parents' needs for support in their caring role:

> *… it would be nice to, for me to have more support because… you're having to, people don't always understand what it's like to live with, with somebody like that, and it's always really on my shoulders to take him out and do different bits, but if I don't do it nobody will.*

7.7   Supporting the transition from further education into work

Very few of the parents we interviewed had children who were working or had had some experience of employment. However, where it had been accessed, experiences of employment support services were typically very positive. It was not always apparent from parents' accounts, however, whether these were statutory or voluntary-sector provided services. Some parents were clear that the roles of an employment support service in advising employers on how to adapt working practices to meet the needs of the young person and mediating between the young person and the employer when difficulties arose had been vital to the success of their child's transition into employment. However, the

eventual loss of such support was a concern as parents believed their young person would continue to experience difficulties with working life.

7.8 Summary

This chapter has focussed on parents' accounts of their son or daughter's experiences of further education, or college, and subsequent transfers.

There was a clear dichotomy between parents who viewed college as a positive step towards the achievement of a higher aspiration for their child (university, a particular career or job), and those who viewed it as a replacement for school in terms of providing an adequate setting for their son or daughter to spend some of their daytime hours. Importantly, this latter group of parents did not perceive there to be any other post-school options.

We heard mixed reports from parents of the adequacy of support received by their child whilst at college. Among the sample of parents interviewed for this study, it was the parents of young people with HFA or Asperger's syndrome who were most troubled by the lack of, or inadequate, support for their child.

Alongside a lack of understanding of ASC, inadequate support was identified as a key reason for a young person's college career to terminate prematurely. A greater number of young people represented in our sample of parents had left college prematurely than had successfully completed their course. Leaving college early, either through exclusion or dropping out, appeared to carry a risk for poorer outcomes and falling 'out of sight of' services. However, we did come across an example of a specialist ASC service successfully intervening to enable a young person to return to college.

Parents of young people who had left college and were not currently occupied were highly concerned about their well-being. This included worries about their mental health, increased social isolation and the loss of skills, all of which were seen to further decrease their child's chances of moving into employment.

Only a small number of parents had experience of their son or daughter working. Those who had accessed specialist employment support were typically very positive of this service. However, there were concerns about meeting young people's longer term employment support needs.

Finally, a key issue emerging from these parents' accounts is the lack of statutory support provided to help young people and plan for leaving college. For some, this contrasted with the level of support advice received when the move from school to college was being planned. Among the parents we interviewed, annual SEN review processes in college did not cover post-college decision-making. In addition, parents reported support from Connexions was variable, both in terms of quality and eligibility.

Chapter 8
Support in Further Education: Practitioners' Perspectives

8.1   Introduction

This chapter reports practitioner's perspectives on the support available for young people with ASC, with and without learning disabilities, accessing further education across the research sites. It begins by looking at the support available for preparing young people for the transfer from school to college; moves on to illustrate examples of good practice in supporting young people with ASC at college; and then looks at some of the challenges with supporting young people with ASC at college. Three short sections then follow: the first looks at issues associated with the lack of full-time college provision; the second looks at the support offered to young people with ASC when leaving college; and the third looks at the support available to young people with ASC when applying for and moving into higher education. The discussion draws out the key findings from the chapter.

8.2   Preparing young people for the transfer from school to college

A number of practitioners - school staff, Connexions workers, transition workers, a transition nurse, autism advisory teachers, staff from education outreach services and children's social workers - reported supporting young people with ASC in their transition from school to college. Such support included providing information about different colleges to help young people and their parents make an informed choice about which college and which course suited them best; taking young people on visits to the college to help the young person see and experience how the college environment and expectations of college students differed from those at school; writing health plans for the college so that they could better understand the condition and needs of the young person, and thus be in a better position to provide appropriate support; and preparing person-centred plans for the young person to share with college tutors (A, B, E). Some practitioners (D) reported that transition to college worked best when the move was gradual and phased:

> *… having their transitions start in the October before they leave and it was just a case of sort of going over and visiting once a week then spending a little bit more time each week until they just did a day a week. So by the time June comes and they leave school, they're really ready to move on.*[13]
> (Autism advisory teacher)

A small number of practitioners (B) also reported working with the young person to plan their bus route to college and offering travel training so that the young person could eventually travel to the college independently.

---

[13] Verbatim quotes are used to illustrate points made in the text.

Practitioners reported that occasionally college staff would attend the young person's Year 11 annual review, or would visit the young person at school in an attempt to get to know and understand them a little better prior to their move to the college (B, E).

8.3   Supporting young people with ASC at college

There were numerous examples of mainstream and specialist colleges serving the needs and abilities of young people across the autistic spectrum. Some sites had specialist college provision for those with HFA and Asperger's syndrome. For example, in one site (D) a two-year college course had been established in a mainstream college for young people with Asperger's syndrome. The course, set-up in partnership with the college and a national autism organisation, taught basic academic skills, such as literacy and numeracy, alongside practical skills such as cookery, woodwork and IT, and Duke of Edinburgh activities intended to boost the young person's confidence and self-esteem, including visiting different towns and accessing the community to try and break down social isolation. The course was aimed at young people who had previously attended mainstream schools and been bullied or expelled, but who then used the college course as a stepping stone to get back into education and ultimately access more academic or vocational college courses.

A mainstream sixth form college in another area reported solid support for their students with HFA and AS who were academically able but could only cope with some social interaction (E). The college's learning skills tutor noted that, in addition to working with college tutors to make them aware of which young people were on the spectrum and what factors helped or hindered each individual young person, structural supports were also in place:

> Some [young people with HFA/AS] will have sessions out of lessons to help them plan their homework, organise their files, discuss social situations that they found difficult and look at strategies for that, that sort of thing. The next stage up, they might require some social support, a socially protected area, a room, a chill out area, so if they need to come out of lessons, calm down, get their together, so to speak, then they can do that. Support assistants who may accompany the students to some lessons, to all lessons, perhaps just to a lesson where there's a lot of social interaction. Exams provision, which is dealt with separately, where they very often need a small room or a separate room, rest breaks, whatever it is that they need, adjusted timetables.
> (Tutor supporting young people with HFA and AS at a mainstream college)

A mainstream FE college in another site (C) offered courses to young people with ASC, with and without learning disabilities. Those with learning disabilities were offered either a three-year course followed by a vocational skills course, or a four-year course for those who would not be moving into employment but would move into social services day provision. Each young person would also have an independent living skills course specifically tailored to them following an assessment. The course would cover independent living, widening participation, personal and interpersonal skills, literacy, numeracy, and vocational skills.

Those with HFA or AS may be with the supported learning unit for only one year before accessing mainstream courses. That one year would typically be spent helping the young person to orientate themselves around the college and build up their confidence within the new environment.

Some practitioners argued that having support workers in colleges who were fully trained in ASC could help young people to settle into college life and perhaps reduce the number of placement breakdowns.

A Specialist Further Education College for young people with Asperger's syndrome

One site (B) had a specialist further education college for young people with AS aged 16-21 years old. The private residential college accepted young people from the county and also from other counties to study for A-levels and move on into mainstream further education, higher education, or employment. College staff undertook transition planning with young people, which could include accessing higher education, housing, and employment. The college had its own transition coordinator who linked in with other agencies and supported young people in their transition to adulthood in numerous ways:

- *Adult Social Care:* College staff could refer young people who did not have a social worker for an adult social care assessment.

- *Housing:* College staff alone, or in conjunction with a social worker from adult services if the young person was eligible, could approach housing associations; help the young person complete application forms for housing, and explain the young person's situation to prospective landlords/local authority housing associations. College staff could also seek to establish floating support for the young person, for example to help with budgeting; or could themselves help people settle into their own homes by, for example, accompanying the young person to choose home furnishings or by helping the young person paint their new accommodation.

- *Employment:* College staff worked to develop students' employability skills, provide work experience placements, and link with Connexions and supported employment services to help the young people find suitable work.

- *Higher education:* College staff took young people to open days at Universities, organised Disability Support Assessments, and met with disability advisors in higher educational institutions to ensure appropriate support would be available for the young person.

- *Socialisation:* College staff also supported young people to learn independent living skills, including cooking and travelling independently, and also to develop socialisation skills and partake in leisure activities, for example by encouraging young people to sit together in a communal lounge to watch a DVD, or by going bowling or to the pub together.

8.4   Challenges with supporting young people with ASC at college

Practitioners also expressed a number of concerns about the support available for young people with ASC whilst at college. First, there were concerns that the college courses and

programmes could be improved as some were not thought to be challenging enough for the more able students with HFA and AS. Second, it was reported that young people with ASC and learning disabilities could spend many years at college moving from course to course, or even repeating the same course, if there was deemed to be no alternative available. This 'revolving door' experience did not further the skills and abilities of the young person or improve their confidence; rather it was simply a way of occupying the young person's time and offering some respite for the family. Third, colleges were not always equipped or staff appropriately trained to work with those with challenging behaviours. This sometimes led to young people being suspended, expelled or dropping out of college. Whilst some practitioners perceived this to be a reflection of the students' inability to cope, others saw it as the college failing some of its students. In situations where a college education was so interrupted, young people were at risk of being rushed into a different college or other environment without thorough planning and preparation which risked creating further difficulties. Such scenarios were reportedly more likely for young people with HFA or AS who were not eligible for specialist colleges and typically ended up in mainstream colleges with varying amounts of support.

In defence of some of the criticisms aimed at local colleges, a Connexions manager in one site elaborated on some of the challenges faced by mainstream colleges in working with young people on the autistic spectrum:

> *Young people with autism are not an easy group to put together a course for. You know they probably all kick off about different things, so it's not, it's very difficult, I think, for the colleges to put together courses which meet the needs of young people with autism. And they might be highly intelligent young people and theoretically we would want them to be dipping into say Level II, Level III courses, but their autism means that that's very difficult for them. And the level of funding that colleges get would mean that it would be very hard for them to put in the level of support that is needed for that particular individual.*
>
> (Manager, Connexions service)

8.5   Lack of full-time college provision

Practitioners reported that some college provision had been reduced from five-day provision to four- or even three-day provision which caused significant difficulties for working families. Those with ASC and learning disabilities who were eligible for social care support could be provided with direct payments or commissioned services to occupy them on days when they were not at college, thus enabling parents to remain at work. However, in most sites such support was not available for those with HFA or AS who were typically not eligible for support from adult services.

8.6 Leaving college

An educational professional in one site (E) described the transition process when a young person with ASC left college. Those moving on to other colleges would be picked up by transition or link workers from the new college, with the old college providing some history about the young person and what strategies had worked well for the young person whilst at that college. If the young person was leaving college to move on to University or into employment college staff would have more involvement. It was reported that the majority of this transition work would be undertaken in conjunction with Connexions PAs; transition workers and adult social workers were rarely involved, even if the young person was eligible for such support.

8.7 The move to higher education

In each site, school, college and Connexions were identified as the services which would be available to support young people with HFA or Asperger's syndrome hoping to attend university. Staff in each of these services reported being able to provide information and advice about higher educational courses and institutions; liaise with disability support officers at the University to discuss the young person's support needs and advise on a support package; and, in some cases, take the young person to the University to show them around. The eligibility criteria for accessing support from statutory transition teams (see Chapter 3) meant that staff in these teams were typically not involved in supporting young people with ASC aspiring to go to university. In addition, the Asperger's team (an outreach service located in adult mental health, see Chapter 10) in one site reported offering support to young people with HFA and AS in choosing suitable University courses and institutions.

8.8 Summary

The transfer from school to college could be a stressful time, especially for young people with ASC for whom the break in familiarity and routine could be most disruptive. Practitioners reported the importance of helping young people with ASC prepare for this transition through, for example, taking those young people on visits to the college; letting them experience 'taster' days at the college to begin to create some familiarity with the environment; meeting the tutors; and possibly even spending one day a week at college during the last school year to ease the transition to a full-time college placement.

The role of transition workers in the transfer from school to college – and the transfer from college – appeared limited; most of the preparatory work and transition planning was undertaken by school staff, Connexions PAs and, occasionally, college staff.

Practitioners described some of the support available for young people with ASC transferring to college, and also some of the challenges. Support included providing a quiet space for those with ASC; having well organised routines and clear timetables; and college

tutors having information about factors that tended to trigger challenging behaviours in students with ASC. Some mainstream colleges reported offering specialist courses for those with HFA and AS which supported their academic abilities but also assisted them with more social and independent living skills. A specialist Asperger's syndrome FE college in one site reported providing holistic support to young people with AS in their college education, socialisation, independent living skills, and also around moving into employment or supported accommodation once they were ready to leave college.

Challenges in supporting young people with ASC at college were reported to be the diversity of young people on the autistic spectrum which created challenges with setting up courses suited to young people with different needs, abilities, and interests; the lack of diverse courses for young people with ASC, particularly those with learning disabilities; and a lack of staff training around how to manage the challenging behaviours of some students.

The lack of full-time college placements was also reported to be a concern by some practitioners, as social care needed to provide funding for additional days' occupation for those young people who were eligible for social care support. Those who were not eligible required additional support from parents during non-college days, which had implications for working parents.

Young people with HFA and AS seeking to move into higher education were supported by schools, colleges, Connexions PAs and, in one site, the Asperger's team in adult mental health. Support included giving young people information and advice about different courses and institutions, liaising with disability support officers at the universities, and occasionally taking young people on visits to the universities.

Chapter 9
Families' Reports of Social Care and Mental Health Support and Unmet Needs over the Transition Period

9.1 Introduction

This chapter focuses on two related areas: the experience of transferring from child to adult mental health and social care services, and the perceived needs for support of young adults with ASC. We use qualitative and quantitative data to provide evidence on these areas.

First, we report our findings on families' experiences of mental health and social care support over the transition period, including the transfer from children's to adult mental health and social services. Compared to the experience of leaving school and, in many instances, transferring to college (see Chapters 5 to 7), only a minority of families were accessing these children's mental health and social care services. Our data is, therefore, inevitably more limited and the conclusions we can draw more circumspect. To begin we report parents' and young people's experiences of mental health transfers. Here we use the data from the young people's interviews to provide detailed case studies of the different mental health transfer experiences reported by the families who took part in this study. We then move on to describe parents' experiences of other transfers within the health service: a relatively uncommon experience. A greater number of families had experienced social care transfers and these are reported in the following section. Following this, the differences in the nature of support provided by children's and adult services as perceived by parents are discussed.

Next, we use the findings from the surveys of parents and young adults to further understand and illustrate the support needs of young people after they have left children's services and as they enter adulthood. A tentative exploration of agreement within young adult – parent dyad on the young adult's support needs is also presented.

Finally we present our findings on how young adults with HFA and Asperger's syndrome perceive the lack of support from statutory services.

9.2 Mental health service transfers

Just four parents had experienced their child making a mental health transfer. There were two typologies of transfer experience between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS):

- those who transferred between CAMHS and AMH
- those who were discharged from CAMHS without being transferred to AMHS to no adult equivalent.

In addition, two further two young people were transferred from community paediatrics into AMH services.

Among the sample of young people we interviewed, four had experiences of transferring from CAMHs to adult mental health.

Anticipating a transfer

The experiences of one of the young people we interviewed provide a clear illustration of the significance, on the young person's part, of the transfer from child to adult mental health.

Case study 1: the stresses of anticipated transfer

> At the time of interview, Emily (aged 18 years) had been receiving mental health support from a psychiatrist and counsellor for a number of years. She was aware that she would need to be transferred to adult mental health. However, to date, this had only been briefly discussed with her, and only in relation to her referral to an adult psychiatrist. She reported being worried about when and how the transfer to adult mental health would happen. She was also concerned about the continuation of her counselling support.
>
>> *He said [child psychiatrist] that I'll have to go to an adult one [psychiatrist] … but I think he's going to tell me next time I see him that I'm going to have to get another person, next time I see him I'll mention it[14]*
>> (Emily)
>
> Emily described this uncertainty as extremely unsettling: particularly the potential loss of much valued and trusted counselling support. The prospect of having to talk about personal and often painful issues with a new person following the transfer to adult mental health was viewed as daunting and potentially too stressful to undertake.
>
>> *YP: I have a counsellor too and I'm just hoping she's not going to change. … She's really nice and I like her and am able to talk to her and she tells me that everything is going to be OK, so I, I just hope she doesn't change. … I probably won't go to another counsellor cos I don't like opening up and telling everybody and having that one-to-one thing, it's not easy to just tell a load of people. … so next time I see her, I'll mention it.*
>> *Int: Do you think you'll find out soon?*
>> *YP: I hope so soon, soon. I'll try and find out.*
>> (Emily)

Moving from CAMHS to AMHS

Just two parents described a move between CAMHS and AMHS for the young person. In both cases parents' accounts suggest the transfer was problematic due both to a lack of continuity between services and the interruption in mental health service support their child

---

[14] Verbatim quotes are used to illustrate points made in the text.

was receiving (gaps of 3 and 9 months respectively. One of the parents noted that the impact of this gap in mental health support was heightened because it coincided with leaving school which was a very stressful period.

Parents spoke about the difficulties arising from the loss of the relationship the young person had developed with the therapist in CAMHS, and having to adapt to a new therapist in AMHS. For one parent, this lack of continuity caused particular frustrations, and suggested that some overlap between therapists in CAMHS and AMHS would be a helpful improvement. Specifically, it was suggested that: the adult therapist should have attended two or three of the therapy sessions in CAMHS to facilitate this overlap; and that there should be greater information sharing between CAMHS and AMHS therapists.

The outcomes of the two cases differ. One young person continued to receive the same level of support from AMHS as was received from CAMHS. For the other young person, the parent believed a less intense level of support was being provided and that this was not sufficient. This lack of support was attributed by the parent to heavy caseloads with AMHS. She also believed that her own ability to support for her son has resulted in him not being regarded as a priority. However, it was evident that the parent felt unsupported in this role:

> *There are times when we get really low with it and we all, you know, we are all in this situation of frustration with it where there's no light at the end of the tunnel for any of us ...*

We now present two case studies which illustrate two very different experiences of the transfer from children's to adult mental health. The first (Sophie) experienced a significant interruption in her mental health support. The second case study (Katy) provides some pointers to the factors, or elements of practice, which ensure a positive transfer experience.

Case Study 2: interrupted mental health support

Sophie's experience of mental health service transfer demonstrates the danger of inadequate planning and information which, for Sophie, had led to a situation of 'no' transfer or at best, a delayed transfer to adult mental health.

At the time of her interview, Sophie was 18 years old and had recently been discharged from CAMHS and was currently waiting to receive an appointment from adult mental health. Sophie felt that this lack of continuity in her mental health support was because her child psychologist had not referred her sufficiently in advance, indeed a meeting with adult mental health services had been promised but had never taken place. Sophie's GP was currently trying to arrange a transfer to adult mental health for her.

> *I was supposed to have been passed, been passed over to adult services .... so like adult mental health. Dr Jones [child psychologist] was supposed to have done it. He said, he promised me that before I turned 18 I'd be able to go, go back to him and he'd get an adult psychologist with him and therefore, I'd be able to meet the adult psychologist and all that sort of stuff ... it didn't happen and I seem to have fallen through the net a bit. ... He's [Dr Jones], he's left it to my GP to sort out and my GP,*

my GP's been brilliant. He's managed to get me the social worker. … So I'm being passed from pillar to post basically.

Although Sophie was grateful for the support of her GP and subsequently, her social worker, she clearly missed specialist psychological support and reported fearing that any progress she made in children's services was in danger of being lost or reduced.

Int: And do you see anyone now?

YP: I still have a social worker, I still have my GP who's busy trying to, he's, bless him, he's trying but he seems to be, he seems to be not getting listened to.

Int: And how have you found your social worker?

YP: She's lovely but she only comes when we need her or we phone her and ask for an appointment. … It can be anything from three months to six months I see her. I do realise I'm not the only person that she sees and deals with but I need something that's regular if you like. … I do miss the psychologist because he did, he did a lot of work for us. … It meant I had someone additional to talk to and someone who understood, was able to give me ideas [about living with ASC].

Case study 3: an informed transfer

The importance of practitioners providing early and adequate information about impending transfers was also raised by Katy who had, in the last year or so, transferred from a psychologist in children's services to a psychologist in adult services. Katy described a hiatus between leaving her child psychologist and gaining an adult psychologist. However, despite this, Katy reported feeling largely comfortable her transfer. This was due primarily to the fact that her child psychologist had discussed the impending change with her. In particular, Katy had valued being told about practitioner from adult services would be seeing her and the fact that her appointments would still be in the same building.

YP: … at the end when I left the Child and Family Service I didn't have anyone one (from adult services) then. I think I probably worried but I think I was OK. … I think about May I stopped seeing the lady from Child and Family, and then September I had someone or, October I had someone again. … She was very good at actually explaining who it was going to be.

Int: This is the Child person?

YP: Yeah, she was, because it was kind of used to be downstairs, the psychology consultancy, so that was quite good because I had a picture of where it was. So that was good and she explained it

WM: So you only had to go upstairs?

YP: Yeah and I knew it was there and I knew it was a psychology person.

(Katy)

Moving from support in CAMHS to no support in AMHS

Among the sample of parents, there were two cases where the young person had been in receipt of CAMHS support but did not transfer onto AMHS. Whilst one parent was content with this termination of support [4-56], the other parent believed this had left their child

with unmet mental health support needs which the parent was currently trying to resolve. The process of accessing adult mental health support was described by this parent as "utterly draining" particularly as it was co-occurring alongside problems accessing other support and services.

> *It's a hell of a burden to keep carrying.*

One of the young people we interviewed had had expected to be referred on to adult mental health by CAMHS but this had not materialised:

> *INT: So did they [CAMHS] transfer you to adult services?*
> *YP: No, I believe they were supposed to but nothing came of that again*
> (Ben)

This young person described feeling uninformed and 'let down' by professionals. This sense of being 'let down' had led Ben to value the emotional support his family, particularly his mother, provided. For this young man, parental support was perceived to be 'reliable' whereas, formal sources of support was viewed as, potentially, unreliable.

Moving from community paediatrics to adult mental health
In two cases the care of the young person was transferred from community paediatrics to adult mental health. Both parents report that, aside from a referral to adult mental health services, there was little else in the way of formal planning or preparation. In both these cases there was a lack of continuity of care, with one young person waiting two years before receiving an appointment from adult mental health.

9.3   Transfers across other health services

For the majority of participants, there was no experience of a transfer or upcoming transfer within other health services related to the care and management of the child's ASC. (One parent described a paediatric to adult health care transfer with regard to a separate health condition.)

Some of families who had been routinely seen by paediatric services because of the child's autism reported the lack of an equivalent service within adult health. This had resulted in unmet needs for support for themselves and/or their child. The lack of preparation for this loss of support could be problematic.

> *I thought the doctor did a good job preparing [young person] but I don't think the health system itself does a good job preparing the carers. I think that it could be clearer.*

This parent described a need for information about what to do next to ensure her child 'gets into the next rung of things'.

9.4   Transfers within social care

Just under half of the parents we interviewed described having contact with social care. Five parents had experienced a transfer between children's and adults' social care, and two described moving from children's social care support to no equivalent support in adulthood. A further three parents reported acquiring adult social care support despite not receiving support from children's social care. This section describes these different typologies of transfer experience.

Moving from children's to adults' social care
Five parents had experienced a move between children's and adults social care support Parents' experience of this service transfer was predominantly negative.

First, parents perceived there had been little to no planning for the transfer and/or the planning had not been done particularly well. Parents reported feeling uninformed about what was happening and some felt the handover from child and adult's services had been inadequate. Some found they had had to be proactive to ensure the planning process moved forward.

Second, some parents perceived they had not been properly consulted during the transition planning process. Third, parents typically struggled with the decision to transfer care of their child to adult mental health service as opposed to adult social care.

Early experiences of adult social care services could also be difficult. Some parents found the lack of pro-active contact from adult social care or a lack of clarity as to the support they would be providing to be daunting:

> *I just felt like for a long time I was on my own. And I think the feeling is the help is there but you've got to go out and get it. No-one comes to you and says "Oh let me ... give you some advice". You've got to, you've got to get your phone book out and, and start ringing people.*

Despite this negative experience of the transfer period, once in adult social care, there was more diversity in parents' experiences. Two parents' accounts suggest positive outcomes, with different aspects of practice possibly explaining this. In one case, the adult social worker maintained regular contact with the family, offered regular reviews of the family's needs and appeared to work in partnership with the parent, taking into account her views.

In the second case where positive outcomes were reported, this parent cites a thorough assessment to meet the needs of the young person through direct payments, and being able to contact the care manager as and when needed.

Other parents, however, were more negative in their views and this centred around a perceived reduction in support from adult services compared to children's services (see Section 9.5 below).

Moving from support in children's social care to no support from adult social care
Two parents who had social care support from children's services did not continue to receive such support from adult social care. In one case, children's services involvement had been quite substantial. Therefore, the termination of this support when the young person turned 18 has resulted in unmet needs for the parent as they supported their children their own:

> *… to have someone here to sort of help me talk, talk him round or help me, point me in the right direction what I should and shouldn't be doing. Cos I handle it in the only way I know how, but what way is right or wrong?*

Acquiring adult social care support despite receiving no children's social care support
Two parents reported their child had acquired adult social care support despite not having been in receipt of social care from children's services. In both cases parents had refused support from children's services, either because it was not perceived to be helpful or because of the perceived 'stigma' around having a social worker. However, both parents had been advised to access adult social care support for the young person and had acted on that advice.

9.5   Parents' comparisons of support from children's and adult services

The accounts of some parents provide enough detail to enable us to make a comparison between their experiences of both children's and adult service support, in both health and social care. There were three overarching issues identified in this exercise:

- the loss of a 'key worker' role
- the shift in from proactive to passive service support
- the unsuitability of care environments in adult services
- the identification of mental health as the main need.

The loss of a 'key worker' role in adult services
Many young people and their parents went from being supported in children's services, to receiving little or no support in adult services. For some parents, such support provided by children's services resembled a key worker role, in that one person acted as the first port of call and coordinated many aspects of the young person's care. A range of professionals were cited that appeared to fill this key worker role – a community nurse, or a children's social worker.

Parents' accounts suggest that these professionals played a vital role in coordinating many aspects of support for the young person. For these parents, this key worker role was lost once the young person left children's services. Some parents found this loss quite difficult, especially within the context of experiencing significant changes associated with transferring from children's to adults services including the lack of a generic specialist within adult health care, and the different ethos of adult services compared to children's services. One parent described this loss of support as 'quite extreme'.

The shift from pro-active to passive service support

The data also suggests families experienced a change from support being pro-active in children's services to passive and reactive in adult services. For example, parents described how children's social care offer help, but the responsibility for being pro-active shifts to the parent once the young person is in adult services:

> They don't come knocking at your door, it's up to you to find the help.

A number of parents described similar experiences, finding adult services comparatively less forthcoming with support than children's services. In some situations this may have been due to the individual nature of the practitioner. Other parents believed that the heavy caseloads in adult services forced staff to refrain from being more proactive and limited the amount of support they received.

The potential implications of this shift in how support is extended to families should be considered. When support becomes passive, and parents take on more responsibility for accessing care, this can affect the parents' well being. As described earlier, one parent described the responsibility as 'utterly draining' and others describe similar impacts of being responsible with little other support.

The unsuitability of care environments in adult services

When comparing parents' experiences of children's and adult services, another issue that was identified related to the perceived inappropriateness of adult day and short-term care environments in terms of the young person's chronological and developmental age. Some parents also perceived these as environments which were not safe for their child:

> she's still very much like a little, little girl, and there are men and women there up to the age of, in their seventies ... and obviously she's very, very vulnerable, being around vulnerable males concerns me a little bit.

The identification of mental health as the main need

For some parents the transition from children's to adult services was associated with the young person's mental health needs being explicitly identified as the main need. For example, the transfer of a young person from the care of a paediatrician to a psychiatrist, or from a disabled children's team to an adult mental health social care team (as opposed to adult learning disability team). Parents sometimes struggled to come to terms with this. They either felt that the young person's learning disability was the primary issue and/or were concerned that their child was being labelled as having a mental health problem.

9.6   Evidence from the surveys of parents and young people

The parents' survey

Just over a quarter of parents of young adults with ASC who were invited to take part in the survey completed a questionnaire, yielding a sample of 29 parents. This sample represented 23 young men and 5 young women (1=missing data) aged 18-24 years. Most

were reported by the parent to have HFA (7%) or Asperger's syndrome (65%), with just under a quarter simply described as having autism (24%).

As with other sets of analyses of the survey data, small sample sizes and variable response rates across the sites (see Appendix H) means we have kept the analysis at a whole sample level and constrained ourselves to simple descriptive statistics. It should be emphasised that the sample recruited to the survey is not as representative sample. Therefore, the figures presented should **not** be taken to be indicative of the general population of young people with ASC. However, despite these limitations these data do provide additional evidence on parents' perspectives of the needs of their sons and daughters with ASC in as they move towards adulthood and, for some, transfer from children's to adult services.

The management of the transfer between services and settings

The survey asked parents to report their views on how well transfers between services and settings were managed. Parents' responses are set out in Table 9.1.

Table 9.1   Parents' report of the management of transfers between services and settings

Nature of transfer	Number of parents responding to each response option		
	Managed well	*Managed OK*	*Poorly managed*
Children's to adult social care (n=13/29[15])	1	2	10
Children's to adult health services (n=15/29)	3	3	9
Children's to adult mental health care (n=12/29)	2	4	6
School to further education (n=21/29)	5	4	12
School to day services (n=7/29)	1	1	5
School to paid work (n=8/29)	2	6	8
School to voluntary work (n=5/29)	2	3	5
College to day services (n=5/29)	1	4	5
College to paid work (n=7/29)	0	0	7

The data displayed in Table 9.1 suggests that, for parents who took part in the survey, the majority found transfers between services and settings which occurred when their son or daughter left school or was no longer eligible for children's services were poorly managed. Unfortunately, the size of the sample prevents us from exploring the factors (such as nature of the child's diagnosis) which might be associated with these experiences.

Parents' perceptions of unmet need

---

[15] This figure refers to the number of parents who reported a transfer experience. Reasons for a response not being available include: those who failed to answer the question; those who ticked 'don't know' or 'not applicable'.

We also asked parents to report their son or daughter's unmet needs with respect to 24 areas of a young adult's life and the services they might use. Parents responses are displayed in Table 9.2. We have grouped needs/services into the following loose thematic categories: skills and functioning; services and service transfers; learning and achieving; independence and growing up; coping with change; and participation and advocacy.

The areas where over half of parents who completed our survey reported unmet need spanned most areas of a young adult's life and related to:
- acquiring independent living skills
- short breaks[16]
- career and employment opportunities
- identifying and achieving future goals/aspirations
- leisure / social life
- adult relationships/sex education
- emotional development
- support to prepare for, and adapting to, change
- advocacy
- opportunities to express aspirations for the future.

Over half of parents reported that, at the time of completing the survey, their child had ten or more unmet needs. Just two parents reported no unmet needs for their son or daughter.

---

[16] It should be noted that this might be reflecting parents' desire for breaks from caring as opposed to the young person's need for a break from being cared for by parents.

Table 9.2   Parents' perceptions of the needs for their young adult son or daughter (n=29)

Need/service	Help not needed	Getting enough help	Need (more) help
SKILLS AND FUNCTIONING			
Communication (n=29)	6	11	8 (32%)[17]
Mobility (n=26)	17	2	7 (27%)
Community equipment (n=24)	18	4	2 (8%)
Behaviour (n=26)	7	10	9 (35%)
Independent living skills (n=25)	5	7	13 (52%)
Self-care (n=22)	12	3	7 (32%)
SERVICES AND SERVICE TRANSFERS			
Social care (n=25)	8	8	11 (44%)
Short breaks (n=26)	11	1	14 (54%)
Transfer to adult health (n=24)	6	9	9 (37%)
Transfer to adult mental health (n=26)	9	7	10 (38%)
LEARNING AND ACHIEVING			
Further education/training (n=24)	6	8	10 (42%)
Career/employment opportunities (n=23)	4	4	15 (65%)
Identifying future goals/aspirations (n=29)	2	10	14 (54%)
Achieving future goals/aspirations (n=29)	1	6	17 (71%)
INDEPENDENCE AND GROWING UP			
Leisure/social life (n=24)	3	6	15 (63%)
Housing (n=24)	11	4	10 (40%)
Benefits/finances (n=26)	6	8	12 (46%)
Transport/getting around (n=25)	9	9	7 (28%)
Adult relationships/sex education (n=23)	7	4	12 (52%)
COPING WITH CHANGE			
Emotional development (n=26)	5	7	14 (54%)
Support to prepare for changes ahead (n=25)	3	6	16 (64%)
Adapting to change (n=25)	2	7	16 (64%)
PARTICIPATION AND ADVOCACY			
Someone to speak on behalf of (n=27)	5	7	15 (56%)
Opportunities to express aspirations (n=25)	4	7	14 (56%)

---

[17] For ease of reading, we only report the % of parents reporting unmet needs.

Parent-child dyad agreements on needs associated with young adulthood

An estimated response rate of just under 17 per cent (n=20/118) was achieved for the survey of young adults with ASC. This sample size was further reduced by the fact that responses from seven of the young people could not be used because demographic and diagnostic data was not available. Thus the final size of the post-transition sample was just 13 young adults (ten young men, three young women) aged 19-24 years (mean=20 years). Of these ten completed the full version of the questionnaire which included reporting needs associated with transition. (Three young people completed the shorter or symbols-based versions.)

We chose to approach the analysis of the data on perceived needs associated with young adulthood by investigating agreement within young adult-parent dyads on this issue. Young adults and parents were asked about 21[18] need areas, with the following response options: 'don't need help'; 'getting enough help'; 'need more help'. All the young adult-parent dyads for whom this data was available concerned young adults with HFA or Asperger's syndrome. Findings from this analysis are presented in Table 9.3. We would stress that what is presented can only be interpreted as representing those dyads who completed the survey, as opposed to young adults with HFA or Asperger's syndrome more generally.

Within Table 9.3 we have highlighted (in bold) those areas where at least a 30 per cent (an arbitrary figure) of dyads 'disagreed'. Areas of 'disagreement' (on the presence of a need **or** the extent to which the need was being met) were: communication, mobility[19], independent living skills, identifying and achieving future goals and aspirations; leisure/social life; adult relationships/sex education; support to prepare for changes ahead; and opportunities to express aspirations. The areas where 'disagreement' was most frequently observed within young adult-parent dyads were: the young adults need for help with 'adult relationships or sex education' and 'independent living skills'.

It is important to remember that, for each of these needs, the source of these observed 'disagreements' lay in a perception that: help was not needed **and/or** that the need was being met **and/or** there was an unmet need. Sample sizes are too small to analyse the data on transition support needs in terms of the source of disagreement between dyads.

However, in terms of the areas where 'disagreement' was most frequently observed, we can report that for the 'adult relationships/sex education' area of need, where there was 'disagreement' between the young adult and parent it lay in the young adult perceiving they were getting enough help whilst the parent reported the young adult needed more help. Where there was disagreement within dyads in terms of the need for help with 'independent living skills', this arose both from dyads 'disagreeing' about the presence of the need and, for those where there was agreement about the need for help in that area, whether or not the need was being met or unmet.

---

[18] The item 'Help with short breaks or respite' was removed from this analysis due to concerns that it may have been interpreted as a need for the parent, not the young person.
[19] This somewhat ambiguous term may have been interpreted as travelling about as well as mobility needs associated with physical impairments, for example.

Table 9.3   Number dyads in agreement about need

Need/service	Number of dyads in agreement
SKILLS AND FUNCTIONING	
Communication	**7/10**
Mobility	**7/10**
Community equipment	8/9
Independent living skills	**5/10**
Self-care	6/8
SERVICES AND SERVICE TRANSFERS	
Transfer to adult health	8/9
Transfer to adult mental health	8/10
LEARNING AND ACHIEVING	
Further education/training	7/9
Career/employment opportunities	8/10
Identifying future goals/aspirations	**7/10**
Achieving future goals/aspirations	**7/10**
INDEPENDENCE AND GROWING UP	
Leisure/social life	**7/10**
Housing	6/9
Benefits/finances	9/10
Transport/getting around	8/10
Adult relationships/sex education	**3/8**
COPING WITH CHANGE	
Emotional development	8/10
Support to prepare for changes ahead	**7/10**
Adapting to change	8/10
PARTICIPATION AND ADVOCACY	
Someone to speak on behalf of	8/10
Opportunities to express aspirations	**7/10**

9.7   Young adults' views of their unmet support needs: qualitative evidence

A minority of the young adults we interviewed explicitly stated that they felt they had unmet mental health needs. Others noted the need for support from agencies with an expertise in ASC who could assist with managing everyday life and the transition to adulthood.

For some, the lack of support served to emphasise their isolation:

> *I didn't choose to get independent, I was forced to be independent. … I wanted and needed the support through the whole time of me growing up … and obviously going into adulthood and that, I needed the support. I didn't get the support so in a way I did get forced into being independent. I literally had to go out into the world with no help or nothing.*
>
> (Karl)

A number of young adults believed the lack of support within adult services for young adult with Asperger's syndrome or HFA reflected a lack of awareness within society of ASC, and disability more generally, and its impact on individuals and families.

> *I'm just so angry with so many things. There's, there's nothing in place for disabled people, at least not where I live. … I just think the whole system's a shambles. There's no services for disabled adults and I find it quite shocking. I think it's an outrage. There's, there's basically, practically no help unless you're a drug addict or you're abusing someone or you're a juvenile delinquent. … I think if you're a disabled person trying to do the best for yourself, trying to really make something of yourself, you just get no help, you just get ignored.*
>
> (Charley)

Amongst those young adults not using adult services, there was general recognition of the important role that their parents continued to play in their lives. Many acknowledged that an absence of formal support placed additional responsibilities on their parents and that this could be 'hard work' and stressful.

> *We've had no help whatsoever from any other outside agency, it's just been my Mum helping me out. She's done a brilliant job as well but some help from another agency would have been great.*
>
> (Charley)

> *Int: If you hadn't had your Dad, what do you think it would have been like?*
> *YP: I'd be struggling a lot, if I didn't have my Dad I would be struggling, probably living on the streets of something.*
>
> (Greg)

9.8   Summary

This chapter has covered four key areas: parents and young people's reports of mental health transfers; parents' experiences of social care transfers; parents' perceptions of the differences in support received from children's and adults services and, finally, the perceived unmet needs of young adults. In the course of this chapter we have drawn on data from the qualitative interviews with parent and young people and the findings from our surveys of parents and young adults.

Within our interview samples (parents and young people), experiences of mental health transfers were very limited and extremely mixed. The accounts of one young person clearly illustrated that anticipating this particular transfer can be very stressful. The impact of interrupted mental health provision, or the loss of support, on young people's (and parents') well-being were described by both parents and young people. A lack of continuity in mental health support coupled with the need to develop a new therapeutic relationship at a time when multiple changes were potentially occurring in a young person's life were particular concerns raised by our interviewees.

In terms of experiences of social care service transfers, again only a small proportion of parents interviewed had experience of this. Within our sample of parents, experiences of this transfer were not positive. Parents were dissatisfied with the way the transfer had been planned or, more specifically, the lack of pro-active planning. Early experiences of adult social care were sometimes difficult for parents. However, despite negative reports of planning around this transfer, the longer term outcomes for the young person of moving to adult social care were perceived, by some parents, to be positive.

Parents whose son or daughter had experienced a loss of support (mental health or social care) at transition often reported that this had placed additional burdens on them as they sought to meet their child's needs.

Parents noticed qualitative differences in the ethos and delivery of children's and adult social care. A number of parents mentioned the loss of a practitioner acting as their key-worker: a role (formally or informally) assumed within children's services by a range of practitioners. The loss of this support, especially at a time of significant change in services and support, was felt acutely by some of the parents we interviewed. Parents also perceived adult services to be passive or 'reactive' as opposed offering support proactively. Some of the parents we interviewed drew attention to the way this increases parents' 'workload' and responsibilities as they seek to ensure their child's needs are met.

There are some principles to draw out of parents' and young people's accounts in terms of practice which support a positive transfer experience. Providing adequate notice of impending changes and addressing information needs associated with those changes were important features of a positive transfer experience for one young person. Having confidence that timely and proactive planning was in progress, thus absolving parents of the need to 'chase' services, would have improved the service transfer experiences for some parents. Equally important is a sense of being properly involved in planning and decision-making. Finally, the findings reported in this chapter raise a question as to whether or not it would be good practice to 'warn' families about the differences in the approach or ethos of children's and adults services. A 'dilution' of support, and a less pro-active approach, was something that some of the parent and young people interviewed reported they had found difficult to adjust to.

Following these qualitative accounts of mental health and social care transfers, we turned to describe some of the findings from our survey of parents. In particular, we focussed on parents reports of unmet need post-transition. High levels of unmet need and across many areas of their sons and daughters lives were reported by the parents who participated in the

study's survey. Sadly, low response rates means we can draw even tentative conclusions from our data in terms of the extent to which this reflects the experience of parents of young adults with ASC more generally. However, we would argue these data serve to illustrate the potential for wide-ranging and high levels of unmet need being experienced by young adults with ASC.

This chapter also reports the findings from an exploratory analysis of agreement within young adult-parent dyads regarding the existence of a support need and/or whether that need was being met based on responses to the surveys. For the dyads who completed the surveys, the areas where 'disagreement' between young adults and parents were most frequently observed were needs for help with adult relationships and sex education (parents consistently perceiving unmet needs but the young adults not), and independent living skills (no consistent pattern underlying the occurrence of disagreement).

The final two sections of this chapter reported on young people's views of their unmet support needs. A sense of isolation and anger at the lack support were two of the emotions expressed by the young people with interviewed. Some young people were very aware that the lack of services placed an additional burden on their parents.

Chapter 10

Meeting the Mental Health and Social Care Support Needs of Young Adults with HFA and Asperger's Syndrome: Practitioners' Views

10.1 Introduction

Access to support from statutory adult mental health and social care services by young people with HFA and Asperger's syndrome was a key area of concern raised in our interviews with practitioners, young people and parents. This chapter reports on the ways that the five research sites had responded to this issue and on the availability of adult mental health and social care support for these particular groups of young adults with ASC.

To begin we briefly report strategic activities in the research sites in terms of transition planning and ASC specific provision which was particularly concerned with young people and young adults with HFA or Asperger's syndrome.

The main section of the chapter describes provision in the research sites which met the mental health and social care needs of young adults with HFA or Asperger's syndrome who, in the absence of an acute mental health need or complex care needs, were ineligible for acute mental health support or support from adult social services. We would stress that this cannot be taken as comprehensive account of provision in the sites and, given the data was collected in 2010 and therefore prior to the publication of the Strategy for Adults with Autism, it may well not reflect the current provision. However, it does provide useful insights into the ways localities were responding to the needs of young adults with HFA and Asperger's syndrome as well as the gaps in that provision.

Support for young adults with ASC and learning difficulties and their families
Before moving onto to report our findings we would stress that, by taking this particular emphasis in this chapter, we are not implying that support for young adults with ASC and learning difficulties, and for their families, within adult statutory services is unproblematic. It is very clear from parents' accounts (see Chapters 6, 7, 9 and 12) that there could be significant concerns and unmet needs for families with a child with ASC and learning difficulties. Indeed, practitioners also voiced concerns and an awareness that current service provision is, or may, be inadequate. In particular, the lack of specialist ASC provision and the demise of conventional day centres within adult services were two key issues emerging from the interviews with practitioners:

> *It's OK to close down all these day centres, but what do you replace them with in terms of social coming together? They're not just occupation, they're places people are familiar with and they know they're going to see people there and all that kind of stuff.*[20]
> (Manager, Connexions service)

---

[20] Verbatim quotes are used to illustrate points made in the text.

10.2 Strategic work

Transition steering groups
Multi-agency transition steering groups existed in each of the research sites and typically included representation from the transition team, a transition nurse, children's social care, adult social care, CAMHS, adult mental health services, Connexions, special schools, mainstream colleges, and occasionally commissioners, representatives from the NAS and other disability specific organisations, housing, parents and young people with disabilities. Transition steering groups typically met three to four times per year. The strategic steering groups oversaw the transition team and service; aimed to ensure that services were linked up; identified any gaps in the local provision of services; and worked on the strategic development of transition pathways for all young people with disabilities. In short, they aimed to deliver/progress outcomes from the Transition Support Programme. Members of these steering groups reported that the issue of eligibility for adult social care support for young people with HFA and Asperger's syndrome was an issue which was discussed, and the suitability of/eligibility of support from adult learning difficulty or mental health teams considered. Some groups had undertaken to identify third sector organisations which could provide support for those not eligible for adult social care. Three sites also reported having ASC- specific transition sub-groups and part of their remit was strategic planning for services and support for young people with HFA and AS.

ASC strategy groups in adult services
The Autism Act and forthcoming Strategy for Adults with Autism had led to the setting up of ASC specific reference groups in adult services in at least two of the sites. Interviews for this study took place before the Strategy was published thus the groups that existed were in their infancy and other sites may well have established similar groups since the time of the interviews (summer/autumn 2010). In one site (C) the group had established a training plan for staff, including social workers, based upon consultations with people with ASC and with Asperger's syndrome. In the other site (E) the group was tasked with ensuring that each criterion in the Strategy would be met locally. The group was thus putting together a training package around autism awareness; working to increase the number of people with ASC in paid employment; and ensuring that all people with ASC would have access to a care assessment and care package if eligible.

10.3 Mental health and social care support for young adults with HFA and Asperger's syndrome

Across the research sites, young adults with ASC and learning disabilities (with an IQ below 70) were typically eligible for adult learning disability (LD) social care services. Interviewees reported that, in the absence of any other significant difficulty (for example, mental health needs; complex health needs) young adults with HFA or AS were not eligible for support from statutory adult social care. However, it was recognised that these young adults may well have support needs and but are currently at risk of both falling through the gap between adult LD and adult mental health social care, and being ineligible for support from adult mental health services.

This section describes the services and support which were available for young adults with HFA or Asperger's syndrome in the sites, focusing particularly on describing specialist autism-specific services. We cover provision from statutory agencies, typically being delivered by NHS mental health trusts or integrated NHS (mental health) and social care trusts, as well as that being provided by third sector organisations.

Community mental health support

In all the sites, adult community mental health services were reported to be supporting young adults with HFA and Asperger's syndrome. For example, in one site (D) young people with HFA or AS who were not eligible for adult learning disability services, but nonetheless required support in adulthood, were picked up by the community mental health teams via the transition tracking sub-group meetings. Those with more complex needs or those in need of more intensive support were referred to a specialist team who worked specifically with young people and young adults with Asperger's syndrome (see below). It appeared that some of these services applied 'lighter' eligibility criteria to enable young adults with Asperger's syndrome to access the service.

Specialist community mental health support to young people with Asperger's syndrome over the transition period

The mental health NHS trust in one of the sites (D) had a specialist team based in community services which provided support to young people with Asperger's syndrome (aged 16 years and upwards) during the transition period. The focus of the team's work includes: reducing social isolation and mental health difficulties; independent living skills; supporting and enabling young people to stay in school, college or move on to University; developing employment opportunities; linking and coordinating with other support services. The service also offered post-diagnostic emotional support.

Specialist integrated support for adults with Asperger's syndrome and a mental health problem

In one of the sites (B) an integrated mental health and social care trust had developed an 'Asperger Specialist Team' which was based in adult mental health. Adults with Asperger's syndrome and a mental health problem were eligible for support from this team. The team had been in existence since 2005. Referrals to the service were via community mental health teams. The team provided specialist assessments (including diagnosis) and advice and support to adults and their families regarding mental health and social care needs. The support provided was therefore wide-ranging and included: the development of independent living skills, accessing supported accommodation, advice on health matters, family interventions, anger and/or behaviour management support, and supporting the move to University.

Autism-specific outreach support

Autism-specific outreach services were identified as being provided in four of the five research sites. Typically these were being delivered by autism-specific third sector organisations.

Sometimes these services were commissioned by statutory services and (part) funded by health and/or adult social care budgets; alternatively access to support from the service was

funded at an individual level through individual budgets. In other instances the outreach services sat outside of statutory provision and there were no formal links between the third sector service and statutory agencies. In some sites more than one provider was providing outreach support.

Outreach support is, by definition, holistic and outcomes-focussed. The roles and activities of the outreach services were therefore wide-ranging and focussed on supporting individuals to achieve positive educational, employment and independent living outcomes as well as providing social and leisure opportunities and emotional and mental health support.

There was some variation between sites as to eligibility in terms of age. Interestingly, a number of the outreach services we identified were doing specific work on transition support or those of transition age. These are described in more detail in Figures 10.1 to 10.3.

Figure 10.1   An outreach service for young people and adults with ASC

A third sector specialist autism service located in Site E was joint funded by health, adult social care and a social enterprise investment fund. It offered support to any young person aged 16 and over wherever they sat on the autistic spectrum, but worked predominantly with those not eligible for adult learning disability services or adult mental health services (i.e. those with HFA or Asperger's syndrome). There was no upper age limit to the service but it was reported that almost half of the service's entire case load was of transition age (16-21).

Figure 10.2   Transition specific outreach support

A third sector all-age outreach service located in Site A had recently employed an adult services worker to specifically work with 19-25 year olds across the autistic spectrum, including those with HFA and Asperger's syndrome. The primary purpose of this post was to support young people and young adults not in college or in receipt of any other service who may be at home and becoming increasingly isolated. Support included taking individuals out into the community, working to improve their self-confidence, and offering support into employment. There were no formal links between this service and statutory agencies.

Figure 10.3   Transition specific outreach support

In site D the local branch of a national autism organisation provided a college course for young people with HFA and Asperger's syndrome, in partnership with a local mainstream college. The two year supported learning course acted as a stepping stone into accessing employment or mainstream courses at the college (or beyond). Aimed at young people aged 16-18, the course was tailored around helping young people with HFA and AS achieve and maintain the skills needed to cope and to function in a college environment, including improving numeracy and literacy and boosting their confidence through, for example, Duke of Edinburgh activities.

Day services

In two sites (B and D) a national autism organisation offered a day service for adults with ASC, including young adults with HFA and Asperger's syndrome. Those with HFA or Asperger's syndrome who used the day services were typically struggling with the move from school to college or from college into work. The purpose of the day service for these young adults was, therefore, to provide opportunities for peer support and to support the young person to develop the skills and confidence required to move into employment. Most attended day services on the basis of funding from adult mental health.

10.4   Summary

This chapter has described sources of mental health and social care support for young adults with HFA or Asperger's syndrome being provided in the five research sites. It should be noted that the research sites were selected partly on the quality of their ASC provision and so the nature and range of services identified may not have represented provision more generally in England at the time the data was collected.

Community mental health teams were identified as a potential source of support for young adults with HFA or Asperger's syndrome. The multi-disciplinary nature of these teams and their holistic approach offered the opportunity to provide support to these young adults which would enable them to achieve outcomes such as independent living, employment or remaining in further or higher education as well as addressing emotional and/or mental health needs.

Specialist Asperger community mental health teams had also been set up in two of the research sites, one of which was an integrated service with adult social care. The other team worked specifically with young people and young adults over the transition period. At the time of data collection, community-based outreach support was being delivered in four of the five research sites. Typically, statutory agencies were using autism-specific third sector organisations to provide these services. Funding was either through service level agreements or on a case by case basis and individual budgets had been used in these

instances. As was the pattern with community mental health services, in two of the sites the outreach service reported being particularly engaged with supporting young adults with HFA or Asperger's syndrome.

Day service support which young adults with HFA and Asperger's syndrome were eligible to use was only available in two of the research sites. This was provided by an autism-specific third sector organisation and places were funded by adult mental health.

Overall, there was greater mental health and social care provision in some sites than others. One site appeared relatively weak in terms of community/outreach support for young adults with HFA and Asperger's syndrome. Mental health emerged as leading on provision and funding, though there were examples of joint adult social care and mental health budgets being used to purchase services.

Chapter 11
Moving towards Adulthood:
Young People's Experiences and Aspirations

11.1   Introduction

In this chapter we report our analysis of how the young people we interviewed spoke about independence and adulthood. We remind the reader that these were all young people diagnosed with HFA or Asperger's syndrome. They were aged between 16 and 25 years (see Chapter 2, Section 2.5).

We centred this set of analyses around six 'indicators' associated with moving towards adulthood: independent travel; developing and engaging in new leisure interests and activities; employment; financial independence; moving away from the family home; and changing and developing social relationships. These were all outcomes which the young people identified as being important to them and/or were perceived as being key achievements or indicators of 'growing up'. Our findings are reported around these themes. We report the achievements and aspirations of the young people in the different areas of their lives and the roles played by services and parents in supporting the young people's moves toward adulthood.

11.2   Independent travel

Developing independent travel skills was the area where the young people were most likely to report progress. Three-quarters of the young people we interviewed were travelling independently, albeit sometimes in a relatively limited way (for example, specific bus routes or train journeys). Only a minority (three young people) viewed independent travel as something for the future and were, at the time of the interviews, ambivalent about developing these skills.

Being able to travel independently was clearly something that most of the young people valued and was regarded as a concrete indicator of a more general movement towards independence. It also enabled them to engage in other activities independent of their parents or other support:

> Int: And do you like going out by yourself on the bus?
>
> YP: Yeah, sometimes it feels quite exciting, almost like being an adventurer or something. Though admittedly that's, that's a very grandiose way to describe, describe I went on the bus so I could buy a few games and go to Pizza Hut and then come back.[21]
>
> (Matthew)

---

[21] Verbatim quotes are used to illustrate points made in the text.

A range of modes of transport were discussed; however, using the bus was the most popular (11 young people), followed by learning to drive a car (five young people). Independent travel by bicycle (one young person) train (one young person) and motorbike (one young person) were far less common. Only four young people noted the importance of being able to walk to places without assistance or being accompanied by other people.

The outcomes of being able to travel independently
The young people we interviewed identified a number of outcomes associated with being able to travel about independently. First, it gave them greater choice and control over how they spent their time. For example, five young people valued being able to catch the bus into town whenever they wanted to. Some of the young people linked the choice that independent travel brought them with a corresponding extension to their social life, for instance, being able to meet up with friends in town:

> *When I've got my drivers licence I can drive into town. Yes, I think I will be able to go out, like go to the movies one day on my own.*
> (Stuart)

Appreciation of this independence was reinforced for some, as they recognised their current or previous dependence on parents. This was particularly the case for young people living in rural areas:

> *I'm learning to drive, so hopefully, like I've had over like 50 odd lesson now, it's not, it's not easy, so hopefully I'll soon be able to drive and I'll be able to get away more.*
> (Emily)

Acquiring independent travel skills also appeared to increase some young people's confidence and sense of self-worth. In particular, Karl noted that he was confident in his driving ability, it was something he could do and felt comfortable doing. Achieving this tangible and respected symbol of adult success was especially important to Karl, as 'success' had been limited in other areas of his life, particularly, in terms of educational achievement.

Support with travelling independently
The young people were asked about the support they had received which enabled them to travel about independently. Parents were frequently mentioned as a source of practical and emotional support in developing independent travel skills. Three young people had received formal 'travel training'. Access to free bus passes was identified by some as a key factor in allowing them to utilise their travel skills and support their independence.

The parental role
A number of young people reported that their parents (typically mother) had played an organisational role; for example, researching driving schools and booking driving lessons, making applications for bus passes. Parents were also typically paying for driving lessons and/or public transport fares:

> *It was Mum who paid for most of the driving lessons and also paid for the tests.*
> (Sophie)

Most young people accepted this 'dependency' on their parents; however, a minority perceived it as an indicator on continued dependency.

It was clear from the young people's accounts that parents also offered emotional support and encouragement; this was most apparent amongst those learning to drive. For some, learning to drive was felt to initially be or had been a 'scary' prospect. Being able to talking to parents about their fears or concerns was welcomed. Parents' encouragement and 'can do' attitude also service to boost the young people's belief in their own abilities:

> *YP: At first I thought, 'Oh god, he's going to take me straight onto a busy road where there's other cars!'. But Mum just told me, 'He's not going to take you straight on. He would never take you straight onto a road with other cars'.*
>
> *Int: So how do you feel now your Mum's told you that?*
>
> *YP: I feel a lot better now.*
>
> (Stuart)

Experiences of travel training

Three young people had undergone formal travel training, organised either as part of preparation for going to college or within a broader independence skills curriculum. All reported positive outcomes from this training. One young person in particular valued the scheme he attended. It had been very comprehensive and phased practitioner support was a fundamental element. At the time of the interviews this young man appeared, perhaps, as the most confident independent traveller, reporting that he was comfortable using buses, trains, had a motorbike licence and also planned to begin learning to drive in the near future.

Bus passes

Four of the young people we interviewed were clear that, without their free bus pass, the extent to which they travelled about (and the opportunities that afforded) would be significantly curtailed:

> *I like getting the bus because, because I'm autistic and, and because I've got a disability I can use my bus pass. I'm allowed to go on free, well pay a £5 thing for the, for the card.*
>
> (Katy)

Realism and personal limitations

Independent travel was however, an area where some of the young people were aware of their own disability and how this could or had guided the type of independent travel they chose or, aspired to use. This was most clearly demonstrated with regard to learning to drive. Ian and Katy did not view learning to drive as realistic due to their dyspraxia and associated poor co-ordination. In addition, whilst not completely ruling out the possibility of learning to drive, three other young people felt they would need "extra" help and support from other people. This was due to either perceived co-ordination or concentration difficulties. Public transport was avoided by a small number of the young people, as it was viewed as too stressful and anxiety provoking. Whenever possible, both Charley and

Edward avoided travelling by bus and preferred to use more private modes of transport such as, taxis. Taxis were preferred as these young people felt they would be less likely to encounter or be forced to engage in public interaction and unplanned social situations. This was important to Charley and Edward, as they were both aware that limited social skills were a significant part of their Asperger's syndrome.

Many of the young people described becoming increasingly confident in their ability to travel independently into town or around their local area. However, some felt that they would need extra help and support if they travelled further afield to new places or into unfamiliar contexts. A common fear when travelling in unfamiliar areas was not getting off a bus or train at the right stop:

> *It's fine me getting on a train, it's just where to get off. It's getting off and… 'cos if I stay on the train and go all the way to London or something.*
> (Greg)

> *Yeah, I can get to town on my own. I couldn't if, if I wanted to go to London. Now that'd be a different matter, I'd have to get the, the… someone would have to help me get the train or I'd have to go with someone. Further afield places I can't get to. I'm fine if I'm going to town and I'm fine going to my youth club, which is round the corner and I'm fine going to the park. So it's local things I'm OK with.*
> (Katy)

11.3   Leisure time activities

Another indicator of the transition to adulthood is engaging in new interests and activities and taking personal responsibility for organising and accessing them. This was not an area where high level of independence was observed. Questions about how the young people spent their spare time revealed that over half (10 young people) preferred to do things which were solitary and home based, such as playing computer games or pursuing specific interests such as fishing or model making:

> *Well I prefer to be, to stay at home cos I'm more of a home boy.*
> (Steven)

For the vast majority of the young people we interviewed, going out with friends was not a frequent or routine event. Only two young people said they regularly went out independently with friends and viewed this as the 'norm'. For example, Andrew described how he went to the cinema with a friend every Monday afternoon. Instead, when social/ leisure time activities were discussed, the young people tended to refer to going to organised clubs/groups or doing things that other people had organised for them.

Thus, four young people had social activities organised for them by either a mentor/social buddy or their support worker. The activities described included going bowling, to the pub and having days out, such as watching a cricket match. Mentor/social buddy organised

activities usually involved only the young person and their mentor whereas activities organised by support workers were more frequently group based. Three young people reported attending a youth club with peers of a similar age. These clubs were clearly an important source of social contact but it was also apparent that they were 'special' clubs and the young people were aware of this and described their friends as generally having 'special needs'.

Just two young people were engaged in mainstream groups: both were learning to dive. It is interesting to note that, in both cases, this was something their parents had investigated and organised for them.

ASC specific provision
Some young people had a clear preference for doing leisure time activities in 'specialist' settings and. ASC specific clubs were seen as particularly appealing. However, only a small minority had accessed such groups.

Three reasons underlay this preference for ASC specific provision: the staff understood about ASC; there was an empathy with the other young people based on the shared experience of ASC; and being with peers with ASC normalised her situation and experiences:

> *I now go to a youth group called 'Getting on' … it's mostly people with, I've recently discovered that it's mostly people with ASD, or with some form of it, so it makes us feel normal if you like.*
> (Sophie)

This young woman believed that this atmosphere of understanding and acceptance made her feel more relaxed and confident, and socially, it was also viewed as less threatening. Her preference for ASC specific groups rather than more generic disability groups was based on past experience of feeling she had little in come with young people with impairments different to hers:

> *If you go into a youth group and it's not all the sort of the same, so there's people with different disabilities and different, all that sort of stuff. You feel, sometimes you can feel a bit like an outsider, if you like, if you're more able bodied that the rest of them. With 'Getting on', there are people of equal, if you like, cos we've all got ASD or some form of autism, so we're on an equal level, feel normal.*
> (Sophie)

At the same time, some of the young people acknowledged that, whilst they had a preference for ASC-specific groups or activities, this was not the case for others with ASC:

> *Um, one of my friends called Duncan, he, he has autism but I don't, I don't think he really wants that sort of help and then the same with my friend Luke, he doesn't want that, he wants to just kind of do his own thing.*
> (Katy)

11.4 Employment

Within the sample of young people we interviewed, having a paid job was valued and viewed as 'part and parcel' of adult life. There was a general perception that employment was 'the next step' after college: it was something that people just did. However, few of the young people had a job or had had any experience of paid employment.

Amongst the six young people no longer in education, none of them had paid work, either full-time or part-time, and only one had any experience of paid employment. However, five described themselves as actively, or soon planning to start, searching for a job. In the meantime, two of the young people were doing voluntary work. Just two of the young people still in education had any experience of paid work through part-time jobs. A further three young people were combining their studies with part-time voluntary work.

Aspirations
When the young people talked about employment, this was generally presented as 'having a job'. Some of the young people were more focused as they wanted to do a certain type of job, such as working with animals or being a mechanic and this was typically related to the college course that they were currently doing or had completed. There was an element of caution in some young people's aspirations, with routine or 'low level' jobs felt to be the most appropriate type of 'starter' jobs for them. Five of the six young people actively seeking work felt it would be best, especially initially, to work part-time. Full-time work was viewed as potentially too demanding and socially stressful:

> *Why do I only want part-time? Because it will be just a lot better for me and a lot easier and not so stressful.*
> (Andrew)

> *… a part-time job to start off with would suit me … to trap myself straight into a full-time job straight after college (where only attends three days per week) would possibly not be a good idea.*
> (Sophie)

Just three young people discussed having a specific 'career' which required higher education qualifications:

> *I'm there [at college] to study basically, I'm there to study and to get my, get my A' Levels so that I can move on to university, get a degree, get a doctorate and become a scientist. I'm quite tough on that path basically.*
> (Matthew)

Only a minority of young people linked their desire for a paid job with aspirations for increased independence from their parents – either in financial terms and/or in terms of being able to travel about independently by being able to run a car. Social benefits were also anticipated by some in that having more money would allow them to do more social activities.

Voluntary work and work experience

Just under half of the young people we had interviewed had had some work experience through voluntary work and/or short periods of work experience undertaken whilst at school or at college. These unpaid experiences were viewed positively as useful preparation for future employment, in particular, as a means to experience a 'real' work environment:

> *Yeah, if I, if I apply for a shop job for instance whilst I'm at college, like working in one of the shops in town, if I tell them I've done shop work [as voluntary work] then I'll, it'll look good on me and also for the future as well.*
>
> (Sam)

Four young people also felt that their work experience or voluntary work had or had had social benefits, as it had helped develop social skills and boost their social confidence, especially, as Charley reported, in new social situations:

> *YP: It was with a theatre group, they wanted me to help, they wanted me to do the animation, just a couple of animations because that was tied to the course that I was doing*
>
> *Int: And how did you find that?*
>
> *YP: Um, yeah, it was quite, it helped me actually. It helped me feel a lot more independent and a lot more, I'm not sure what the word is, … but it helped me feel a lot more independent and I thought I was getting myself out there. I also joined in some of the games at that group and everything and it helped me feel a lot more comfortable around people.*
>
> (Charley)

Two young people from the same authority (Site No.5) were particularly positive about their voluntary work and how they felt it supported them. Here, it is important to note that both young people worked at the same café run by a locally based charity for people with mental health conditions. This was clearly a specialist service and once again, it is the provision of 'specialist' practical and emotional support that both the young people valued. In particular, their enthusiasm for the café was based on the fact that it supported work opportunities in a relaxed and informal setting tailored to meet their individual needs. Both described this support in terms of having staff that understood their ASC needs and so paced work at an appropriate level for them, thus reducing the potential for them to become stressed and anxious. Once again, the relevance of 'sameness' was also noted, as both young people talked about meeting and working with colleagues with whom they felt comfortable and relaxed. Both these young people were aware that their parents had organised this opportunity for voluntary work, taking the initiative to find the work and organise an interview for them: they had effectively 'made it happen':

> *YP: I came home one time and he [Dad] said, 'I've got something you can do when, when you're not at college.' I was like, 'Oh god, not this again (laughs). So I was like, OK, so we went down and my Dad took me in, into "Tea and Cakes". First thing I thought was, oh this is going to be boring. It wasn't, it's learning, it's helped me to cook and clean.*
>
> *Int: So you're enjoying the voluntary work then?*
>
> *YP: Yeah, I'm enjoying it well.*
>
> *Int: How about the people there, have they been helpful?*

YP: Pretty helpful … they help me one step at a time.

(Greg)

Experiences of help and support to find paid employment

Amongst the five young people who were currently seeking employment at the time of the interview, three felt that formal sources of professional advice and support had been largely been absent and any support and advice that they had received was viewed as too general with little recognition of their ASC and specific needs. Only one of these young people reported gaining help from a supported employment advisor, however, he had been disappointed with the support he had received. The young person felt that the advisor had not listened to him, recognised or tried to understand his needs, and made what, he felt were, 'inappropriate' and unhelpful job suggestions:

YP: Yeah, people that were supposed to help me but they didn't help me, the people from the Job Centre …'

Int: Do you see anyone at the Job Centre now?

YP: No, not any more, I used to but she used to always get me the wrong job … her name was Karen and she tried to find, well tried to find people with special needs jobs really.

Int: Why don't you see Karen anymore?

YP: 'Cos she didn't help. She always got me the wrong, a job that wasn't appropriate for me.

Int: And so did you decide not to see Karen anymore or did Karen one day say to you, 'I don't think I can help you'?

YP: Well she didn't get in touch with me anymore. It just fell through… dunno

Int: How did you feel about that?

YP: It doesn't bother me really because she didn't help that much.

(Andrew)

There was just one young person whom we interviewed who had found the formal support and guidance she had (and still received) was helpful. At the time of her interview, Katy worked part-time (three hours per week) as an administrative assistant. Katy explained that she had a disability employment advisor who had, and continues to be, extremely helpful. To start, her employment advisor had helped her find a paid job whilst still at college. This had included her advisor providing practical support with completing the job application form, preparation of her CV, and practising independent travel skills to work. Katy valued her advisor's positive, 'can-do' attitude and understanding of ASC and Katy's specific needs. Furthermore, Katy appreciated her advisor's ongoing support and knowing that her advisor was there if she needed to contact her. Katy recognised that there would be times, especially, when she finished college and started looking for another job when she would need encouragement and confidence boosting. Knowing that her advisor was still there was thus important to Katy.

Support from parents

In contrast to the majority of young people's experiences of formal support, informal sources of support, especially from parents, were viewed as more helpful. For example, Andrew highlighted how his mother had contacted potential employers and organised a

couple of interviews for him. Likewise Karl valued being able to discuss interview preparations and then practice these with his mother. In contrast to practitioners' lack of ASC understanding, parents' knowledge and understanding of the young people's individual needs made the support they received from their parents helpful and effectives. Parents' involvement, interest and willingness to listen to young people was also a source of emotional support.

Perceived barriers to paid employment

The young people who were looking for, or anticipating looking for, work demonstrated an acute awareness of the barriers that they may face when seeking employment. Many identified the current economic climate as a key barrier:

> *Int: Is it hard to find a job?*
> *YP: It is in the current economic climate, cos most of the shops in town aren't taking on anybody …*
> (Sophie)

> *I'm worried that in the future there might not be any vacancies for jobs regarding vehicle maintenance [young person's career choice] and also since, since the Government are in a bit of a financial crisis at the moment, I'm, I'm afraid it might continue for another decade or so.*
> (Sam)

For some, this awareness arose from either the young people's own experiences of job seeking or the experiences of family and friends:

> *I've tried to apply for a job, you know, like working in, working in shops and cafes and things like that but it's just, there's a big waiting list. I've handed in me phone number for them to get in contact with me and I've tried applying for a paper round but money's tight at the moment.*
> (Sam)

In addition, most of these young people believed having ASC was an additional barrier to gaining paid employment. A lack of understanding of the condition amongst employers was a key aspect of this particular barrier:

> *YP: I think autism and Asperger's was only found out about 10 years ago so it's quite a new thing to research, isn't it? So people are still learning about it and employers don't know that much about it. Cos when I go for a job interview, people say, 'oh what's Asperger's' and I tell 'em and then they won't employ you.*
> *Int: And how does that make you feel?*
> *YP: Quite peed off, cos I'm still me, I'm quite an honest young person but people, they don't understand that.*
> (Ian)

One young person certainly felt he had experienced specific discrimination after writing that he had ASC on a job application form. Although not formally stated as a reason, Greg felt

that his rejection was related to his ASC and had left him angry and wary of disclose his ASC in future applications:

> *YP: … they [potential employers at recruiting interview], they just said 'have you got Asperger's or any disability or anything?' And I said, my Dad said, 'yeah, he has got Asperger's'. And they said, 'well we'll let you know.' And they, they didn't phone us back or anything, so that means no.*
> *Int: How does that, how does that make you feel?*
> *YP: Uptight and I've wanted to, I, it, well it, it makes me feel pretty angry actually cos it's, it's one thing I really wanted to do but I couldn't do it. I even said to my Dad, 'I want the Asperger's out of me' but there's no chance of that …. it's, it's with me all the time.*
> (Greg)

11.5 Financial independence

Not all the young people discussed the importance of money or its management in relation to progress towards independence. Amongst those that did, it was having one's own bank account and/or a personal allowance which were associated with becoming 'more grown-up'.

Whilst the majority of young people we interviewed had their own bank account, none of the young people felt they had taken complete control of managing their own finances and only one young person felt that he could or wanted to do so. Indeed, this young person expressed some frustration at other people managing his money, which led, as he perceived it, to a situation of daily rationing where he was given spending money:

> *Yeah, £5 a day, I would like more but … yeah, cos sometimes the £5 a day it annoys me.*
> (Simon)

Thus most felt that, although their parents were increasingly gave them some degree of financial independence, they would need ongoing support for the foreseeable future. This was frequently based on the belief that managing money, especially budgeting and understanding how banks and bank accounts work was difficult. There was a general fear of spending too much money. For three young people this was grounded in past experiences of debt, as a result of overspending:

> *I've got to say if I was on my own I'd spend too much money and get myself into debt, I have done that before.*
> (Andrew)

> *… to be perfectly honest, I'm a compulsive spender.*
> (Ian)

As with other areas of these young people's lives, the active help and involvement of parents was recognised. For example, parents had initiated discussions about having an

account, helped the young person choose a bank and complete the appropriate paperwork forms.

Money management training
Three of the young people we interviewed had receiving money management training as part of an independent living skills course. All had found this useful. They believed that the individualistic nature of the training - targeted to meet their disability specific needs, delivered at a pace they dictated and by from staff who understood about ASC, especially Asperger's syndrome/HFA – ensured its effectiveness.

11.6   Moving away from home

A very small minority of young people had moved out of the family home. Most (15) viewed such a move as something for the future: it was a 'big' step to take. This was based, irrespective of the young people's age (whether 16 or 20 years), on the fact that they did not, as yet, feel ready to leave home. Some in particular regarded it as quite daunting. There was recognition that leaving home involved assuming more control and responsibility for their lives which in turn meant learning to live without, or with reduced levels of, support from parents, especially mothers:

> *YP: Um, I don't intend to move out until like my twenties, mid twenties, late twenties/early thirties*
> *Int: Why's that, do you think?*
> *YP: Cos I'm not sure I'm ready to, to stand on my own two feet yet, cos once you leave the nest, it's basically you versus the world and if you're not ready, it's gonna all come up to you and overwhelm you.*
> (Steven)

Many also felt they currently lacked the skills required to manage everyday domestic responsibilities:

> *YP: I've still got things to learn basically*
> *Int: What sort of things do you think you've got to learn?*
> *YP: Doing my own laundry, more cooking basically and, and I don't think I'm at that stage where I can go and live on my own cos if I did, probably my house will, my whole house would be a mess really. … So I've still a lot of stuff to learn basically.*
> (Tracy)

For a smaller proportion of young people, leaving home was also viewed as a future aspiration due to economic realism:

> *Yeah, because firstly in order for me to be able to get in a shared flat or bedsit or summat, I'll need to, I'll need to get, save up some money first so I can afford it.*
> (Sam)

Perceived needs for support

The young people typically said they would need the help and support of their parents to actually move away from home, and half believed they would need ongoing help with everyday domestic tasks. Indeed leaving home was not associated with moving far away as ongoing parental support was anticipated or expected. Only one young person felt that he was relatively independent in terms of managing domestic tasks and chores. When asked why, he explained this in terms of going to residential college and the independence course he had undertaken.

Only three young people looked to, or anticipated, statutory services would help them to live independently.

Amongst those who had moved out of the family home, there were instances of high levels of parental involvement in supporting independent living:

> *Int: Does your Mum come as well [to the care support meetings]?*
>
> *YP: Yes*
>
> *Int: And do you like your Mum going?*
>
> *YP: Yes*
>
> *WM: Do you think you need your Mum to help you?*
>
> *Int: Definitely*
>
> *WM: Why do you need your Mum, do you think?*
>
> *YP: Um…. because she helps say things right, and explains things better than me… and says more things.*
>
> (Andrew)

The experiences of young people who had moved from the family home

The young people who had moved out of the family home were doing so with quite different levels of support. This ranged from living in shared accommodation with 24/7 support to living independently with limited, routine social work support. Living independently of their parents was regarded as a largely positive development. Continuity of practitioners/carers supporting independent living was particularly valued. The experience of living alone was, however, found to be lonely at times.

11.7   Changing and developing social relationships

The final indicator of adulthood we explored in our analysis concerned changes in social relationships and autonomy in organising and maintaining this aspect of their lives. In a previous chapter, we reported that for many young people the transfer from school to college had resulted in positive social outcomes such as the development of friendships with more like-minded peers. The earlier section on leisure time activities highlights the link between participating in organised activities/groups and the young people's social lives. With respect to this, three young people were very clear in their views on the positive benefits of attending autism, indeed HFA/AS, specific rather than mainstream activities or groups. In addition, those with mentors of buddies enjoyed the company and opportunities

such support gave them and recognised the positive impacts it had had on their social skills and confidence. However, only a small minority appeared to have a social life which they enjoyed and nurtured beyond these settings and support:

> *YP: … me and my support worker, and she'll take me somewhere and we can have the whole day together.*
>
> *Int: How does it help you?*
>
> *YP: Well because I have a, someone that I can see and talk to and not just that, do stuff with. Cos I mean even though I have quite a few friends it's very much, it's often at places [youth club] …*
>
> *Int: What do you think life would be like if you didn't have this sort of help?*
>
> *YP: I'd feel, I'd feel really sad cos I wouldn't have anyone that'd do that with me and I wouldn't get as many goals done because, I'd probably feel quite lonely because, I know this sounds odd, cos I do a lot during the week but when I, when I come home I get lonely. … I can get the bus now to places and I'm learning about bus timetables. Also I feel more confident because my support worker's really friendly and she really listens to me and she always takes on board what I say and we achieve stuff all the time.*
>
> (Katy)

Importantly, when future aspirations were discussed in the interview, a key theme a wish to extend their social life with more opportunities to see or go out with friends. Some young people clearly felt that their current social life was limited and also recognised that the activities they now did were largely solitary

Boyfriends and girlfriends

Amongst the young people in this study, just under a quarter (four) did not express any thoughts or have any real opinions about having a boyfriend or girlfriend. These young people ranged in both their age (from 16 to 23 years) and their level of understanding; there was no clear pattern or trend. Amongst the remaining 14 young people, nine talked of having or having had a boyfriend or girlfriend and the remaining five young people indicated that they would like to have a boyfriend or girlfriend but it was clearly a future aspiration. College appeared to be an important place to meet a boyfriend or girlfriend and maintaining a relationship was often dependent on attending college. When a course finished and the young people left college, they frequently described relationships petering out. Meeting-up was viewed as less frequent and everyday social contact harder to sustain. Only one young person described meeting their current (and past) partner through an online social site.

It was clear from the accounts of some young people that parents had been quite pro-active in encouraging and maintaining these relationships:

> *She's [Mother] fine with it, and in fact, sometimes some of the suggestions to go and see him [boyfriend] are actually hers.*
>
> (Sophie)

A couple of the young people viewed their ASC as a barrier to gaining and/or retaining a girlfriend. This stemmed from perceived inadequacies in their own social skills and/or prejudice and mis-understanding of AS:

Yeah, soon as I tell 'em I've got Asperger's, they say that they're, they're turned off.
(Ian)

Future aspirations

Having a stable relationship with a partner was discussed as a future aspiration by just four of the young people we interviewed. For two of these young people (both females), they envisaged having children as an integral part of a stable relationship:

> *But I would like to have a partner and have kids, it's always been my dream to have kids and then go and live in America, that's always been my dream. … A partner, a husband, that's a family basically …*
> (Tracy)

In contrast, one young person noted that he had consciously decided not to have children, as he feared that they too would have ASC. His own understanding of the high levels of help and support his parents had given him appeared to have influenced this opinion:

> *I know the difficulty of having autistic children because I, I am autistic and I know how hard it is to raise autistic children … I'd rather not have autistic children.*
> (Ben)

11.8 Summary

This chapter has focussed on young people's accounts of their perceived movement toward adulthood. We organised the findings around six indicators of adulthood: independent travel; developing and engaging in new leisure interests and activities; employment; financial independence; moving away from the family home; and changing and developing social relationships. The extent to which the young people had experienced progress, or growth, varied across these different areas. Some of these outcomes of adulthood were, for most, stuff of the future. In other areas, most reported progress.

The majority of interviewees were enjoying travelling independently, though some in more limited ways than others. Being able to travel about independently was typically viewed as affording wider independence, choice and control over their lives. For many it had widened social and leisure opportunities. A minority had experienced travel training, all of which reported it had been valuable. It important to note that being able to travel independently placed financial demands on families, and thus a family's financial resources could restrict young people's ability to utilise their independent travel skills. Finally, the young people often identified parents' playing an instrumental role in achieving the ability to travel about independently; for example, arranging and financing driving lessons; applying for bus passes.

Whilst many of the young people described having social and leisure lives of some sort, it was only for a minority that this appeared to be something they themselves proactively

organised, and it is this which represents developing and maturing towards adulthood. The majority of young people who were actively engaged in social and leisure activities outside of the home were doing this in supported settings or with buddies or mentors. Parents were sometimes identified as having a hand in organising this. Some of the young people expressed a very clear preference for spending their leisure time in 'specialist settings' and HFA/Asperger's syndrome specific clubs were seen as particularly appealing.

Very few of the young people had had any experience of work, though there was agreement that gaining employment was a clear step towards adult life. However, overall, there was a sense of caution with regards to making this step and very few had what might be regarded as aspirations for a particular career. Instead, most wanted to take tentative steps into the world of work. Those who had done voluntary work were typically very positive about this experience and saw it as a useful stepping stone towards employment. There was very limited experience of formal support with gaining and maintaining employment and experiences of this support were mixed. Once again, however, parents emerged as playing a more helpful role. The young people who were seeking employment valued their parents' support which ranged from contacting potential employers, helping the young person practice for job interviews and providing emotional support. However, there was little optimism amongst these young people in terms of the likelihood of successfully finding work, the current economic climate and perceived discrimination against people with ASC on the part of employers were both cited.

Only a very small minority of young people interviewed had moved away from the family home and most interviewees were very clear that they did not feel ready for such a move. Many felt that, even in the future, such a move would only be possible with the support of their parents – both in achieving and sustaining the move. Indeed this was the situation with the couple of young people who moved out of the family home. Very few young people perceived statutory services as a potential source of support.

Finally, these interviews also explored experiences of, and aspirations for, more permanent relationships. Most had a view on this and spoke of having a girlfriend or boyfriend in the past, and a desire for further relationships of this nature. Leaving college seemed to act as a hiatus in opportunities to develop these sorts of relationships. However, aspirations of more permanent relationships were only discussed by a minority of these young people. A few of the young people believed their condition placed a significant barrier in terms of them achieving a permanent relationship and having children.

Chapter 12
Reaching 'Chronological Adulthood' and
Achieving the Milestones of Adulthood: Parents' Views

12.1   Introduction

This chapter explores parents' perceptions of their sons and daughters progress towards, and achievement of, 'adulthood milestones' (see Chapter 2, Section 2.5 for the description of the interview sample). One of our approaches to the analysis of the parent interviews was to centre on a number of indicators or milestones that are commonly take to suggest progress in transition into adulthood: gaining employment; moving from the family home; and developing and extending social networks. For each indicator, the discussion explores parents' hopes and expectations and the perceived roles of parents and services in preparing the young people for these different facets of 'adulthood'. The final section of the chapter reports the concerns expressed by parents regarding their child's 'coming of age', the changes that brought in terms of services and support, and the expectation of greater independence. We begin with a short discussion of what 'adulthood' meant for these parents in terms of their child with an autistic spectrum condition.

12.2   Parents' perceptions of markers of adulthood

Parents identified the achievement of skills or life stage milestones (such as leaving full-time education, leaving home, doing more things without parental/adult supervision) as markers of adulthood. Parents typically felt that 'achieving adulthood' would not follow a 'normal' trajectory and, quite, possibly their child's 'adulthood' would be (very) different to those of non-disabled young adults.

It was the parents of young people with AS or HFA who typically gave a number of examples of their child's skills and achievements which they perceived as indicating the young person was growing up and into adulthood. Thus the young people had developed over a number of years a range of self care skills, such as washing, dressing and preparing meals, or had learned to drive, or had become confident at using public transport. Managing money was seen as another key skill. Increased personal responsibility emerged as a key indicator of adulthood, comprising both greater autonomy in decision-making and taking initiative in 'moving their lives on'. Thus, parents described noticing their child was starting to make their own decisions and was relying less on them in the decision-making process. Some young people had been proactive in enrolling on college courses, or writing to employers about voluntary work experience with little input from parents.

Increased independence was sometimes associated with starting college, because this had prompted the young person to start using a bus or to start managing workloads. Parents also linked support from a youth service in the voluntary sector or a desire to work as supporting or driving greater personal responsibility. Some parents admitted being

surprised at their child's ability to cope with greater level of independence or new activities, such as using public transport on their own.

However, parents sometimes stressed that such skills for independent living were merely superficial indications of independence. For example some of those who had learned to drive were reluctant to drive far or go anywhere on their own:

> *He won't do anything alone .. he has to have somebody with him, even if he's driving in the car he's got to have somebody with him. [22]*

'Incomplete' adulthood

Sometimes parents juxtaposed the young person's academic abilities or position in work with their relative inability to look after themselves which emphasised a dilemma in efforts to achieve adulthood. One example was of a young person who was in paid employment but needed to be prompted and assisted to wash and change clothes. Some parents expected their son or daughter to continue to need their assistance once living elsewhere, particularly regarding the management of finances, or would need to have an identified 'safe place' to seek help. These experiences show that development into adulthood seemed a slow process and parents did not expect young people to have fully fledged independence any time soon, if at all. One view was that parents would never stop feeling responsible for their child:

> *He's now an adult with Asperger's not a child with Asperger's (laughs) and it was that realisation that, you know, just getting him through school wasn't the end of it, and it never will be the end of it...*
> (4-45)

12.3 Employment

Young people's experiences of employment

There was some evidence of that young people were sustaining work after a period of in-work support from employment support services. In many cases, however, the jobs were 'stop gaps' as opposed to a step towards fulfilling an aspiration. Working was not always without struggle. Coping with changes in tasks or role was a common difficulty reported by parents. The young person's difficulty adapting to the work environment and/or the nature of the work meant that whilst there were signs that some young people were achieving a key indicator of adulthood – participation in the labour market – this status often seemed fragile.

Unstable employment

Amongst those who had some work experience, there were a number with an already unstable employment history. Each had been employed a number of times but none of these jobs which had worked out. It was not always clear why young people had left jobs,

---

[22] Verbatim quotes are used to illustrate points made in the text.

but there were indications that reasons included: the work being low skilled, repetitive and had not held their interest; or that they had been dismissed for breaking workplace rules. Parents of children with tendencies to become frustrated and angry when misunderstood commonly expressed concerns that responding in this way might put their job at risk, and that finding another job would not be easy.

Parents of young people still in education
There was a wide variation in expectations regarding employment among parents whose young people were still in education. Interestingly, this variation was found both for parents of young people with ASC and learning difficulties and those with children with HFA and AS. However, the latter group of parents' expectations seemed to be more grounded beliefs about the lack of suitable employment opportunities as opposed to their child's inability to work *per se*. Where paid employment was not perceived as possibility, some felt supported work or voluntary work were alternatives. There was evidence that dealings with Jobcentre staff or benefits medical assessors had caused some parents to lower their expectations for their child achieving paid employment.

Parents' expectations for their child's employment were clearer where the young person had firm aspirations which were considered realistic by the parent. Demonstrating a particular academic ability, for example in mathematics, science or ICT, had helped families to map out career plans sometimes involving university. For example, some parents outlined steps that young people planned to take to gain qualifications in college and university, and/or to move into defined careers. This notion of whether an aspiration was realistic was primarily informed both by the young person's abilities and the limitations or difficulties which having an autistic spectrum condition imposed on them. For example, becoming a teacher was seen as an unrealistic aspiration despite high academic abilities.

The perceived lack of appropriate employment opportunities
Parents who expected their child to be able to work had anxieties about whether their child would be successful in finding and securing work. There was some pessimism about the availability of suitable work opportunities, and that, unless jobs were designated to people with special needs, their young person would not be offered a post. Some parents struggled to believe that a suitable work environment would be found which would be suited to their child's needs and abilities including: an understanding employer and colleagues, a calm workplace, part-time hours, clear expectations, work tasks organised in a structured routine and/or no requirement to interact with the public.

A reluctance to move into employment
A different barrier to moving from full-time education and into employment identified by parents was the changes it necessarily brought about in the young person's life, and the resistance there was to such change. Being in education was, to the young people, a known entity or, as one parent described, a 'comfort blanket'. There was, therefore, a reluctance to move on to new activities in new environments:

I think what she's thinking, she's gonna do this course for two years, and then she's turned round and said to me "And then I'm gonna do another one after that" (laughs). So I don't think she's very keen to leave the … learning environment.

(4-196)

Parents could be equally reluctant in instigate change especially where they felt they needed more time to plan ahead, or where they perceived limited opportunities in the labour market. In these situations they were happy for their son or daughter to 'bide their time' in the engaging and stimulating environment found in college, rather than be bored at home.

Parents' perceived roles and the roles of services
For some parents, helping their son or daughter find a suitable job seemed to be outside their control or sphere of knowledge and expertise:

… we find it quite hard to strike the balance in trying to get him to be independent but also being able to do stuff that he can achieve and not be outside of his comfort zone, and, and I think that's where we might need guidance … when looking for jobs to say well maybe not that, but this one might be good.

(2-96)

Indeed some had already tried in vain to obtain suitable employment for their son or daughter. There was a sense that young people with special needs were at the mercy of the labour market and employers' perceptions and there was little parents could do about it.

Not unexpectedly, therefore, parents who aspired for their son or daughter to work perceived the need for expert support for their child, including work skills training, job search assistance and in work support was reported. Services most likely to be identified as the source of such help were Connexions, Jobcentre Plus and local voluntary sector organisations. Schools and colleges were also perceived to be play an important role in helping the young people to be employable and 'work ready', particularly in terms of providing opportunities for work experience.

However, parents were often still actively involved in work preparation activities. These included: teaching about using public transport, facilitating their child's involvement in useful extra-curricular activities, and organising work experience placements.

For those with a son or daughter in work, some parents reported having to liaise with their child's employer about work tasks and problems. Their own work commitments (particularly if employed full-time) were identified as a barrier to supporting their child to access and stay in work. Parents also described difficulties they had encountered talking to an employer about their young person's work. They believed this was because it was perceived as breaking societal norms which define the young person as an adult and, therefore, responsible for their own work.

Not surprisingly, therefore, a number of parents flagged up the critical importance of support to settle and stay in work. Some parents reported valuable support from voluntary

sector employment services. More specifically, additional help to sustain work in the form of anger management training was in prospect for one person.

When paid work was not a possibility
Some parents whose young people were still in full-time education but who did not expect them to work, predicted two possible future roles: either paying for the young person to attend daytime activities or caring for/occupying their child at home. They acknowledged this might mean giving up work themselves.

12.4   Independent living

Similar to expectations about employment, parents' views about the prospect of their son or daughter moving out of the family home to live independently differed and could not solely be explained in terms of the severity of the young person's autism. Views about the prospect of gaining paid employment did not necessarily accord with expectations about leaving home and/or living independently. Thus, some parents of young people with AUT did not expect the young person to enter paid work or to be able to cope with living independently. Others thought their son or daughter would work one day but would not be able to live independently without support. A similar range of views was apparent among parents of young people diagnosed AS or HFA. However, the belief that their child would at some stage in the future would be working and living independently was most likely to voiced by parents of these young people with these particular diagnoses.

In large part, parents who hoped their son or daughter would one day leave home to live independently or with support also said that this aspiration was far from being achieved. Only a handful had defined plans or begun had taken steps towards it; for example, applying for supported or social housing. It also transpired from parents' accounts that some of the young people themselves held aspirations to moving out of the family home but did not envisage this happening in the foreseeable future. The tension in some young people of wanting independence but also fearing it was well illustrated in one parent's comment that her son would like to build a bedsit onto the family home.

Inabilities or skills deficits as barriers to independent living
Parents identified inabilities or skills deficits which they perceived as acting as barriers to their child living independently. These included life skills (such as, money management, cooking, using public transport) as well as more cognitive skills such as noticing the passing of time, organising time and activities, and decision-making. Parents believed the young people would either need support to manage independently or need help to develop more these skills.

It is worth noting that there were young people who had coped well living in supported accommodation whilst at residential college who, upon returning home, were assessed as having low needs and were not granted supported housing. The parents observed that these young people's levels of independence were regressing since living at home again.

Preparing and supporting the young person's increased independence

Not all parents interviewed expected their child to live independently. As reported above, some parents expected their son or daughter to need support from statutory services to enable them to live away from the family home. Just one of the parents we interviewed had a child who was being supported to live independently. However, from both this and other instances where families were working towards the young person leaving home, it was clear that some parents were playing a lead role in achieving supported independent living through their proactive efforts to initiate assessments, and pursue and coordinate statutory services.

In other families leaving home was not being actively planned; however, these parents did flag up a current need for their son or daughter to develop greater independent living skills, such as cooking, cleaning, money management and decision-making. Some of these parents did not question that it was their own responsibility to teach such skills regardless of whether the young person perceived a need to acquire them. Indeed, many were able to describe the way they were encouraging their young person to increasingly assume responsibility for decision-making.

On the other hand, there were other parents who argued that services should provide lead on supporting the development such skills. A key issue for parents, and something which seemed to partly drive this desire for external support, was that many parents struggled to find ways to motivate the young person to do more for themselves. Many acknowledged feeling that their child was overly dependent on them and that they 'did too much for them', and yet had not found effective ways to redress this situation. This would suggest the need for, at least, advice and guidance for parents about how to encourage independence. On this same issue, a view iterated by a number of parents was that lessons about independent living skills needed to come as early as possible to avoid young people falling into patterns of dependence.

Other reasons for citing the need for statutory services leading on independence skills training were: some young people were perceived as responding better to guidance from adults other than their parents; learning from an outsider would encourage less dependence on parents; and teaching an autistic child living skills was not a simple matter and needed expert input.

Parents had mixed views on the quality of independent living training or support their son or daughter had received. Typically, special schools' teaching on independent living skills was perceived as very valuable. Some young people attending college took courses intended to develop skills for independent living though doubts were expressed about the adequacy of courses which seemed to offer only 'tokenistic' support (such as making only one trip into town).

Some parents expressed disappointment with the level of living skills input provided by staff in children's social care or multi-agency 'transition teams', where the focus had primarily been on transition *planning* as opposed to *preparation* for transition to adult life. However, there were positive examples of statutory and non-statutory offering or delivering skills

training for independence, or information pertinent to moving into adulthood, such as about social security benefits, sex, drugs and alcohol.

12.5   Developing and extending social networks and relationships

Data relating to parents' hopes and expectations for social interaction and relationships was partial, as this topic was not a main area of enquiry for the study and parents tended to say more about their expectations regarding employment and independent living. However, the data available suggests that parents drew some confidence about a socially active future for their child where they were already showing signs of going out alone on social expeditions and where they were supported in social activities by statutory and non-statutory services.

Greater social interaction without service support was indicated by young people who had started going alone to local shops or pubs, or to meet friends in town or for an evening out. It was not always clear what had prompted moves towards social activity, though starting college brought new friends to some people who previously had no friends, and a holiday had provided opportunities for going out alone in what was perceived by the young person as a safe environment. However, as with other 'markers' of adulthood, parents stressed limitations to young people's social activity. Thus young people would require encouragement to go out, would only mix with people they knew already, or would only visit one place when they went out:

> *He tries to be sociable and he, he walks round to our local pub…I know it probably sounds quite small to us but for him it's quite a big thing...He will do that on his own. I think because we live in quite a quiet village, they all know him…he's always comfortable.*
> (4-99)

Thus needing to be within a comfort zone or to feel safe extended to young people's spheres of social interaction just as it was attached to their feelings about moving away from home or out of education.

Another group of young people were attending special needs social clubs (one of which was specifically for young people with Asperger's syndrome), were taken out by carers paid for with social care direct payments or by befrienders from non-statutory organisations working disabled people. Parents believed this sort of support was very beneficial in terms of developing 'social independence' and social isolation. Young people benefitting from this support were found in each of the study areas and represented the range of autistic spectrum conditions.

Some of young people with AS or HFA, all of whom were over 18 years, were said to have had a boyfriend or girlfriend in recent months. Other parents of children with AS/HFA spoke of their child wanting to have a boyfriend or girlfriend, or to get married, but that this seemed a far off dream. A few young people had expressed to their parents concerns about

their ability to sustain a long-term relationship. Not expecting to marry was another view that had been relayed to parents.

The role of parents and services in developing and extending social networks
Parents said little about their own role in preparing their son or daughter for social interaction and relationships in adulthood, though this might be because it was not discussed in all cases. Some parents said that they encouraged social activity, particularly where the young person was not occupied by college or work during the day.

However, there was more data about the need for support from services. As noted above, some parents praised the support of services providing social clubs or befriending services. In addition, support from a Community Autism Nurse to provide guidance about social issues was missed where it had stopped recently. Some parents felt that, currently, opportunities for social interaction were lacking and that there were needs for access to befrienders or peers in similar circumstances, more suitable and safe activities in the local area, and transport which would allow the young person to go out independently of their parents.

12.6 Parents' concerns

Parents expressed many and multiple concerns about their child's future which centred around the transition to adulthood life-stage.
* The young person's ability to manage his/her life.
* A lack of progression or meaningful daytime occupation.
* Increased vulnerabilities associated with independence.
* The threat of harm and police involvement arising from behaviour problems.
* Poor or worsening mental health.
* Parents' own ability to continue the caring role.

These are now explored in more detail.

The young person's ability to manage his/her life
An often repeated concern of parents, regardless of the young person's age, was that their child seemed reluctant or unable to be responsible for their future. This was manifested in young people having a propensity to 'live in the moment', being unconcerned about their prospects, assuming that things will fall into place, and/or in relying on parents or services to make decisions and arrangements on their behalf:

> *I don't think he realises that once you get to a certain age, once you finish education you are expected to go out to work, and it's very difficult with someone with his condition to make them understand that. He's quite casual about his approach with lots of things, so it's difficult to make him understand.*
> (3-10)

… see he'll never take responsibility for himself. .. I want him to get a full-time job and be able to take his own, like instead of me chasing him all the time to do things, I want him to do it himself …

(4-14)

A lack of progression or meaningful daytime occupation

Many parents were uncertain about what would occupy their son or daughter after college, or if plans for university or work failed. In particular, parents worried that their young people would be facing a future lacking in stimulation, motivation or purpose. This was a concern both of parents who thought their son or daughter was capable of working and those who did not. Parents were concerned about the impact of this lack of occupation on their children, a lower self-esteem, depression and criminal behaviour, were all perceived as risks if young people did not have enough to occupy them:

I mean I've got visions of him being on the dole…can't get an apprenticeship, can't get a job because he's got special needs and people are going to take able bodied first. He's going to be on, on the dole for years on, years and years and years, fed up, upset, his self-esteem will go through the floor again, and I won't be able to get him out of his bedroom and motivate him, even to take me shopping.

(3-714)

Increased vulnerabilities associated with independence

A recurrent theme in many parents interviews was that 'superficial' markers of adulthood, such as physical size and appearance and the achievement of the less demanding independence milestones (for example, travelling alone on familiar routes on public transport, going shopping unaccompanied) heightened their child's vulnerability or risk of harm, abuse or exploitation. Parents perceived this to stem from their child's autistic spectrum condition; for example, an inability to make judgements about levels of risk or danger; an inability to judge their own capabilities/independence skills, immature social development/skills; a lack of ability to predict the consequences of actions:

Because of her vulnerability she will talk to anybody and she doesn't understand ... the fact that you talk to different people in different ways … she's a little bit overpowering with strangers and … that could be dangerous.

(4-56)

This perceived increase in vulnerability was a source of considerable concern for parents of both boys and girls, and particularly where there were plans for the young person to move out of the family home. Some parents described situations where this vulnerability had been exposed, for example: following through risky dares, driving dangerously, criminal behaviour, taking illegal drugs, talking with strangers, and signing up to a mobile phone contract but failing to manage the monthly payments.

The threat of harm and police involvement arising from behaviour problems

There was real anxiety among some parents that if their child became angry or upset when they were not there to calm and comfort them that the young person would harm

themselves and/or others. A few parents reported experiences of police involvement situations involving their child.

Mental health

A number of parents expressed concerns about their young person's mental health. They described episodes of depression, anxiety or low mood. Worries about their child's self-esteem were also commonly voiced by parents. These concerns were heightened where the young person was aspiring to leave the family home and, thus, parents felt they would be less able to support and monitor the situation.

Parents' own ability to continue in caring role

Irrespective of their child's age or specific diagnosis, a common concern among parents was their young people's care and wellbeing if, and when, they become unable to act as the main carer or supporter:

> *… that is every, every person's fears that has got a child that is disabled, either physically or mentally, it's their biggest worry, you know, what happens to them when I'm not here.*
>
> (2-15)

Parents whose children would require very high levels of support if they moved from the family home particularly feared that such support would not be available when required.

12.7 Summary

This chapter has reported what parents told us about their desires and aspirations for their son or daughter as they entered adulthood in terms of three indicators of adulthood: gaining employment, moving from the family home, and developing and extending social networks. These were the indicators that most pre-occupied parents' accounts. The latter part of the chapter reported parents' concerns regarding their child's future.

Overall, parents did not believe their child was on a 'normal' trajectory for achieving adulthood. Indeed, most believed their child's adulthood years would be different, and sometimes markedly different, to those of non-disabled adults. The notion of an 'incomplete adulthood' emerged from our analysis of parents' interviews and captured the fact that progress, and even success, in one indicator of adulthood (for example, employment) cannot be taken to assume similar levels of development or maturity in other areas, such as independent living.

The employment experiences of the majority of the young people and young adults represented by our parent interview sample were problematic in one or more ways. First, the jobs themselves were not, parents' believed, fulfilling their child' potential. Changes of role/job requirement was another commonly reported difficulty. Some of the young adults already had an unstable employment history. A lack of stimulation or lack of adherence to workplace rules were the two most frequently reported reasons for leaving, or losing, a job.

Amongst parents of young people still in education, a key concern was the lack of employment opportunities. Some parents identified the 'mis-match' between their child's abilities and yet their need for support to maintain employment as a seemingly insurmountable difficulty. These parents were also likely to note that reluctance on the part of their son or daughter to move from full-time education into employment did not support active engagement in planning for this next step.

Some parents felt totally unskilled in supporting their child into employment, for some this was based on unsuccessful attempts to secure their son or daughter a job. Those who had sought help from Connexions, JobCentre Plus and local voluntary sector organisations had mixed experiences of the quality and appropriateness of support received.

Not all parents expected their child to ever be able to live independently, and moving out of the family home was consistently seen as something for the medium-term and not an immediate aspiration. However, where this was perceived to be a realistic aspiration for the longer term, parents typically reported the need for their son or daughter to further develop and extend their independent living skills. Many parents of young people who had left full-time education had assumed responsibility for this, though some argued that this was something statutory services should be/were responsible for. This desire for professional involvement was partly explained by the fact that parents sometimes reported finding it difficult to motivate their son or daughter to acquire these skills and/or to break a pattern of dependency between the young person and themselves.

Parents typically reported that either their young people's social networks and relationships had developed in an age-appropriate, limited, manner, or that they remained dependent on formal provision (for example, special needs social clubs, befriending services) for their social lives. Parents' accounts of conversations with their sons or daughters revealed that long-term partnerships, marriage and children were outcomes some young people aspired to, but were not perceived to be realisable.

Finally we looked at the concerns parents expressed as they thought about and discussed their son or daughters' adulthood. There was a strong sense that some parents felt very burdened by these, sometimes very significant, concerns. This burden was intensified because of the perceived lack of support available for their son or daughter and for themselves.

Chapter 13
Supporting Positive Outcomes in Early Adult Life:
Practitioners' Views and Experiences

13.1   Introduction

This chapter compliments the preceding two chapters which were concerned with young people/young adult's and parents' views of moving towards adulthood. It reports practitioners' views and experiences of supporting young adults with ASC in terms of moving towards adulthood and, in particular, three of the so-called indicators of adulthood namely: employment; moving out of the family home; and new and developing social and leisure lives.

We focus on reporting the support available in the sites to help young adults with ASC achieve these indicators of adulthood and the perceived barriers, aside from those associated with the severity of the autism *per se*, to their attainment. Our final results section focuses specifically on young adults with HFA and Asperger's syndrome and staff views on gaps in support in adult social care and potential solutions.

13.2   Views on the post-school outcomes of young people with ASC

There was a sense of frustration on the part of education practitioners that the significant investment made in children and young people with ASC during their school years was not necessarily continued into their adult lives. Practitioners from other agencies also shared a concern about the lack of positive outcomes for young adults with ASC. When interviewees discussed this issue this was often, but not exclusively, with reference to young people with HFA and Asperger's syndrome and we return to this issue in a later section (see section 13.6). Interviewees also noted that families also have expectations for services and support from adult services which will ensure their son or daughter's continued development and quality of life:

> *There is a generation now of people who've had higher expectations through the, the pupil's education. It's personalised education and so on and so forth, they expect to be able to spend time, you know, doing meaningful activities and so on, and then it just all stops and they are left at home with their mum again.*[23]
> (Education practitioner)

> *… we educate them for nothing because then they go home and sit and watch television all day.*
> (Autism advisory teacher)

---

[23] Verbatim quotes are used to illustrate points made in the text.

13.3 Employment

There was agreement that, where appropriate, achieving a successful employment experience was extremely beneficial. However, managers and practitioners acknowledged there were significant barriers to young people with ASC who were able to work successfully gaining and sustaining employment.

Barriers to employment
A lack of opportunities

Many interviewees believed that there were insufficient employment opportunities which could provide the appropriate level of support. A lack of understanding of ASC among employers was also highlighted. The absence of public transport or the fact that the young person could not travel independently further served to reduce the opportunities available.

Low aspirations

A number of practitioners reported that, as with many young people with disabilities, some young people with ASC were not encouraged to aspire to any sort of employment. Low aspirations and associated lack of self confidence were not conducive to gaining or maintaining employment.

Lack of support

The need to provide employment support to young people with ASC was acknowledged by practitioners:

> *[employment support is needed] … to keep people in work, stop them reacting badly to things and getting sacked, demoralised, having to attend interviews they cannot handle, lose confidence and end up back in a cycle of depression and psychiatric admission.*
> (Practitioner autism specific organisation)

Across the sites services identified as providing or being responsible for such support included: Connexions, schools/colleges, local supported employment services, and local autism-specific voluntary sector services.

The **transition teams** located within children's services appeared to have relatively little involvement in supporting young people with ASC into employment and did not appear to know a lot about employment opportunities or supported employment services for those young people in their locality. However, staff in these transition teams did note that they expected this to become something they dealt as a result of changes in policy regarding the employment of disabled people and benefits entitlements. In the sites where the transition teams were based in adult services or co-located in children's and adults services more activity and knowledge around supporting young people with ASC into employment was apparent. The perceived role of these teams was predominantly one of sign-posting: to the job centre, work preparation (job coaching) programmes and other external providers offering work experience and paid work; supported employment providers. One team also reported delivering travel training to enable a young people to take up work. Across all but

one of the research sites, young people with HFA or Asperger's syndrome were not eligible for support from the transition service and thus did not even have access to such signposting.

In only one site were **Connexions** PAs identified as playing an active role in supporting young people with HFA or AS into employment. This included visiting (potential) employers and providing information about: the young person's condition and how it affected them; guidance on how best to work with that young person; and the potential benefits of employing somebody with HFA or AS (including their reliability, punctuality and dedication to completing tasks to a high standard). The Connexions worker also worked with Job Centre Plus, Mencap and other organisations to ensure that those eligible for support were actually receiving it. This Connexions worker reported using the S139a forms to explain an individual's support needs to employers.

In the other sites, Connexions PAs reported a more restricted role in terms of employment support, referring young people with ASC on to supported employment services and/or Job Centre Plus (for those with HFA or Asperger's syndrome). There were a number of reasons why these Connexions services did not identify themselves as actively involved in supporting young people with ASC into employment. The most commonly cited were: the young people typically transfer to college, not employment; employment being seen as the responsibility of the transition team; and a lack of capacity within the Connexions team

Practitioners in all sites reported using **supported employment services**. Young people with autism and learning difficulties were typically provided for within wider learning disability employment support. However, a common concern was the lack of an equivalent form of support for young people with HFA or Asperger's syndrome who may not be eligible for 'mainstream' supported employment services. An example of a well-regarded supported employment service which could be accessed by young people across the spectrum is described in Figure 13.1. A national autism-specific third sector organisation provided employment support to young people with ASC in two sites. For example, in Site B, the organisation provided some support with helping people settle into employment, for example by taking people shopping for appropriate work clothes, working out transport options and routes, and helping the individual to understand their work role.

Autism-specific services tended to play a role in supporting young adults into employment, but were not found across all the research sites. Thus the presence of autism-specific voluntary sector organisations in a locality tended to ensure there was at least some provision of employment support for young people with HFA or Asperger's syndrome, though limited resources meant that these services could have capacity issues. Finally, an autism outreach services which was part of statutory mental health provision (Asperger's team, Site D) provided low level employment support through information provision (about ASC generally and the specific needs of an individual) and training to employees.

Figure 13.1   A practitioner-endorsed supported employment service

A supported employment team, funded by the local authority, had been established in one research site in response to a growing demand for work placements and job opportunities from disabled people using adult day services. The team's remit was to work with people aged 16 and over with learning disabilities. However, the team also worked with those with HFA and Asperger's syndrome.

The team had links with special schools and mainstream colleges. If employment was raised in a young person's person-centred plan or transition review then a referral was made to the supported employment team. Post-referral a member of the team might attend the young person's annual reviews to get to know the young person, their aspirations and also their support needs. Referrals could also be made by the young people themselves, Connexions, Job Centre Plus, the community learning disability team, and other employment agencies who needed support in working with people with disabilities

Job-seeking support provided by the service included: job searching; producing CV's; practising for job interview; supporting individuals going for interviews

Once employed, the service offered: travel training; shadowing / demonstrated how to perform work tasks; employer training; advising regarding reasonable adjustment to the workplace and/or role; gradual withdrawal of support, but case kept open. ,

The team also support the local college in setting up work placements.

13.4   Moving away from the family home

The general perception of the professionals we interviewed was that many young people in the late teens and early twenties are too young and too vulnerable to move away from home – regardless of whether or not they have any disabilities. However, for young people with ASC, the high degree of change involved in moving away from home meant that leaving home was one of the main challenges these young people would face.

Across the research sites transition teams spoke of discussing moving away from home with young people with ASC, but this appeared to within the context of helping a young person to think about their future and tended not to involve any specific planning. Further, in the majority of research sites, transition teams did not work with young people with HFA or AS (see Chapter 3) and thus could not offer any signposting or support to this group.

Interviewees reported that young people with ASC and learning difficulties may be able to access supported housing options through statutory services or voluntary sector providers,

such as Mencap. A small number of interviewees reported that we supported housing options offered could be unsuitable, for example rooms in shared housing instead of single units/ flats where they would not have to cope with living with other people who perhaps did not understand their condition. In one of the research sites strategic work on accommodation planning for people with learning disabilities, including those with ASC, was underway. This site also had a 'build policy': building specialist housing and flats for those with disabilities and establishing increasing numbers of places for autistic young adults. The only issue was that the service was county-wide thus young adults could end up having to move away from family, friends and their local community.

Opportunities for supported living/supported accommodation were limited across the research sites, particularly for those with HFA or Asperger's syndrome. Interviewees reported that they had found that young people with HFA or Asperger's syndrome were not entitled to any help with housing/independent living as their needs were not perceived as significant by local authority housing departments. Thus, rather than offering some sort of supported housing provision, such young people were typically advised join local authority housing list as early as possible, indeed in some sites the recommendation was to do this as soon as they turned 18 years of age. However, autism-specific voluntary sector organisations and autism-specific private providers were being used in by some sites where the young person had additional (typically mental health) needs.

Finally, a specialist residential college for young people with Asperger's syndrome was identified as providing good housing support to its students when the time came for them to leave. The college approached housing associations on the young person's behalf; assisted with housing applications and helped to arrange support for young people who were not eligible for a social worker. As part of its curriculum, the college also delivered teaching and training on budgeting and support services. It also delivered counselling sessions focusing on moving away from home. College staff also helped with furnishing, decorating and moving in. Where a young person was eligible for adult services, the college would carry out this work in partnership with statutory services.

13.5   Social and leisure lives

Opportunities for young people with ASC to develop friendships and partake in social and leisure activities as they progressed into adulthood were regarded as important by interviewees:

> *If they have a social life, that works wonders for their confidence.*
> (Social care manager)

> *We do believe that one way of enabling these youngsters to be part of the community when they leave school is that they have their leisure opportunities that they can go to.*
> (Manager of an autism-specific service)

> *That can be a big root of self-esteem and confidence.*
> (CAMHS manager)

However, across the research sites there was relatively little statutory provision for young people and young adults with ASC which addressed their social and leisure needs: either in terms of supporting young people to develop and extend their social and leisure lives or providing such activities. Rather, it was autism specific voluntary sector organisations which tended to be providing such support.

The impression of those we interviewed was that young people and young adults with ASC were not likely to use generic disability youth and/or social/leisure services. Indeed, these were perceived as not appropriate for young people with HFA or Asperger's syndrome. For these young people, identifying specialist interest/hobby groups or clubs was seen by practitioners as a route to developing social networks having left school. Internet-based groups and forums were also reported to be popular with young people with HFA and Asperger's syndrome as they supported emerging friendships without forcing immediate social interactions, but with the potential for meetings and arrangements to attend leisure activities to follow on from these virtual contacts. A number of interviewees flagged up the particular difficulties young people and young adults living in rural areas can face in maintaining or developing their social and leisure lives once they have left school. Lack of financial resources (for public transport, event or admission charges etc.) could further stymie efforts to engage in social and leisure activities.

Across the sites a handful of social workers, transition service managers and adult mental health commissioners referred to the potential for Direct Payments and/or Individual/ Personal Budgets to enhance a young person's social life. For example, direct payments had sometimes given to young people in children's services and/or in adult services to buy in support to attend youth clubs or other social activities:

> *Part of the self-directed support is about social inclusion, to get people using community facilities, so accessing social activities can be on their [support] plan with support and obviously the idea is then the individuals get used to the environment, maybe develop their own sort of network of friends and then the support can slowly withdraw.*
> (Commissioner, adult mental health services)

Identifying social and leisure needs over the transition period

The **transition team** in just one site reported actively incorporating planning around young people's social needs into transition planning work and as part of the services/support the team provided. Thus, annual review/transition planning meetings included discussion about what social activities young people would like to do. Once identified the transition worker would: identify a suitable event/club/activity; arrange transport; support the young person to attend on a maximum of three occasions and provide information and advice to staff based in the setting. This took the form of a one-page profile covering support needs, behaviours, triggers, and how best to work with the young person. However, it was reported that arrangements had often broken down after the transition worker withdrew

owing to transport issues or staffing issues, for example, if the worker was not there and the young person panicked without that familiar face. Transition workers in this site were also trying to buddy up young people with similar needs who they felt may get along with one another.

Similarly, only in one site did **Connexions** workers refer to supporting young people with ASC to access social and leisure activities. Here Connexions workers liaised with colleagues in social care, college tutors and with parents to find out if young people were accessing leisure activities. They would then try to set up leisure opportunities, for example by arranging assessments for young people to access services through the local authority youth service or through a voluntary organisation.

ASC specific social groups and leisure activities

Across all the sites there were examples of local autism-specific voluntary organisations running social clubs, befriending services, music and art therapies, sporting activities, and special interest groups (for example, film making; website development). A national autism organisation also ran social groups in many of the research sites. Some of the services/ support being provided by these organisations were specific to young people/young adults with Asperger's syndrome including: support groups; drop-in sessions; organised activities; the setting up of a dedicated social networking site; and social events.

13.6   The lack of support for young adults with HFA and Asperger's syndrome

A lack of eligibility for support from adult social care was regarded as playing a significant role in increasing the risk of poor outcomes for young adults with HFA and Asperger's syndrome:

> *We call it the lemmings effect here. You get to a certain point and you've had Children's Services all this time in your life, you get to eighteen, all of a sudden your age changes and you drop off the end of the cliff. … There's no service, the whole point in a transition assessment is for us to determine what they need to continue on to adulthood. Well we can do that, but who's going to put that service in? It's just a piece of paper, it's just an, it's just an assessment, at the end of the day, that we give to the, to who, when it, you know, when it's high functioning, who are we giving that assessment to? Because there's no-one that's going to follow through to support them to continue on to adulthood.*
> (Transition worker)

> *Even if the transition process is 100% right, it still falls down if there is not enough suitable adult provision.*
> (Manager, Connexions service)

There was a deep concern that the needs of young adults with HFA and Asperger's syndrome would continue to remain a low priority and, because they are ineligible for adult

social care, that they are invisible to commissioners and those working at a strategic level on support for young people and young adults with ASC:

> *... this high functioning stuff is not budgeted for or, it's not on the agenda of the commissioners or, and it's just, you know, in this climate it's just not going to be really, is it?*
> (CAMHS Consultant)

Potential solutions
Social care teams dedicated to working with 'vulnerable groups'
Many practitioners argued that young people with HFA and AS would benefit significantly from low-level, preventative support services:

> *One of the saddest things is they don't need an awful lot of money spending, that is what kills me. We're not asking for massive great big packages, £60/70 quid a week would make all the difference.*
> (Social worker, adult services)

For some this low-level support was specifically seen as preventive: preventing mental health crises, entry into the criminal justice system and welfare dependency.

Personalisation and personal budgets
A small number of practitioners had experience of using personal budgets with young people with HFA and AS (in those sites where this group of young people was eligible for this funding), and felt this was a group of disabled young adults who could particularly benefit from personalised approaches to support. More widely, interviewees saw the potential benefits that personalised support could bring to this particular group. However, it was acknowledged that there still remained the need for appropriate support/services which, importantly, were expert in working with young adults with HFA and Asperger's syndrome:

> *So direct payments is all well and good, but only if there's actually people out there that are the right people to provide the right kind of support.*
> (Manager, autism specific organisation)

Facilitating peer support
Some of the social and leisure activities and opportunities described in Section 13.5 fulfilled a dual purpose of providing social activities and peer support opportunities, particularly for those with HFA and Asperger's syndrome. We also came across more specific examples of support groups/networks for young people with HFA and/or Asperger's syndrome, see Figure 13.2. Where these were available they were being provided by autism specific voluntary sector organisations.

Figure 13.2   Peer support for young people with HFA and Asperger's syndrome

Asperger's Support Network

In one site the local branch of the national autism organisation had established an Asperger's Support Network for young people aged 18 and over who either had a clinical diagnosis of Asperger's syndrome or who exhibited a number of AS traits. Most young people were referred to the group from adult mental health.

The group was set up as a peer support network and the goal was that people would support one another, facilitated through volunteers, and ultimately the group would become self-supporting. With some funding from Supporting People, social groups for people with AS were set up in six towns across the county and were held monthly. All groups had a base venue and members decided what they would like to do each month. Some went out for a meal or to the cinema, while others preferred to stay at the venue and chat or play games. The Network also ran a website which was open to the family members of people with ASC. The website contained information about Asperger's syndrome, hosted forums and chat rooms, and acted as a social networking site.

Autism Resource Centre

The Autism Resource Centre hosted a number of groups, including weekly social groups, discussion groups, women's groups, Saturday outing groups, and a day service which included sessions on creative writing, social skills, IT, cooking, and anger management. Most of the social groups were free and open to anyone, though very much aimed at people with high-functioning autism or Asperger's syndrome, aged 18 plus.

13.7   Summary

This chapter follows two chapters which reported young people's and parents' views about, and experiences of, young adulthood. It adds the practitioner perspective to this issue and has looked particularly at three indicators of adulthood: employment, moving from the family home and changing and developing social and leisure life. The final results section explored practitioners specific concerns regarding young adults with HFA and Asperger's syndrome and potential solutions to meeting unmet support needs.

Many of the practitioners we interviewed were concerned that, on leaving school or college, many young adults with ASC are not achieving their full potential. Young adult with HFA and Asperger's syndrome were particularly identified as being at risk of poor outcomes and this was partly ascribed to them not being eligible for support from adult social care <u>and</u> the lack of appropriate support.

Support for young people with ASC, and particularly those with HFA and Asperger's syndrome, to achieve positive outcomes in early adult life was limited across the research

sites. Whilst young people with ASC and learning disabilities were able to access all the learning disability specific services and support – in relation to social activities, housing and employment – but these were not necessarily suitable.

Managers and practitioners recognised the benefits of employment for young people with ASC and the need to support young people with ASC to gain and maintain employment. However, employment support was relatively limited. However, some local supported employment services and autism specific services reported providing such support. Barriers to supporting young people with ASC into employment were identified as low aspirations of the young people, lack of support from services, and lack of opportunities.

Moving out of the family home was recognised as a particularly challenging step. Whilst those with ASC and learning disabilities were recognised as having support needs and were eligible for support from housing departments and organisations such as Mencap, access to support with independent living and appropriate social housing were significant barriers to young people with HFA and AS achieving this milestone.

Statutory services did not see as their responsibility, or prioritise, positive outcomes in terms of the social and leisure lives of young adults with ASC. Practitioners noted that, for various reasons, generic LD provision may well be inappropriate for young adults with ASC. In some sites there had been a blossoming of social and leisure opportunities for young people with HFA and Asperger's syndrome, the majority of which had been established by non-statutory autism specific organisations.

The dilemma of how best to support young adults with HFA and Asperger's syndrome, for whom LD adult social care is not appropriate, was something raised by many interviewees. Many called for these young adults to be eligible for preventive low-level support and the model of "vulnerable adult" teams was seen as a possible way forward. Individual budgets were seen as having the potential to allow very personalised support to be put in place though the issues of eligibility for such support, and the need for ASC-skilled support, both were frequently raised. Finally, the potential role of peer support opportunities was noted, and the role of statutory services in facilitating the availability of such support is an interesting question.

Chapter 14
Discussion

14.1 Introduction

Improving outcomes for adults with autism is a key objective for the government, evidenced by the publication of the Autism Act (HMSO, 2009) and subsequent strategy and guidance documents (Department of Health, 2010a; Department of Health, 2010c). Evidence of poor outcomes in adulthood, including a failure to realise full potential and achieve the so-called markers of adulthood such as employment, independent living and 'adult' relationships (for example, Brugha et al., 2009; Rosenblatt, 2008; Reid, 2007; Howlin et al., 2004; Howlin 2000) prompted this policy emphasis.

This study has focused specifically on young people on the cusp of leaving school (the most significant change experienced by young people) and in the early post-school/college years. That is, the population of individuals with ASC who are at the interface of children's and adult services or who have achieved 'chronological adulthood', and are, to some degree, making steps towards the so-called markers of adulthood. In order to improve the outcomes of adults with autism, it is essential that we understand, and evaluate, transition planning processes and current systems and services for supporting young people and young adults with ASC. At the same time is it essential that we also understand the lives of individuals and their families as they experience this life stage. This research makes a significant contribution to these two evidence gaps. Concerns, and a relative lack of evidence, about the transition experiences of young people with HFA and Asperger's syndrome meant that this sub-population were a particular focus in this study.

The study sought the views of young people, parents and practitioners, ranging from strategic/managerial to front line staff. Qualitative and quantitative data, including data on costs, was collected. A rich dataset was gathered, the findings from which are reported in detail in Chapters 3 to 13. Each chapter concludes with a summary of findings reported therein. We have chosen to structure the report around a number of closely defined topics which we hope means the reader can identify and access the findings particularly pertinent to their interests or information needs.

It is not possible or helpful at this stage in a project report to refer to all the findings and issues emerging from the data. One of the purposes of this final chapter is, therefore, to look across, and to synthesise, the views and opinions of these various stakeholders and also to identify key issues and messages. It is also important to discuss some of the key implications of the findings and suggest some areas for further research. These form the main sections of this chapter. First, however, we briefly consider the limitations of the study.

14.2   Study limitations

One of the strengths of this study is the rich qualitative dataset achieved, and particularly the views and experiences of young people and young adults with HFA and Asperger's syndrome (AS). The strategy to use a survey of families to sample for the qualitative phase was very effective, supporting purposive sample and recruitment rates, and ensured that a range and diversity of views and experiences were accessed. However, there are two disappointing areas.

First, the survey of parents and young people yielded very low responses rates and was extremely variable between research sites. This severely compromised the way we could analyse the data. Specifically, we could not explore and compare families' 'post-transition' outcomes against the different models of transition planning and support in place in the research sites. In addition, the data could not be taken as, in any way, representing the wider population of families with a young person with ASC. As a result we chose to limit our analysis and use the quantitative data only to illustrate or test the conclusions being drawn from the qualitative research. However, the absence of robust quantitative data means we have not been able to explore or test the extent to which findings from the qualitative research are representative of the experiences of families with ASC at a population level.

Second, not all research sites provided adequate financial data. This lack of data, coupled with the low response to the family survey, significantly restricted the work we could do on costs.

In addition, it must be recognised that the transition pathways described in Chapter 3 and the discussion of statutory and non-statutory services offering some transition support or support in early adulthood for young people with ASC are not necessarily comprehensive reviews of all relevant and existing services in the research sites. What is provided is a snapshot of the key services as reported by managers and practitioners in the research sites. In some sites, potentially key staff members decided not to take part in an interview for this study and thus we may have missed information about basic or innovative practices.

14.3   Key issues emerging from the findings

The transition pathways and planning for leaving school
The transition pathways described in Chapter 3 revealed five different approaches to supporting leaving school and, for some, the transfer to adult social care, for young people with ASC. Only two pathways, at least theoretically, included a process by which young people with ASC who did not have a statement of educational needs and/or were in contact with children's services, would be supported in planning for this very significant change in their lives and/or would be known to adult services.

It is important to note that, based on the accounts of parents who participated in this study, the statutory transition planning processes did not necessarily prove to be a positive experience for parents. However, the problems and difficulties encountered did not differ from those reported by other studies which have looked at transition planning experiences

for other groups of disabled young people (for example, Sloper et al., 2010). Indeed, the parents were interviewed were generally satisfied that their child's ASC-specific needs had been understood and recognised within the transition planning process.

Likewise, within our sample, there were both positive and negative accounts from those who planned for their child leaving school outside of the SEN reviewing and planning pathways. Some parents found themselves reluctantly assuming the role of planning for their child leaving school: a role which some felt inadequate to assume and which could place considerable stresses on parents.

However, whilst difficulties with the planning process *per se* were described by parents or, indeed, identified by practitioners, it was the lack of post-school options and, for those ineligible for adult social care, the lack of support which most pre-occupied parents and practitioners. This is an issue identified by other recent studies (for example, VanBergeijk et al., 2008; McConkey 2010).

Compared to other groups of disabled young people, the level of cognitive ability *per se*, does not necessarily act as an indicator of the degree to which a young person will be able or willing to engage in planning around leaving school. We heard from young people with HFA and AS, parents and practitioners that there can be a reluctance to engage in planning for leaving school. A lack of aspirations, or unrealistic aspirations, were other challenges reported by parents and practitioners.

The young people interviewed reported that they appreciated support to help them be prepared to engage. However, practitioners spoke of resource constraints preventing them from doing this important, preliminary work with young people.

In addition, parents and practitioners both noted that, for young people with ASC, involvement in planning could be stressful and challenging in itself. Difficulties with change, social interaction and communication are core features of ASC but participation in transition planning demands facing change and interacting and communicating with people, some of whom may be relatively new in a young person's life.

Experiences of further education
The accounts of college life of many of the young people we interviewed revealed it to be a positive experience. Socially, the difficulties many had experienced at school diminished or were not experienced at college. Our interviews with practitioners also revealed a lot of examples of positive practice to support young people with ASC in college.

However, looking at the evidence gathered from parents and practitioners suggests that a successful college career is not the experience for all young people with ASC. There was evidence from parents' accounts that support plans were not always implemented. In addition, some practitioners believed that there was scope to develop or improve the courses/curricula which are appropriate or tailored to young people with HFA and AS. These findings concur with previous work on the further education experiences of young people with HFA and AS (Chown and Beavan, 2011; Martin et al., 2011).

However, the greatest area of concern was with regard to suspensions, expulsions and/or simply dropping out of college. These were typically viewed by parents and practitioners as outcomes of colleges failing to properly support young people with ASC and manage any challenging behaviours. This was seen to particularly be an issue in mainstream college settings. Young people who left college prematurely emerged as a highly vulnerable group. The circumstances of their departure appeared to preclude any advice or planning around next steps, and if ineligible for support from adult social care, invisible to statutory services.

Planning for leaving college
The lack of advice and support to young people and their families as they anticipate leaving further education appears in stark contrast to the heavy involvement of statutory services in planning transfers from child to adult services and/or post-school destinations, and preparing the young people for these changes. For example, across all the research sites numerous individuals were identified as supporting or being involved in planning and preparing for the transfer from school to college. Yet, the interviews with practitioners yielded very little evidence of activity and involvement in planning for leaving college, and this correlates with the accounts of parents. Indeed, the only post-college transfer where there may be clear systems of support concerned the transfer to higher education. The perceived role of Connexions at this stage in a young person's life appeared to be very variable across the research sites. Concerns about the lack of planning, guidance and support with respect to leaving further education have been in the past with respect to students with learning difficulties (Hudson, 2006). However, we would argue that these concerns are equally valid for young people with HFA and AS.

The lack of post-education options
The lack of post-school, and post-college, options was an issue for young people across the spectrum. Parents and practitioners both agreed that, for some, moving from school to college was not a positive choice but a decision forced by the lack of any other option. The lack of post-college options equally meant that some young people remained at college, moving from course to course, rather than moving on to new activities and opportunities. A further issue for young people with HFA and AS who were only attending college part-time was the lack of activities and options for the remainder of their week. Young people in this situation who were also living in rural areas and/or had restricted access to money were seen as additionally compromised.

 A lack of meaningful daytime occupation after leaving full-time education was an enormous worry for parents. Parents described their sons and daughters becoming increasingly socially isolated and losing the skills they had acquired through school and college. There were also significant concerns about the young people's mental health. The accounts of some of the young people with HFA and AS who we interviewed corroborate parents' stories. There were also consequences for the parents themselves including assuming responsibility for trying to create and coordinate activities and opportunities for the young person, and endeavouring to support them.

Experiences of employment for young people and young adults with HFA and AS
A particular focus of this research was the outcomes in young adulthood for those with HFA and AS. For many of these young people, paid employment may be an appropriate

aspiration. However, young people, parents and practitioners were in agreement that a number of barriers existed to this aspiration being realised, namely: the lack of appropriate and suitable employment opportunities, and insufficient support to identify, gain and maintain employment. The current economic situation was perceived to particularly disadvantage the employment prospects of disabled young people who would be perceived as a 'riskier' and/or more costly option by employers.

Certainly, based on our interviews with practitioners in the research sites, policies and practice around roles and responsibilities for supporting young people with ASC into employment appeared to be specific to localities. Furthermore, this was an area where we were most likely to find practitioners had little to discuss or report. Transition teams did not appear to view employment as an outcome in which they actively engaged in helping young people to achieve. The perceived (and actual) role of Connexions in supporting young people from college into employment varied considerably between sites. Whilst employment services may be viewed as the agency with responsibility for supporting entry into employment, we gathered some evidence to suggest there may be lack of understanding of ASC among Job Centre and Job Centre Plus staff.

It is important to stress that we did encounter some very positive outcomes of supported employment services – based both in the statutory and third sector. At the same time there was a sense from some parents' accounts that achieving employment was perceived as a 'fragile' attainment which might not be sustained. Certainly the time-limited nature of employment support was of concern.

Support for young adults with HFA and AS
Across all our research sites the 'lead' (statutory) provider of services and support for young adults with ASC who are not eligible for support from adult social care was adult mental health. Community mental health teams and, in some places, specialist 'Asperger teams', were identified as the first port of call for young adults with HFA or AS who were struggling with the transition to adulthood. All these services provided multi-disciplinary, but time-limited, support.

The use of mental health as the 'lead service' in adult services is interesting. It could be argued that a service located in mental health service may be more concerned with addressing the 'symptoms of mal-adaptation' (for example, aggression, anxiety, self-harm and other mental health problems) as opposed to supporting and meeting the needs associated with having an autistic spectrum condition *per se*.

The other main providers of support for young adults with HFA and AS identified by our practitioner interviewees were third sector organisations, all of which were autism specific. Some of the outreach services described by practitioners were very positively endorsed by parents and young people. However, it was clear that knowledge of and access to such support was extremely variable.

Certainly, ASC specific, and indeed HFA and/or Asperger specific support, were the sorts of services which the young adults we interviewed used and valued. Amongst these young

people there was a clear view that generic disability, or learning disability, services were not appropriate for them.

A striking finding from our interviews with young people was they felt unsupported, and many were very conscious of their reliance on their parents, and yet did not readily identify social services as a potential source of support.

Adult social care support
Certain sections of this report have focused specifically on the needs and experiences of young adults with HFA and AS. This emphasis was in response to particular concerns, and a lack of evidence, about the transition experiences of this particular group.

However, this should not be taken to imply that adult social care provision for young adults with ASC and learning difficulties is unproblematic. A lack of training, understanding and awareness of ASC among some frontline practitioners, and the inappropriateness of some learning disability services for young people with ASC (featuring for example, high levels of sensory stimulation) create difficulties for some young people with ASC who are eligible for adult social care support. The experiences of parents within our interview sample confirm this. Equally, practitioners expressed concern about the lack of appropriate ASC-specific provision, and limited post-college choices and options for families.

Moving from the family home and independent living
The consistent view of young people, parents and practitioners was that, for many young people with ASC, moving from the family home and into some sort of independent living situation was not something that was appropriate or feasible in the early years of adulthood[24]. It was spoken about as something for the future, as opposed to a current priority or aspiration.

However, there was also agreement that 'work' to support and enable the young person to achieve this was required. Equally, there was a danger that independent living skills acquired in school or college were lost in the post-education months and years when young people were at home and unoccupied. Parents reported particularly struggling with knowing how best to motivate and encourage their young adult sons and daughters, who may be anxious or ambivalent about leaving the family home, to acquire these skills. This was a key area of unmet need for young people with HFA and AS who were not eligible for adult social care. This is a critical issue given that the lack of such support in young adulthood has the potential to threaten the achievement of independent living later on (Barnard et al., 2001; VanBergeijk et al., 2008). There are clear implications here for parents too, some of whom felt they could not, in the long-term, sustain the level of involvement and support they were providing to their son or daughter.

---

[24] We are not referring here to the move to residential placements/care settings with intensive or high levels of support. For young adults with ASC and learning difficulties and/or challenging behaviours placements in such settings were being sought by some parents and practitioners following college.

182

Workforce issues

The young people with HFA and AS whom we interviewed were very astute about the skills required of practitioners who worked with and supported them. They distinguished between the need for practitioners to be knowledgeable about ASC but at the same time recognising and acknowledging that they could not understand living with this condition. Crucially, they stressed that the ASC is a unique, individual experience and practitioners should not make assumptions about an individual's needs and abilities. This requirement of an 'individualised' knowledge could be a challenge when new practitioners, for example those from Connexions, a transition team worker, became involved with a young person during the transition planning period. Many of the practitioners we interviewed recognised that a personalised approach to working with young people with ASC was essential as training and text books could only outline the general challenges faced by this group.

The role of parents

A recurrent theme emerging from the interviews was that parents appeared to be very involved in supporting and, in cases, 'managing' their son or daughter's life. This was clear from the interviews with the young people and the parents. Practitioners voiced difficulties about deciding where, metaphorically speaking, to put parents on the continuum of involvement in transition planning. This tension seemed to be particularly acute when practitioners were aware that, in the post 18 years, the parent may well be assuming caring responsibilities because the young person would not be eligible for formal support. An ambivalence on the part of the young people to engage in planning and/or take responsibility for decision-making further served to make it very difficult to identify and agree roles and responsibilities for parents and young people within the transition planning process.

The accounts of the young adults we interviewed suggest that high levels of parental involvement in their lives are not, typically, unwanted. Across the accounts of their lives, parents were consistently identified as being the reason behind achievements and progress towards greater independence and 'adulthood'. Statutory services were not perceived as a place to go for support. Common roles assumed by parents were researching potential opportunities/activities, doing what was required to allow/enable the young person to participate or access an activity, and supporting the young person, practically and emotionally, as they accessed the activity. This pattern of involvement was found across all areas of the young people's lives; for example, learning to drive, hobby/interest groups, voluntary work, paid work, maintaining contact with friends and, for one or two, moving out of the family home.

The proactive and deep involvement of parents in trying to promote and develop their child's independence and movement towards adulthood is, perhaps, counter-intuitive. However, the perceived need, for at least some young people, to nudge and organise in order to encourage and facilitate change and personal growth appeared to leave parents feeling there was no option but to become actively involved in 'managing' their young person's life. The alternative - one of increasing social isolation and a lack of meaningful day-time occupation – could not be countenanced.

The practitioners who participated in this study also identified that ineligibility for statutory support would inevitably mean some parents assumed the role of 'informal key worker' for their son or daughter. However, it is important to stress that, among the parents who participated in this study, this was not a role they wanted to assume. Indeed, many expressed feeling that they did not have the knowledge and skills to properly fulfil this role – thus posing a threat to positive outcomes for their son or daughter - and felt they could not sustain this role indefinitely.

Autism-specific issues during transition
As already noted, the current study was designed to complement an earlier study on models of multi-agency transition planning for disabled young people and those with complex health needs (Sloper et al., 2010). Whilst the data collected by the two studies does not fully overlap, by comparing the findings from both pieces of research it is possible to identify factors and issues which appear to be specific to, or more problematic for, young people with autistic spectrum conditions.

The 'Disability and complex health needs transition project' (Sloper et al., 2010) highlighted that multi-agency transition services appeared to devote most of their attention on young people with severe learning disabilities, with the risk that those with complex health needs but no learning difficulties may not be able to access advice and support as they prepared and planned for leaving school. In the current study, similar concerns emerge for young people with HFA or Asperger's syndrome. Equally, however, the study has produced evidence on systems and structures of service during the transition period that do ensure all young people with a diagnosis of ASC receive some sort of support during the transition period. Joint working between social care and mental health services appears to be a promising approach here. There is evidence to suggest that partnerships between social care and mental health to provide transition support are more likely to be found for the ASC population compared to other groups of disabled young people.

Whilst the 'Disability and complex health needs transition project' (Sloper et al., 2010) reported the benefits of person-centred planning at transition, the current study identified some potential difficulties of using person-centred planning approaches with young people with ASC. These included the social demands associated with working with new practitioners and participating in meetings, and the anxieties which can arise from anticipating change and taking responsibility for, or being actively involved in, decision-making. In addition, parents of young people with HFA and Asperger's syndrome and practitioners identified a reluctance to engage, or an avoidance of, in planning for adult life which was ascribed to the autism diagnosis. This inhibited both the involvement of young people in planning for their future lives and their willingness to work towards longer term goals of independent living.

In terms of services and support for young adults with ASC, the current study highlighted that some of the learning disability services were not suited to the needs of those with autism owing largely to their sensory sensitivities. The 'Disability and complex health needs transition project' (Sloper et al., 2010) highlighted substantial levels of unmet need, particularly in relation to a lack of options around employment, housing, meaningful day-time occupation, social and leisure activities and, in some areas, access to FE college

courses. Similar concerns and experiences of unmet need were identified in the current study. A further recurrent theme in terms of positive experiences of transition planning and positive outcomes in adulthood for young people with ASC is the need for services and professionals (within community services, employment services, businesses/work-places, universal and specialist health and social care) to have a sufficient level of understanding and expertise in ASC.

The dilemma of how best to support young adults with HFA and Asperger's syndrome, for whom LD adult social care is not appropriate, was raised by many interviewees as was the issue of eligibility for statutory support. Many called for these young adults to be eligible for preventive low-level support and the model of "vulnerable adult" teams was suggested as a possible way forward. Certainly, parents were deeply concerned about their sons' and daughters' increased vulnerability as they assumed greater independence and left the routines and boundaries of school behind. The young adults with HFA and Asperger's syndrome who participated in this project were very clear that learning disability and 'generic' autism services were not appropriate for them. Many desired the opportunity to meet with other young adults with HFA or Asperger's syndrome. Direct payments and personal budgets were seen as having the potential to allow very personalised support to be put in place though the issues of eligibility for such support, and the need for ASC-skilled support, were frequently raised. Finally, there was evidence that ASC-specific voluntary sector organisations, sometimes being commissioned by statutory agencies, were delivering highly valued services.

14.4   Implications for policy and practice

In this penultimate section we consider key implications of the findings in terms of policy and practice. We acknowledge that policy concerned with support to children and young people with special educational needs and disabilities, including transition planning, is currently under reform (Department for Education, 2011) and models of implementation are being piloted. We believe that the findings from this study will be of relevance to policy makers charged with fine-tuning policy and developing guidance as well as in the on-going work associated with the implementation of the Autism Act (2009) and autism strategy *Fulfilling and Rewarding Lives* (Department of Health, 2010a).

This section is structured around the following topics:
*   transition planning, strategies and processes
*   the move from further education
*   continuity of mental health support at a time of change
*   services and support for young adults.

Transition planning, strategies and processes
*   Some of our research sites had systems in place which ensured that all young people with ASC had transition support and a referral route into adult services. This was not always the case. In addition, access to specialist Connexions support for those with HFA and AS was variable across the sites. Unfortunately, poor responses to the family

survey meant we could not explore in any detail the impact of these different models to young people's outcomes. However, previous research has shown that models of transition planning and support do impact on outcomes for young people and parents (Sloper et al., 2010). The fact that young people with HFA and AS are undergoing transition in the absence of appropriate support is therefore of concern and needs to be addressed.

- Previous research and policy and practice guidance refer to the need for ASC specific services. In this study we have been able to explore the impact of ASC-specific characteristics on needs and experiences over the transition period. The term transition means change: for young people and young adults with ASC this means making steps along the path to adulthood and, for some, transferring from children's to adult services. Yet change is something many young people with ASC engage with only reluctantly. They may not feel 'ready' to take greater responsibility for their lives and lack any motivation to do so. Low self-esteem may affect the aspirations they hold for themselves. The social demands associated with involvement in transition planning can be very stressful and can be counter-productive to the young person's involvement. Transition planning practice, for example person-centred planning, need to take account of these characteristics and responses to this life stage. This also draws attention to the need for practitioners to be knowledgeable and skilled in working with young people with ASC, including HFA and AS.

- The presence of appropriate support in adult services will not, on its own, be sufficient in supporting positive transition outcomes. Young people and families need to be signposted and/or referred to such support. At the moment, transition planning processes are centred around transfers from children's to adult services and typically operate within SEN reviewing processes. Young people ineligible for support from children's services and without a SEN, including young people with HFA and Asperger's syndrome, are at risk of being invisible to strategic groups and commissioners of adult statutory services. At the same time, families' awareness of such support is likely to be hit and miss.

The move from further education
- Support and advice in planning for the move from further education into employment or other settings appeared to be largely absent in the five research sites. This did not appear to be a service routinely or systematically offered by college staff, nor did there appear to be consistent practice in the involvement of Connexions. This contrasts sharply with the work done to plan and prepare for the transfer from school to college. It would suggest itself as an important area for further investigation.

Continuity of mental health support at a time of change
- The wholesale nature of change in services and support can be a very difficult experience and one to which, it would be argued, young people with ASC are particularly vulnerable because of the nature of their condition (see also Kaehne, 2011). To lose or interrupt mental health support during this time, or require a change of therapist, appears to be counter-intuitive. Ensuring continuity of condition

management over the late teenage years has been something which has been achieved for some chronic (physical) childhood health conditions, requiring flexibility and joint-working from paediatric and adult services. We would argue that work investigating the feasibility of such a model for mental health support for young people with ASC, and particularly, perhaps, those with HFA and AS would be worthwhile.

Services and support for young adults

- The findings from this research confirm and reiterate the findings and conclusions of a number of previous pieces of work (for example, Knapp et al., 2007; National Audit Office, 2009; Higgins, 2009). These and other reports call for 'low intensity', early intervention/preventative holistic support for young people with HFA and AS, and make a strong case for the cost effectiveness of providing such support (National Audit Office, 2009). As with other pieces of work, a number of ASC-specific services, some of them joint funded, delivering such support were identified by this project adding to the existing body of knowledge. However, there is an absence of evidence on the (cost) effectiveness of these interventions and this will be a barrier to these services being commissioned. Crucially, any study of effectiveness needs to take a cross-agency view on costs and cost-effectiveness.

- Many parents despaired at the lack of meaningful daytime activities and opportunities which were appropriate for their son or daughter. This was the case for parents of young people across the spectrum. Provision in rural areas was perceived to be particularly problematic. The lack of opportunities and activities places considerable organisational, time and financial burdens on parents as they seek to 'create' a meaningful life for their child. Some third sector organisations were providing day services and it is important that these are investigated and evaluated as part of a menu of possible solutions to this issue. Whilst some might baulk at specialist, non-inclusive provision, some of the young people we interviewed were very clear that they preferred spending time in such settings which they saw as 'normalising' them.

- Social isolation is a key concern for parents of young people and young adults, particularly those with sons or daughters with HFA and AS. At the same time, there was evidence from some of the young people themselves that they particularly valued spending time with others with the same condition. Indeed, some third sector organisations were providing peer support opportunities. This would appear to be something warranting further attention. In particular, exploring the effectiveness of different modes of providing such support.

- Overall, experiences of employment were disappointingly low and, where achieved, there was a sense of fragility. The current economic climate was perceived to further disadvantage this group of young people. Access to specialist employment support did not appear adequate, and experiences of mainstream job support by young people with HFA and AS suggested a lack of expertise and understanding of HFA and AS among frontline staff suggesting itself as an area for attention. Voluntary work placements in settings where ASC was understood and accommodated were consistently viewed very positively by our young adult interviewees. Further consideration of the strategic and

planned use of such placements, and their impact on longer-term outcomes, may be productive.

14.5 Suggested additional further research

There are some suggestions in the previous section for research to evaluate possible new models or approaches to supporting young people and young adults with ASC over the transition period. In addition, we would suggest that research specifically looking at employment services knowledge of, and ways of working with, ASC would be valuable.

The desire to replicate the earlier 'Disability and complex health needs transition project' (Sloper et al., 2010) and resource constraints meant this study captured the stories of young people and their parents at a single point in time. Whilst there are some longitudinal studies of the clinical or psychiatric trajectories of children and young people with ASC, further longitudinal research which captures a broader set of outcomes, including parent/ family outcomes, is required in order to further understand the factors which support or hinder positive outcomes in childhood and into young adulthood, and the consequences of not providing appropriate support during the transition period. Identification of factors, events and situations which buffer against, or alternatively act as tipping points toward, negative outcomes or prevent the achievement of the full potential of young people with HFA and AS would be extremely valuable.

Finally, one of the key planks of the Autism Act was improving the knowledge and understanding of ASC across staff in all sectors who work with and support people with ASC. It is, perhaps, to soon to evaluate the extent to which this policy has been implemented and its impact. However, we do know from numerous other sectors that changing attitudes and practices, and implementing new knowledge, can be hard to achieve. Research investigating the effectiveness of autism-awareness and autism-understanding training, and identifying the components which contribute to effectiveness, suggests itself as an important topic.

References

Alcock, J. and Howlin, P. (2003) *An evaluation of Prospects Supported Employment Service for individuals with Asperger syndrome,* Report for the Department for Work and Pensions.

Audit Commission (2007) *Out of Authority Placements for Special Educational Needs*, Audit Commission for local authorities and the National Health Service in England, London.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T. and Meldrum, D. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP), *Lancet,* 368, 9531, 210-215.

Barnard, J., Harvey, V., Potter, D. and Prior, A. (2001) *Ignored or Ineligible: The reality for adults with autism spectrum disorders,* National Autistic Society, London.

Beecham, J. and Knapp, M. (2001) Costing psychiatric interventions, in G. Thornicroft (ed.), *Measuring Mental Health Needs*, Gaskell, 2nd edition, London, pp.200-224.

Beresford, B. (2004) On the road to nowhere? Young disabled people and transition, *Child: Care, Health and Development,* 30, 581-587.

Beresford, B. and Cavet, J. (2009) *Transitions to Adult Services by Disabled Young People Leaving Out of Authority Residential Schools*, Social Policy Research Unit, University of York, York.

Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T. and Forte, J. (2011) Transition for teenagers with intellectual disability: carers' perspectives, *Journal of Policy and Practice in Intellectual Disabilities,* 8, 1, 53-61.

Billstedt, E., Gillberg, I.C. and Gillberg, C. (2011) Aspects of quality of life in adults diagnosed with autism in childhood: a population-based study, *Autism*, 2011, 15, 1, 7-20.

Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott, F.J., Purdon, S., Harris, J. and Bankart, J. (2009) *Autism Spectrum Disorders in Adults Living in Households Throughout England: Report from the Adult Psychiatric Morbidity Survey 2007,* NHS The Health and Social Care Information Centre, Social Care Statistics.

Charman, T. and Clare, P. (2004) *Mapping Autism Research: Identifying UK priorities for the future,* National Autistic Society, London.

Chown, N. and Beavan, N. (2011) Intellectually capable but socially excluded? A review of the literature and research on students with autism in further education, *Journal of Further and Higher Education,* DOI:10.1080/0309877X.2011.643771.

Communities and Local Government (2008) *The English Indices of Deprivation 2007,* Department for Communities and Local Government, London. Available online at: http://www.communities.gov.uk/publications/communities/indiciesdeprivation07

Cope, C. (2003) *Fulfilling Lives: Inspection of social care services for people with learning disabilities,* Department of Health, London.

Curtis, L. (2011) *Unit Costs of Health and Social Care 2011*, PSSRU, University of Canterbury,

Dean, J. (2003) *Unaddressed: The housing aspirations of young disabled people in Scotland,* Joseph Rowntree Foundation, York.

Dee, L. and Byers, R. (2003) Facilitating transitions for people with profound and complex learning difficulties, *Journal of Integrated Care*, 11, 34-38.

Department for Children, Schools and Families/Department of Health (2007) *A Transition Guide for All Services,* DCSF Publications, Nottingham.

Department for Education and Employment (DfEE) (2000) *Connexions: The best start in life for every young person,* DfEE, Nottingham.

Department for Education (2011) *Support and Aspiration: A new approach to special educational needs and disability – A consultation,* Department for Education, London.

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century,* The Stationery Office, London.

Department of Health (2006a) *Better Services for People with an Autistic Spectrum Disorder,* Department of Health, London.

Department of Health (2006b) *Guidance on the Statutory Chief Officer Post of the Director of Adult Social Services,* Department of Health, London.

Department of Health (2008) *Transition: Moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*, Department of Health/Department for Children, Schools and Families, London.

Department of Health/Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services*, Department of Health, London.

Department of Health (2010a) *Fulfilling and Rewarding Lives: The strategy for adults with autism in England,* HMSO, London.

Department of Health (2010b) *Towards 'Fulfilling and Rewarding Lives': The first year delivery plan for adults with autism in England,* Department of Health, London.

Department of Health (2010c) *Implementing 'Fulfilling and Rewarding Lives': Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy,* Department of Health, London.

Eaves, L. and Ho, H. (2008) Young adult outcome of Autism Spectrum Disorders, *Journal of Autism Development and Disorder,* 38, 739-747.

Fiorentino, L., Phillips, D., Walker, A. and Hall, D. (1998) Leaving paediatrics: the experience of service transition for young disabled people and their family carers, *Health and Social Care in the Community*, 6, 260-270.

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

Grove, B. and Giraud-Saunders, A. (2002) *Connecting with Connections 2: Learning from experience – findings from the Lewisham disability pilot,* Institute for Applied Health and Social Policy, King's College, London.

Grove, B. and Giraud-Saunders, A. (2003) Connecting with connections: the role of the personal advisor with young people with special educational and support needs, *Support for Learning*, 18, 12-17.

HM Government (2009) *Valuing Employment Now: Real jobs for people with learning disabilities*, Department of Health, London.

HM Treasury and Department for Education & Skills (2007) *Aiming High for Disabled Children: better support for families,* HMSO, London.

HMSO (2009) *Autism Act,* HMSO, London.

Hendricks, D. and Wehman, P. (2009) *Transition from School to Adulthood for Youth with Autistic Spectrum Disorders: Review and recommendations*, Sage.

Heslop, P., Abbott, D., Johnson, L. and Mallet, R. (2007) *Help to Move On: Transition pathways for young people with learning difficulties in residential schools and colleges,* Norah Fry Research Centre, York Publishing Services Ltd., York.

Heslop, P., Mallett, R., Simons, K. and Ward, L. (2002) *Bridging the Divide at Transition: What happens for young people with learning difficulties and their families?* British Institute of Learning Disabilities, Plymouth.

Higgins, B. (2009) *Good Practice in Supporting Adults with Autism: Guidance for commissioners and statutory services,* National Autistic Society, London.

Howlin, P. (2000) Outcome in adult life for more able individuals with autism or Asperger syndrome, *Autism,* 4, 63-83.

Howlin, P., Goode, S., Hutton, J. and Rutter, M. (2004) Adult outcome for children with autism, *Journal of Child Psychology and Psychiatry,* 45, 212-229.

Hudson, B. (2006) Making and missing connections: leaving disability services and the transition from adolescence to adulthood, *Disability and Society*, 21, 47-60.

Kaehne, A. (2011) Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems, *Advances in Mental Health and Intellectual Disabilities,* 5, 1, 9-16.

Knapp, M. et al. (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities.

McConkey, R. (2010) *Transitions and Young People with Autistic Spectrum Disorders,* University of Ulster.

Madders, T. (2010) *You Need to Know*, The National Autistic Society, Marstan Press, Bexleyheath.

Martin, K., Hart, R., White, R., Sharp, C. (2011) *Young People with Special Educational Needs/Learning Difficulties and Disabilities: Research into planning for adult life and services,* (LG Group Research Report), NFER, Slough. Report available at http://www.nfer.ac.uk/nfer/publications/SENT01/SENT01.pdf

Morris, J. (1999) *Hurtling Into a Void: Transition to adulthood for young people with complex health and support needs,* Joseph Rowntree Foundation, York.

Morris, J. (2002) *Moving into Adulthood: Young people moving into adulthood,* Joseph Rowntree Foundation, York.

Murphy, D., Beecham, J., Craig, M. and Ecker, C. (2011) Autism in adults: new biological findings and their translational implications to the cost of clinical services, *Brain Research*, 1380, 22-33

National Audit Office (2009) *Supporting people with autism through adulthood*, The Stationery Office, London.

National Development Team for Inclusion (2011) *Preparing for Adulthood,* Press Release, Available online at:
http://www.ndti.org.uk/uploads/files/Preparing_for_Adulthood_PR_Nov_2011.pdf

NHS (2012) *Autism and Asperger syndrome NHS Choices,* Accessed online (27 April 2012) at:
http://www.nhs.uk/conditions/autistic-spectrum-disorder/Pages/Introduction.aspx

O'Sullivan, T. (1998) *The Transition of Young Adults with Disability: A study of the effectiveness of inter-agency transitional planning,* Executive Summary*,* URL http://www.doh.gov.uk/research/mch/studies/execsum13-24.htm

Office for National Statistics (2004) *2001 Census: Neighbourhood Statistics - Ethnic Group* (KS06), Office for National Statistics. Available online at: http://neighbourhood.statistics.gov.uk/dissemination/

Pownceby, J., Ratcliffe, D., Abbott, J. and Kent, P. (1997) *The Coming of Age Project: A study of the transition from paediatric to adult care and treatment adherence amongst young people with cystic fibrosis,* Cystic Fibrosis Trust, Bromley.

Reid, B. (2007) *Moving on Up? Negotiating the Transition to Adulthood for Young People with Autism*, National Autistic Society.

Ritchie, J. and Lewis, J. (2003) *Qualitative Research Practice,* Sage, London.

Romeo, R., Knapp, M. and Beecham J. (forthcoming) Evidence on the Cost and Cost-effectiveness of Interventions for Autism Spectrum Disorders: a review. *Journal of Autism and Developmental Disorders.*

Rosenblatt, M. (2008) *I Exist: The message from adults with autism in England,* National Autistic Society, London.

Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. and Cusworth, L. (2010) *Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and costs*, Social Policy Research Unit, University of York, York.

Taylor, J.L. and Seltzer, M.M. (2010) Changes in the autism behavioral phenotype during the transition to adulthood, *Journal of Autism and Developmental Disorders,* 40, 12, 1431-1446.

Taylor, J.L. and Seltzer, M.M. (2011) Employment and post-secondary educational activities for young adults with autism spectrum disorders during transition to adulthood, *Journal of Autism and Developmental Disorders,* 41, 5, 566-574.

VanBergeijk, E., Klin, A. and Volkmar, F. (2008) Supporting more able students on the autism spectrum, *Journal of Autism and Developmental Disorders,* 38, 1359-1370.

Van Bergeijk, E.O. and Shtayermman, O. (2005) Asperger syndrome: an enigma for social work, *Journal of Human and the Social Environment,* 2, 23-37.