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# **Young people with High Functioning Autism and Asperger's syndrome planning for and anticipating the move to college: what supports a positive transition?**

**Wendy Mitchell and Bryony Beresford**

**Social Policy Research Unit, University of York**

## **Keywords**

Autistic spectrum condition, Asperger's syndrome, High-functioning autism, transition, post-16 education, college, young people

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# **Young people with High Functioning Autism and Asperger's syndrome planning for and anticipating the move to college: what supports a positive transition?**

## **Abstract**

For many young people in England the move into further education involves a transfer from the school where they were educated from around 11 years of age to a further education college. For those with high-functioning autism (HFA) or Asperger's syndrome (AS) this can be a challenging process. Past research has demonstrated some of the problems these young people can encounter. This paper adds to the evidence base describing how to best support these young people, focusing specifically on 'young person endorsed' practice. Data is gleaned from qualitative interviews with 18 young people with HFA/AS. Findings reveal that young people welcomed the involvement of practitioners; however, specific forms of help and knowledge were particularly valued. In addition, it was parents, as opposed to professionals, who typically emerged as the most significant and valued source of support. Implications for practice are discussed, including the support needs of parents.

## **Keywords**

Autistic spectrum condition, Asperger's syndrome, High-functioning autism, transition, further education, college, young people

## **Young people with High Functioning Autism and Asperger's syndrome planning for and anticipating the move to college: what supports a positive transition?**

### **BACKGROUND**

For young people in the England, staying in education in the school year following their sixteenth birthday involves a transfer from the school where they were educated from around 11 years of age to a further education setting. (Rydzewska, 2012). This can either be in a setting co-located with the school (known as 'Sixth Forms'), or on separate campuses (further education (FE) colleges). FE colleges are much larger than Sixth Forms with a city-wide/semi-regional catchment area. Some FE colleges are residential; these typically provide vocational courses or are specifically designed for disabled young people. Whichever educational route a young person takes, leaving school is a significant milestone, particularly if it involves moving to a FE college.

This paper focuses on the experiences of this move by young people with Asperger's syndrome (AS) and high-functioning autism (HFA). Autism is a lifelong developmental disability which affects an individual's abilities to make 'sense of the world, process information and relate to other people' (National Autistic Society). Whilst there are these core difficulties, individuals are affected by the condition in different ways and to different extents. Some have significant learning disabilities and associated high levels of support needs. Others do not have learning disabilities or, indeed, can be of above average intelligence. This includes young people with High Functioning Autism (HFA) and Asperger syndrome (AS). However, these

individuals still experience difficulties with communication and have specific learning and social needs. For young people with AS and HFA, the changes and demands associated with this transition can be very challenging (Rydzewska, 2012; Baron-Cohen, 2008; Reid/National Autistic Society (NAS), 2007). There are expectations of increased independence, greater demands for self-directed learning, self-management of time, less structured timetables as well as new peer groups and social situations. For some, the move may also entail a change of location. Indeed, these social changes can be more challenging than the educational demands of studying at an extended level (Chown and Beavan, 2012; Geller and Greenberg, 2009; Reid/NAS, 2007; Adreon and Durocher, 2007). Furthermore, whilst the intellectual abilities of these young people may support their adaptation to a more intellectually demanding educational curriculum, a lack of social skills, or confidence in their social skills, may compromise their ability to integrate into the new setting, develop social networks and manage expectations of independence and self-reliance (Muller *et al.*, 2008; VanBergeijk *et al.*, 2008).

Thus, whilst young people with HFA/AS may well struggle with adapting to this new social and learning environment, their needs for support may not be identified. High levels of cognitive ability and educational achievement may 'mislead' staff into assuming they are coping with the demands of further education (Zager and Alpern, 2010; Adreon and Durocher, 2007, Camarena and Sarigiani, 2009, VanBergeijk *et al.*, 2008). Research confirms this. Young people report feeling unsupported, or inadequately supported, once they reach college (Beardon *et al.*, 2009; Camarena and Sarigiani (2009). This might be in terms of general socio-emotional support, and/or particularly with respect to support with 'making sense of' and integrating into

the social aspects of college life (Beardon *et al.*, 2009). A lack of awareness and understanding of autism spectrum conditions (ASC) among staff and students emerges as a common experience. The absence of ASC 'friendly' (especially quiet) spaces may also hamper students' abilities to adapt and cope with college (Chown and Beavan, 2010). There have been numerous calls for improved support for students with HFA/AS in post-16 settings (Adreon and Durocher, 2007; Camarena and Sarigiani, 2009; McConkey, 2010; Beardon *et al.*, 2009; Hendricks and Wehman, 2009), and for post-16 settings (both staff and other students) to be more 'autism aware' (Reid/NAS, 2007; McConkey, 2010).

A smaller number of studies (largely UK and American) have explored the experiences of young people with HFA and/or AS t anticipating the transfer to post-16 education. An English study of ASC college students reports that pre-transition fears focused on travelling to college, navigating college buildings, meeting new people and making friends (Chown and Beavan, 2010). Opportunities to experience college life before the transfer were valued and seen as beneficial (Zager and Alpern, 2010; Camarena and Sarigiani, 2009). Families can also feel under-informed as they try to support their son or daughter in this transition (Autism West Midlands, 2007) and studies report parental concerns over the lack of ASC-expertise among practitioners working with their child during this period (Reid/NAS, 2007).

Practice guidance or recommendations related to the transfer to post-16 education for young people with HFA/AS are also found in research and practitioner literatures. Opportunities for pupils to visit and spend extended periods in post-16 settings is a commonly advocated as a key part of preparing for the transfer from school to

college (Chown and Beavan, 2010; Reid/NAS, 2007; Autism West Midlands, 2007; Adreon and Durocher, 2007; Hendricks and Wehman, 2009; McConkey, 2010; Roberts, 2010). Similarly, the need to develop travel plans with young people prior to college transfer is stressed (Geller and Greenberg, 2009, McConkey, 2010). Others have described techniques to develop the social skills of pupils moving to post-16 settings (Geller and Greenberg, 2009; Hendricks and Wehman, 2009; VanBergeijk *et al.*, 2008; Datlow-Smith and Sherron-Targett, 2009).

This paper adds to this growing evidence base on how to best support young people with HFA and AS as they make decisions about, and prepare for, the transfer to post 16 education. It reports the views and experiences of young people and particularly focuses on the processes and practices found helpful, rather than problems encountered.

## **METHODOLOGY**

The findings reported here are from one element of a larger project on transition and young people with ASC in England. The project had a particular focus on those with a diagnosis of HFA or AS due concerns about unmet needs among this particular population given that they may not be eligible for additional support from children's services, and are typically ineligible for support from adult social care. The project comprised a number of elements: i) an exploration of transition planning pathways and support across a number of Local Authorities in England; ii) interviews exploring professionals' experiences of supporting young people and young adults with ASC; iii) a postal survey of parents and young people with ASC (15-24 years); and iv) qualitative interviews with young adults with HFA or AS and parents (Reference

withheld, authors). It is findings from this last element (iv), and specifically the interviews with young people/young adults, which are reported in this paper. The project was reviewed and approved by an NHS research ethics committee, and research governance gained from each local authority.

## **Sampling**

The sample for the qualitative interview element was drawn from individuals who took part in the postal survey (see (iii) above). The survey sample (n=133 parents; n=76 young people) was recruited by services/practitioners in five Local Authorities who mailed the survey to all families known to them who fulfilled the project inclusion criteria (families with a young person aged 14-25 years and a diagnosis of ASC). The final question of the survey asked respondents to indicate if they would be willing to participate in an interview about their transition experiences.

The following criteria were used to identify a sampling pool for the qualitative interviews (see (iv) above) with young people: positive response to taking part in an interview; diagnosis of HFA or AS (self-reported); and aged between 15 and 21 years. This age range was chosen in order to capture young people who were on the cusp of leaving school and those in, or with recent experiences of, further education. This yielded a sampling pool of 26 young people. A letter of invitation to take part in an interview, accompanied by an information sheet and response form, was mailed to these individuals. Eighteen individuals responded positively to this invitation via email or through returning the response form. Arrangements for the interview were made during a phone call which also allowed further discussion between the researcher (WM) and participant about the interview. Written consent from

interviewees was taken at the time of the interview.

### **Sample**

The sample varied in terms of age, gender and schooling (see Table 1). Thirteen of the 18 young people had a 'statement of special educational needs (SEN)'. This is the output from a statutory assessment process which describes a child's special educational needs and the help/support they need to receive whilst in compulsory education. Young people with a SEN statement are eligible for, and will undergo, statutory transition planning processes in the years leading up to their transfer from children's services, including planning around leaving school.

**Table 1 Sample characteristics and transfer to further education**

ID	Gender	Age at interview (years)	Type of school	Type of college**	Eligible for Statutory transition planning process***	Age at transfer (years)
YP1	Male	25	Special	Specialist	Yes	18
YP2	Male	16	Mainstream *	Mainstream†	Yes	16
YP3	Male	20	Mainstream	Mainstream	No	16
YP4	Female	18	Mainstream	Mainstream	No	16
YP5	Male	18	Mainstream	Mainstream	Yes	16
YP6	Male	19	Mainstream	Mainstream	Yes	16
YP7	Male	20	Special	Mainstream	Yes	16
YP8	Female	18	Mainstream	Mainstream	No	16
YP9	Male	18	Mainstream	Mainstream	Yes	16
YP10	Female	18	Mainstream	Mainstream	No	16
YP11	Male	16	Mainstream	Mainstream	Yes	Planned
YP12	Male	20	Mainstream	Mainstream	Yes	16
YP13	Male	23	Mainstream	Mainstream	No	16
YP14	Male	20	Mainstream	Specialist	Yes	16
YP15	Female	19	Mainstream	Mainstream	Yes	16
YP16	Male	16	Mainstream	Mainstream	Yes	15
YP17	Male	15	Mainstream	Mainstream	Yes	Planned
YP18	Male	16	Mainstream	Mainstream	Yes	16

\* Some young people will have had full- or part-time access to specialist units in mainstream settings

\*\* Includes part-time and full-time courses, specialist and mainstream curricula

\*\*\* via Statement of Special Educational Needs

## Interviews

Semi-structured interviews were chosen as this provided flexibility to tailor interviews to the specific transition experiences of each young person whilst also ensuring that key project themes were addressed consistently across the sample (Ritchie and Lewis, 2003). Two topic guides were developed, one for use with young people anticipating the move to college, and one for use with those who had made that move. Interviews covered a range of topics related to transferring to adult services,

young adulthood and, specifically, school/college transfer preparations and experiences (especially, social and learning support both formal practitioner programmes and informal practices with family and other people). Topic guides were piloted with two young people with HFA/AS and revised in light of their comments.

Interviews were conducted in interviewees' homes. Written consent, including permission to audio-record the interview, was obtained at the start of each interview. Interviews lasted around 60 to 90 minutes. Half (nine) chose to be interviewed with another person present, for eight this was a parent and for one, a carer. It is recognised that the presence of another person can change the dynamics of an interview and raises the danger of the other person influencing participants' responses (Beresford, 1997). However, it was also apparent that these nine young people were initially anxious and the presence of a trusted other person provided reassurance. Some of the young people also wanted someone with them to support recall of particular details of their stories.

### **Data analysis**

A thematic approach to a descriptive analysis of the interview data was used. Transcripts were read by two members of the research team in order to identify themes/topics related to the young people's experiences of anticipating and preparing for leaving school and their post-16 education experiences, including services and practice which they found helpful and supportive. Transcripts were then systematically examined for data related to these themes with each respondent's data being summarized and organized under these themes. Each

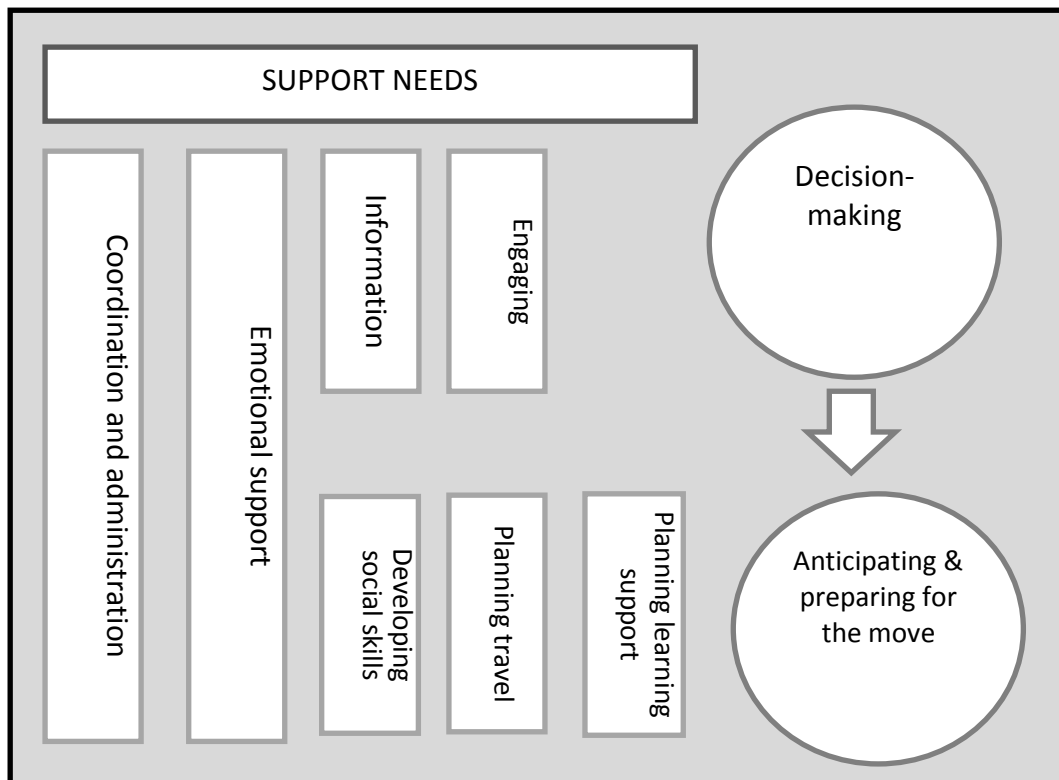
entry was referenced back to its location in the transcript using the transcript page number. Verbatim quotes were also logged in these extended interview summaries. A process of scrutinizing the extended interview summaries and analytical writings were used to examine and describe young people's experiences of decision-making around leaving school, planning for and anticipating the move to college, including the services and support they valued and found helpful during this period.

One aspect of this analytical process was to test whether interviewees' experiences varied according to the local authorities in which they resided. However, young people's circumstances and contact with individual practitioners provided more explanation for differences in experiences than wider authority practices or policies.

## **Findings**

There was a clear distinction in the young people's accounts of the process of decision-making around their move from school to college and the period during which they were anticipating and preparing for the move. Support needs varied across this period: some extended across this whole process, others were specific (or emphasized more strongly) with respect to one aspect of this process, see Figure 1.

Figure 1: Support needs arising from the transfer from school to college



The needs for someone to assume a coordinator/administrator role and for emotional support were present throughout. In addition, the different stages (decision-making; anticipating/preparing) generated more specific needs (e.g. Information and developing social skills). In terms of addressing these support needs a number of sources of support – formal and informal - were described by the young people, as were aspects of practice they found particularly helpful. These will be described and explained in the following sections. In addition, as well as the tangible tasks, the qualities and skills of practitioners clearly contributed to the young people’s perceptions of positive support. Our final section of the findings reports this. Before moving to explore these different issues, it is important to report a higher level finding regarding the level of parental involvement in the young people’s lives.

Almost all of the young people we interviewed reported that their parents had played, or were playing, an important role. Importantly, no evidence was found that parents' support and involvement was not welcomed. There was evidence that, for at least some families, the extent of parental involvement had been influenced by a lack of support from statutory services.

### **Support needs cutting across decision-making for and anticipating the move to college**

We begin by describing young people's support needs which cut across the whole process of moving to college, and the sorts of help and support which they valued in addressing those needs. These were:

- an individual to assume a coordinating/administrative role
- emotional support.

#### *The need for an individual to assume a coordinating/administrative role*

The young people acknowledged that the transfer from school to college entailed some degree of administration and/or coordination. The majority of young people reported that their parents had assumed that role. The absence of any reported involvement by school or college staff may be explained by the fact that it is likely the young people would be more aware of, or exposed to, their parents' activities/ involvement compared to anything a practitioner was involved in. However, equally, we should remember that not all (around a quarter) of our interviewees were supported within statutory school leaving/transition planning processes as they did not have a statement of educational needs. Parents' assuming responsibility is, therefore, a feasible explanation. However, knowledge of having a statement of SEN

was often limited amongst those young people that did/had had one. Furthermore, the five young people that did not have a statement of SEN at school did not report markedly different transition planning experiences or levels of support from school/college staff and other practitioners compared to those with a statement of SEN. Both groups looked to their parents for support.

Whilst a few had simply been conscious of 'mum sorting it out', most provided quite detailed information about their parents' contributions to coordinating and administrating the move to college. This included organising meetings and college visits, and liaising with the college over their support needs. Importantly, these were activities that some young people openly acknowledged they would not have been able to carry out themselves.

*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. (YP5)*

### *Emotional support*

The process of decision-making, anticipating and waiting to move to college and then settling in inevitably raised anxieties and concerns. Having someone to talk through these concerns was highly valued and, where this was mentioned by young people, it was parents (typically mothers) who had been the primary source of emotional support. None of our interviewees mentioned using school or college staff as sources of emotional support.

Two aspects of getting emotional support from parents which appeared to mean it

was particularly helpful and valued were: i) this support was 'on tap', enabling them to raise fears and concerns at their own pace and time; and ii) parents understood them, their individual needs, and the impact of autism on their lives.

*... they [teachers] don't really know as much as my Mum ... cos they don't, they, my Mum understands me most cos she lives with me. (YP18)*

### **The decision-making phase: support needs and valued practice**

In this section we turn specifically to the decision-making phase and the sources and types of support that young people had valued and found helpful. Findings are presented in terms of roles and contributions of professionals and parents and, finally, we report the importance of visits and taster days.

#### *Supportive roles and practice: professionals' contributions*

The young people identified two roles assumed by practitioners which had been particularly helpful as they made plans for their post-16 education.

- supporting and engaging with planning for leaving school
- information provision.

The young people valued support from practitioners such as, teachers, Connexions (youth service supporting transitions into FE, training and employment), practitioners, careers advisors to help them engage with planning for leaving school. Some noted that concerns and anxieties around leaving school had made them inclined to avoid the issue. Practitioners who had taken an active role in initiating and leading initial discussions had been welcomed. For example, one young person particularly

valued his school organizing an initial planning meeting with the local careers advisor, as this helped him overcome his reticence to focus on the future.

Second, the young people consistently reported needing, and valuing, information which was clear and easy-to-understand (both written and verbal). Practitioners who had provided information in an honest and comprehensive manner were also highly valued. In contrast, incomplete or partial information was seen as confusing and could raise questions in young people's minds about the reliability or trustworthiness of the practitioner.

### *Parents' roles*

Parents were consistently portrayed as being indispensable in the process of decision-making. Two key roles emerged: information gatherer/provider and sharing the decision-making process.

Most young people reported their parents had played an important role in gathering information about potential post-16 destinations. Parents were reported to have gleaned information from a range of sources, including written college prospectuses, speaking to practitioners and the internet. Parents' knowledge of how to effectively search the internet was particularly mentioned by some of the young people.

As well as simply gathering information, some young people also described how their parent's 're-provided' gathered information in ways which were accessible and/or delivered at an appropriate time and/or setting. For example, one young person 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. This was largely after attending transition planning meetings (with his mother) within which he frequently felt he did not understand or could not take on board all the information being discussed:

*... 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 day later ...at a time when I was less stressed and it was more easy for me. (YP11)*

The young people also typically reported that they had discussed post-16 options with parents and decision-making was presented as shared. Only a minority placed their parents in a relatively peripheral role in this process.

#### *The importance of visits and taster days*

The final area of practice which was valued, and supported decision-making about post-16 educational options, were visits and taster days. The majority of our interviewees had experienced these and they were generally regarded as positive experiences with a number of benefits. These included the value of actually experiencing settings 'in action', seeing and getting insight into courses/options, and being able to talk to staff. The opportunity to visit more than one option and/or extended or multiple visits to the same college were viewed as particularly helpful. For those considering residential college, residential visits were valued though this did not seem to be something that was routinely offered. As well as supporting decision-making, these visits also contributed to the young person feeling ready and

prepared for the move to this new educational setting. Ensuring such visits took place early on the decision-making process was important. It allowed for repeat visits and time to explore other options if an early choice or preference proved unsuitable.

### **Anticipating and preparing for the move: support needs and valued practice**

We now turn to issues related to anticipating and preparing for the move to college, and the support which young people valued during this stage. These included: support need arrangements, developing social skills, and learning to travel to the college. Among the young people interviewed, parents were predominantly identified as taking responsibility for addressing these issues and/or providing support which was helpful or valued by the young person.

#### *Support needs arrangements*

Making arrangements around the young person's support needs (academic and/or non-academic) was something which involved school and/or college staff and/or parents. It was clear that knowing support arrangements had been made and confirmed prior to starting at college was helpful and reassuring to the young people as they anticipated this move. The young people did not appear to have much knowledge of this process and there was not a clear difference between those with and without a statement of SEN with regard to the level and/or knowledge of support preparations reported. For example, one young person without a SEN statement described feeling well-supported reporting opportunities to discuss her plans for leaving school with both school staff and a careers adviser.

Learning support was not always available (particularly in mainstream settings) or, if available, did not match the level of support received at school. Where this had occurred, there was evidence that parents, being aware of this change and/or potential support gaps, had helped their son/daughter prepare for, or find an alternative solution, *before* starting at college. This was demonstrated when one young person described how her parents had recognised reduced levels of college learning support compared to school (fewer learning support assistants and one-to-one support), and suggested she record lectures so they could help her catch-up with work at home.

*My parents have said that it might be easier for me to take a tape recorder in and record the lesson 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 ... (YP8)*

#### *Developing social skills*

Coping with the social demands of college was a common cause of concern. Discussing fears and anxieties with parents had been very helpful for some young people and a few reported their parents responding by adopting a 'coaching' role. For example, they talked through and co-developed strategies to manage social situations and interaction.

*She's [mother] helped me with ... I ask, 'What do I say when this happens?' or 'What do I do when talking to someone about this?', and she's really given, helped me with some advice on that. That really helped. (YP12)*

*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 ... (YP6)*

None of the young people we interviewed reported receiving social skills support from a practitioner.

### *Learning to travel to college*

Finally, for some of the young people interviewed, new transport or travelling arrangements were a significant aspect of preparing the move to college. Just one young person reported having received an identifiable and formally organized programme of transport preparation and training prior to college transfer. This had clearly been very useful:

*... she [bus buddy] would go with me on the bus, at the beginning but as I got more independent she'd park out there and she'd wait, she'd sit in her car, follow me on the bus. I'd stay on the bus and then I'd come home. (YP2)*

For others, 'travel training' had been provided informally by family members.

*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 (YP5)*

### **Practitioner qualities**

We have already reported the roles practitioners assumed in supporting young people's transition to college. Young people's accounts also contained information about the characteristics, or qualities, of practitioners which contributed to

experiences of positive support. We discuss these in this final sub-section.

First, the young people were very clear that practitioner support was usually most effective when the practitioner knew them well, particularly, the way their autism manifested itself and their strengths and weaknesses.

Second, practitioners' reliability emerged as a strong theme from the interviews. A number of the young people highlighted the importance of practitioners 'doing what they said they would do'. This was demonstrated most clearly through negative experiences. For example, young people reporting practitioners promising to provide information, arrange meetings or establish college links but ultimately these things had not happened, and no explanation offered. This left the young people feeling frustrated, uninformed and to varying degrees, expressing real anger.

Finally, knowledge of ASC was essential. However, some young people also highlighted that practitioners had to appreciate that, whilst knowledgeable about ASC, they could not fully understand life with ASC. This was summed up by one young person's comment that open-mindedness and a willingness to listen was needed, rather than false empathy.

*With [college support worker] 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'. (YP9)*

However, if a practitioner did have real experience of ASC to draw on, this was

valued. One young person had found her careers adviser easy to talk to and understanding of her ASC needs and concerns because:

*... she had the experience. She has a son with ASD ... yeah, so she understands which make a big difference to people like me. (YP4)*

## **Discussion**

Rather than dwell on the well-documented difficulties associated with transition for disabled young people and, specifically young people with HFA and AS, this paper has focused on reporting the systems and practices which young people identified as helpful to them as they planned for and anticipated the transfer to post-16 education. In our analysis of the data, we have sought to identify common themes or principles from across individual experiences in terms of the sorts of support, formal and informal, and features of supportive practice which are valued and helpful to these young people: in other words 'young person endorsed practice'.

Overall, the young people 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 valued. It is important to note, however, the absence of any significant differences in the accounts of young people with and without a statement of SEN. Both groups reported practitioner support and looked to their parents for help and guidance. The lack of any identifiable added benefit to a SEN transition pathway is interesting and has a number of explanations. It may simply be the case that statutory transition planning processes were not overtly badged as such, or that the

young people were not cognizant of these processes. Alternatively, it may be an indicator of the support schools offered to all young people as they contemplate leaving school. Finally, it may reflect the way in which, in the absence of statutory support and guidance, parents fulfilled this role.

Moving on from school clearly generates the need for information about possible options and opportunities to experience post-school options were particularly welcomed. These experiences were identified by a number of interviewees as playing a critical role in decision-making with opportunities to visit potential colleges affording a chance to develop a more informed understanding of college life. The young people in our study particularly valued repeat or extended visits. The merit of school/college links are well-documented (Chown and Beavan, 2010; Reid/NAS, 2007; Hendricks and Wehman, 2009, Autism West Midlands, 2007), however, evidence from young people's accounts and other evidence gathered in the wider study (Reference withheld, authors) suggests these are the sorts of activities and opportunities which are often reduced or cut in response to constrained resources cost-saving environment. Research into the cost-effectiveness of this aspect of planning and preparing for the move to post-16 education would be useful in terms of guiding practice and service delivery decision-making.

The move to further education is typically a time when new practitioners become involved in a young person's life. These might be college staff, careers advisors and/or staff based in children's services 'transition teams'. Getting used to, or adapting to working with, new individuals is, in itself, a further challenge for these young people within the wider context of significant change in their lives. Whilst this

may be inevitable, there were clear messages from the young people about supportive practice.

First, a key source of difference in the quality of support received from practitioners centred on knowledge of ASC and understanding of the implications of that diagnosis for the particular individual. The young people were very perceptive of the extent to which practitioners understood their condition and disliked it when practitioners made presumptions about their specific needs and situation based on ASC generalisations. Implementation of the Autism Act (2009) and Autism Strategy (Department of Health (DH), 2010) in England occurred after fieldwork for this project took place. Autism-awareness training is a key element of the strategy and, it appears, is an area where many local authorities are making good progress (National Audit Office, 2012). The findings from our study reiterate the importance of autism-awareness training but also the need to use this understanding alongside an understanding of the individual's needs and abilities.

Practitioner reliability was another quality stressed by young people. The fact that individuals with HFA/AS can apply a very literal interpretation to information or what is said to them offers an explanation of why this is a particularly important issue for this group (e.g. Baron-Cohen, 2008). Young people may also not appreciate that practitioners have multiple demands on their time and/or the wider constraints which can impede the rate at which progress can be made. Great care is needed, therefore, to avoid misunderstandings about commitments practitioners make.

The majority of young people in this study 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. A sizeable minority believed that their parents (predominantly mothers) had taken a leading (even lead) role in facilitating, supporting and in some cases, 'managing' their move to college. For these young people, parents' ability to plan ahead and/or foresee potential problems (such as reduced levels of learning support) was particularly valued. Some of the young people provided insights into the role parents can play 'coaching' or preparing them for new situations which they might encounter at college, especially social situations.

Whilst young people with HFA and AS may not be perceived as having the same level of needs as some groups of disabled young people, this and other studies find a higher than usual level of involvement by parents. Key reasons for this level of involvement identified in previous research include parents perceiving their young person as unable to self-manage this particular change in their lives and a lack of involvement by statutory services (McConkey, 2010; Reid, 2007). These reasons very much reflect the explanations of the young people who took part in this study in terms of their parents' involvement.

Parents of disabled young people can be viewed as negatively influencing post-school outcomes, being portrayed as over-protective (e.g. Bowey et al. 2005). It is important, therefore, to contextualise these findings within a wider understanding of parental involvement in the lives of their adult children as, at one level, there appears to be little difference. We know, for example, that parents exert a strong influence on young people's decision-making around leaving school (Whitson and Keller, 2004),

and that the roles parents may find themselves assuming during in this process include: information-seeking; supporting access to experiences relevant to the choice; acting as a sounding board; and a source of advice and emotional support (Young et al., 1988; Whitson and Keller, 2004; Lindstrom et al., 2007).

Within our interview sample, feeling adequately skilled to manage the demands of getting to and/or being in a new and complex social situation were significant concerns and these findings align with previous research (Chown and Beavan, 2010; McConkey, 2010; Geller and Greenberg, 2009, Hendricks and Wehman, 2009, VanBergeijk *et al.*, 2008; Adreon and Durocher, 2007). However, access to professional support with skill development – social skills, travel skills - was highly unusual. This is not surprising given that many young people with HFA or AS will not be under statutory transition planning and support processes within SEN provision, nor will they be eligible for wider transition support from children's services (Reference withheld, authors). Furthermore, access to advice and support from young people's services (e.g. Connexions) is now dependent on local decisions in terms of the type and extent of service offered. In the absence of formal support in this area, parents were assuming responsibility for, ensuring supporting their son or daughter was as prepared as possible for college life. However, whilst parents of any 16-18 year old expects to be involved and available to advise and support their child, the demands being made of parents of young people with HFA/AS are greater. Parents may feel they do not know how to 'skills-train' their son or daughter (Reference withheld, authors) or may not be capable of supporting their child in this way.

This is not the first piece of research to question whether parents should be expected to fulfill 'key-worker' and/or support worker roles. Failing to ensure a young person chooses the right post-16 destination, is prepared for college and adequately supported in that setting may well result in difficulties at college (drop-out, exclusions) and poor outcomes, both in terms of academic achievement and well-being (Berney, 2004). The longer-term costs and consequences of these negative outcomes are, potentially, considerable: both on the individual, family and the state (National Audit Office, 2009)

Furthermore, whilst some of our interviewees had been willing to share concerns with their parents, not all young people will want to discuss social concerns with their parents. Providing other opportunities to discuss and prepare for the social demands of college would seem to be important. This might be something taken on by schools or by disability /ASC support staff in colleges during the early weeks of the academic year. Providing opportunities or facilitating peer support is another option which deserves further consideration, including support through virtual networks (Parsons *et al.*, 2004).

### **Study limitations**

As with any piece of qualitative research, the purpose of this research was to explore and describe a range of views and experiences and care needs to be taken when drawing wider conclusion and implications. The fact that the sample was self-selecting imposes further caution. We do not know the extent to which the post-16 transfer experiences of the young people who chose to participate in this research are similar to other young people with HFA/AS. For example, a self-selecting sample

might differ in terms of their opinions regarding the type of support they valued and who provided support, especially, the role of parents.

Half the interviewees chose to have a parent/carer present during the interview. The possible impact of the presence of parents/carers on young people's accounts also needs to be borne in mind. As noted earlier, this was on balance felt to be beneficial: the young people clearly wanted their parents/carer to be present and were visibly more relaxed and confident when they were present. We believe this enhanced the quality of data collected though we acknowledge that parents/carers' presence may have affected the way these young people presented their stories.

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