

Choosing a secondary school for young people with autism: A multi-informant study

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Abstract

Deciding on a secondary school for children with autism is notoriously difficult for parents. While current UK legislation emphasises the choice that parents of children with special educational needs should have in educational decision-making, there is a dearth of research in this area, which means that little is known about how parents come to make decisions about secondary-school placements and the types of support, if any, they receive from professionals. The present study aimed to determine the factors that immediately influence secondary-school choice for young people with autism in one London local authority from the perspectives of multiple informants. Semi-structured interviews were conducted with parents of children with autism (n=7), young people themselves prior to secondary school entry (n=6), parent advisors (n=5) and secondary-school professionals (n=5). Parents emphasised the anxiety and burden of the decision-making process. There was, however, substantial agreement among adult groups on the factors necessary for a successful secondary school placement: a nurturing, flexible and inclusive environment that emphasised both academic and life skills. Few adults, however, mentioned the importance of children's social relationships – a factor that featured prominently in the reports from young people. These findings highlight both the different perceptions of those involved in making decisions about the educational placements of children with autism and the challenges associated with weighing up these potentially conflicting perspectives. More work is needed to ensure both that information is transparent and accessible to all parents and that young people are actively involved in decisions that ultimately affect their lives.

Keywords: autism, education, school, parents, decision-making, special educational needs

The transition to secondary school can be difficult for any child, but especially so for those diagnosed with an autism spectrum condition (Batten & Daly, 2006). Anecdotally, parents' decisions about their autistic¹ child's school placements – ranging from mainstream to those that offer specialist provision to varying degrees – are notoriously difficult. They often report significant frustrations concerning the quality of provision, the availability of reliable advice and the responsiveness of the relevant authorities to their personal situation (House of Commons Education and Skills Committee, 2006). The process of choosing a school is said to be “bureaucratic, stressful and time-consuming” (Tissot, 2011, p. 1).

These anecdotal experiences of parents stand in sharp contrast to the stated intentions of recent governments in England. Parental involvement in their child's education, including choice of school placement, has been an explicit goal in government policy in England since the late 1980s (Department for Education (DfE), 1988). For children with special educational needs (SEN), the Education Act 1996 (DfE, 1996) gave parents the right to “express a preference” for their child to attend a particular school, which could include a continuum of placements, ranging from general mainstream provision to specialist provision of varying degrees. Subsequent policy has often been justified with the assertion that parents should be at the heart of educational decision-making (Department for Education and Skills (DfES), 2002).

The current Children and Families Act 2014 is no exception. Under the Act, local authorities have a duty to involve parents and young people in educational decisions, giving them greater choice and control in the support and services they receive (DfE, 2014). It promises to cut the bureaucratic ‘red tape’ that too-often besets families' interactions with the education system and improve information sharing, with local authorities being required to publish a transparent “local offer” detailing their services to support young people with SEN and their families.

One of the most significant of the planned changes relates to inclusion in a mainstream setting. Since the Warnock Report (1978), the aim of education policy has been to include children – including children with SEN – within mainstream provision at the child's local neighbourhood school (DfES,

¹ The term “autistic” is the preferred language of many people on the spectrum (e.g., Sinclair, 1999). In this paper, we use this term as well as person-first language to respect the wishes of such individuals.

2001). The latest SEN reforms, however, initially sought to remove any “bias towards inclusion” where that bias “obstructs parent choice” (DfE, 2011, p. 18). Parents of children with SEN, including children with autism, are therefore legally entitled to state their preferred placement on school choice applications – a placement that local authorities must consider. Local authorities can reject placement applications that are deemed “unsuitable for the age, ability, aptitude or SEN of the child or young person; or the attendance of the child or young person that would be incompatible with the efficient education of others; or the efficient use of resources” (DfE, 2013, p. 66).

These reforms clearly speak against a rights-based perspective on inclusion – one that calls for inclusion of all children and young people with SEN, including those with autism, in mainstream schools on the basis that they should have the same sorts of opportunities as children without SEN and are unlikely to receive such opportunities in environments that are separated from the mainstream (Allen, 2008; see Ravet, 2011, for discussion). Yet the case for ‘special schools’ remains respected in some quarters. Children and young people with autism often do face additional challenges with their learning and behaviour and are at increased risk of developing mental health problems in ways that can seem to make it challenging to include these children effectively within mainstream schools and to obtain appropriate educational provision compared to children with other SEN (House of Commons Education and Skills Committee, 2006; Parsons, Lewis, & Ellins, 2009). Furthermore, while more than 70% of children with autism attend mainstream schools in England (DfE, 2012), teachers in these schools frequently report that they do not have the necessary training to support them appropriately (Robertson, Chamberlain, & Kasari, 2003). Children can, therefore, be at risk of exclusion from so-called inclusive settings. Some authors therefore advocate a ‘needs-based’ perspective on inclusive practice, one that preserves a range of educational provision (mainstream *and* specialist) to meet the specific needs of some groups of children and young people with SEN, including children with autism (Jordan, 2005; Lindsay, 2007).

In addition to these complex debates around inclusion, there are other reasons why the new legal framework might fail to meet the concerns of parents of children with autism, who are charged

with the task of determining the most beneficial placement for their child. First, although there are many interventions and educational approaches available for children and young people with autism, the reality is that many of these approaches, even those used at specialist schools, have not been rigorously tried-and-tested and even in the few that have, there is disappointingly little evidence on which approach – or indeed which setting (mainstream, specialist) – works best for which individual (e.g., Parsons, Guldberg, MacLeod, Jones, Prunty, & Balfe, 2011; Warren, McPheeters, Sathe, Foss-Feig, Glasser, & Veenstra-Vanderweele, 2011; though see Reid, Osborne, & Waddington, 2012). Indeed, in a major review of special educational needs and disability arrangements in England, the Office for Standards in Education (OFSTED, 2010) found that “no one model – such as special schools, full inclusion in mainstream settings, or specialist units co-located within mainstream settings worked better than any other” (p. 3). This lack of knowledge and training often makes it very difficult – both for school staff to know how best to identify these young people’s needs and to respond to them effectively and for parents to know which school will be the best fit for their child.

Second, limited resources for education generally, and for costly specialist provision in particular, shapes whether parents have an adequate range of choices as to where to place their child with autism. Research examining parents’ views on educational provision has consistently shown that, when it comes to secondary schooling, parents have little confidence in the effectiveness of inclusion in mainstream provision for their children with autism (Batten & Daly, 2006; Humphrey & Lewis, 2008). Parents are concerned about large child-to-teacher ratios, bullying and rejection of their child from their non-autistic peers and especially, a lack of access to autism-specific knowledge, expertise and support (Batten, 2005; Reid & Batten, 2006; Kasari et al., 1999; Starr & Foy, 2010; Starr, Foy, Cramer, & Singh, 2006; Whitaker, 2007). Yet the number of children with autism (approximately 90,000 in the UK) far exceeds the number of available specialist places (~7,500), especially at secondary level (Batten & Daly, 2006). This shortfall in specialist provision is worse in some local authorities than others (Lindsay, Dockrell, Mackie, & Letchford, 2005), with a significant proportion of young people with autism in costly out-of-authority placements (approximately 23%) (Audit Commission, 2007). Indeed, parents of

children with autism attribute both the failures of inclusion (Waddington & Reed, 2006) and the delays in agreeing which school is the best place for their child (Tissot, 2011) to local authorities' significant lack of funding. Parents might therefore feel that they have no choice other than to consider mainstream provision for their child as a result of lack of alternative provision.

Deciding which school is 'right' for a young person with autism is therefore likely to be extremely challenging for parents – and goes far beyond a straightforward choice between whether to opt for a special or mainstream school. On the one hand, parents appear to want provision that is targeted towards the individual needs of their child, employs experienced educators that are knowledgeable about autism and has a highly structured, yet flexible learning environment that is sufficient to meet their child's educational and social needs (Starr & Foy, 2006; Whitaker, 2007) – factors that might tip the balance towards specialist provision. On the other hand, parents also recognize the importance of schools having high ambitions and aspirations for their children (Charman, Pellicano, Peacey, Peacey, Forward, & Dockrell, 2011), adopting an inclusive ethos (Byrne, 2013; Humphrey & Lewis, 2008) and which target autistic children's social skills, which might be better facilitated in mainstream provision, where typical children might serve as role models for appropriate social interaction (Waddington & Reed, 2006; also see Lord & Hopkins, 1986; Pellicano, 2012). These multiple factors, together with others including parents' socio-economic status (e.g., Ball et al., 1996) and the child's experience of inclusion in the primary phase (Byrne, 2013), are likely to influence the decision-making processes of parents of children with autism.

Such decisions will also critically depend on the extent and nature of the information they receive from professionals about available provision for their child and the broader context of social and political considerations within which such choices are made, especially with regards to inclusion. Research with parents of children with SEN other than autism has found that their decision-making processes regarding school placements are heavily influenced by other people, including professionals but also family and friends (see Bryne, 2013), as well as by background assumptions of what is right and appropriate for 'disabled' people. Yet the few existing studies on this issue with parents of children with

autism consistently highlight the lack of, or conflicting, information these parents receive or the context within which they receive it (see Pellicano & Stears, 2011). In a large survey-based study, Parsons et al. (2009) found that UK parents of children with autism were less likely to state that they had enough information on which to base their school-placement decisions than parents of children with other SEN. When examining parents' perceptions of the factors affecting their autistic child's inclusion, Waddington and Reed (2006) showed that, rather strikingly, none of the parents (n=20) felt that they had received sufficient help in choosing an appropriate school placement compared to 50% of local authority workers (n=22), who reported feeling that parents had sufficient support in choosing schools. Finally, Lilley (2014) highlighted the often-conflicting information received by Australian parents of young children with autism from professionals regarding primary school placements, which clearly related to where their child lay on the autism spectrum and the presence of additional intellectual disabilities. We therefore know very little about the extent and nature of the information that parents of children with autism receive from others about available school placements in their locality and how they weight this information with the factors noted above.

The present study

The current study sought to examine in greater detail the nature of school choice for young people with autism within the current context. Specifically, we investigated parents' decision-making processes about their autistic child's secondary school placement. Using semi-structured interviews, we asked whether parents considered the type and/or the quality of provision they sought, how they accessed this information and how equipped they felt in making these decisions. To provide a fuller picture of these issues, we also elicited the views and perspectives of key professionals, including school staff and parents advisors employed by the local authority, about their experiences of supporting and working with parents and young people with autism. In this paper, we do not consider the role of deeper social and ideological factors in shaping the underlying preferences of our informants, although these factors will be important to attend to in future work.

All of these participants lived and worked within one London local authority (akin to a school district in the US). The authority is relatively small but densely populated, with many residents experiencing considerable social and economic deprivation. Specific ethnic minorities, including a large Bengali community with distinctive socioeconomic needs (O'Hara & Martin, 2003), also make up a significant proportion of the population. There is one autism-specific special school that caters for both primary and secondary pupils within this authority but no autism-specific unit co-located within a mainstream secondary school. The secondary schools, and the children and young people with autism within these mainstream settings ($n > 300$), are therefore supported by an outreach service of specialist teachers. The borough has a parent partnership service, whose remit is in part to support parents with choosing school placements for children with SEN. The degree to which parents of children with autism access this service and how the information they provide influences parents' school placement decisions is unknown.

Current policy frameworks also emphasise the importance of involving young people with SEN, including those with autism, in the educational decisions that ultimately affect their lives (DfE, 2013). Remarkably few studies, however, have directly elicited autistic children's views about their transition to secondary school. Jindal-Snape, Douglas, Topping, Kerr and Smith (2006) interviewed 5 children educated within one Scottish local authority and found that preparation for the transition to secondary school was a central theme. Despite the size and complexity of their new secondary school, the children were generally positive about transition, valuing in particular the opportunities (e.g., school visits) to help familiarise them with the setting. We therefore also sought the views of young people themselves on their impending transition to secondary school.

Method

Participants

Twenty-one participants took part in this study, including 7 parents, 6 young people with autism, 5 secondary school professionals and 5 parent advisors. All participants worked or attended school in one London local education authority.

All parents of young people with autism attending their final year (Year 6) of mainstream primary school during the academic year 2012 – 2013 (n=16) were invited to participate in this study. Seven of these families (45%; 6 mothers) agreed to take part. Of these 7 families, 6 of their children with autism, all boys and aged between 10 years; 11 months and 11 years; 11 months, also participated (see Table 1). Parents reported that all children had received an independent clinical diagnosis of an autism spectrum disorder according to the ICD-10 (World Health Organization (WHO), 1993) or DSM-IV-TR (APA, 2000) criteria. All children were in receipt of a Statement of SEN, a legal document that details the child's needs and services that the local authority has a duty to provide, which specified autism as their primary need.

insert Table 1 about here

Five school professionals also took part in this study. All secondary school headteachers (n=16) in the local authority were contacted via both letter and email and invited to take part. Only one (male) secondary headteacher agreed. We therefore randomly selected 5 of the remaining 15 secondary schools and contacted the Special Educational Needs Coordinators (SENCOs) in each of these schools, who are responsible for the day-to-day operation of the school's SEN policy. Four SENCOs consented to participate (3 female). The headteacher and SENCOs had been in their current positions from between 1 and 26 years.

Finally, five parent advisors (all female) from the local authority's parent partnership service were approached to take part. All 5 agreed to participate. All had a minimum of three years of experience in their role. Two were also parents of children with autism.

Procedure

Semi-structured interview schedules. The interview schedules for parents, young people, school professionals and parent advisors were similar but differentiated to suit their distinct roles. Parents were asked their opinion on the ideal secondary placement for their child, factors that might have influenced

their choice of secondary school placement, the help and assistance they sought and what was provided, and their hopes and aspirations for their child's future. Young people were asked their likes and dislikes about school in general and their thoughts and feelings about their new secondary school in particular, including their transition to this school, using simplified language and visual aids, where appropriate. School professionals and parent advisors were asked to consider the factors they felt were important when choosing a secondary school for a young person with autism, their opinion on the most appropriate provision for students with autism and their experiences of supporting families in making decisions about secondary school placements.

General Procedure. Ethical approval for this study was granted by the Department's Research Ethics Committee at the University. All participants gave informed written consent form for themselves or their child to take part. Young people were also informed about the study and gave their assent to participate.

Parents, young people with autism, school professionals and parent advisors were seen individually on a single occasion for a face-to-face semi-structured interview. Four mothers were interviewed at home and 3 at their child's school. Five of the 7 parents spoke English as their first language; these interviews were conducted in English. Two Sylheti-speaking parents were accompanied by an interpreter to translate the questions and their responses. Children were interviewed individually either in their home or at school. All school professional and parent advisor interviews took place in English at their workplace.

The length of interviews varied (parents: 17 – 46 minutes; young people: 8 – 19 minutes; parent advisors: 22 – 48 minutes; school professionals: 28 – 41 minutes). All interviews were audio-recorded for later transcription, with the exception of one interview with a young person, who declined to be recorded.

Analysis. Interviews were transcribed verbatim. The resulting data were analysed using thematic analysis, with particular attention to the phases outlined by Braun and Clarke (2006), including (a) data familiarisation, (b) generation of initial codes, (c) searching for themes, (d) reviewing themes, (e)

defining and naming themes and (f) report production. We adopted an inductive approach, providing descriptive overviews of the key features of the semantic content of data within an essentialist framework. All three authors independently familiarised themselves with the data, meeting regularly to review the results, resolve discrepancies and decide on the final themes and subthemes.

Results

Semi-structured interviews with parents

Parents provided a very emotive overview of their pathways to choosing a secondary school placement for their child. We identified four overarching themes.

The 'right environment'. All parents expressed a desire for a secondary school that would optimise their child's potential. They wanted a school that would "bring out the best in the qualities that he has", "that would cater for his needs," and "make him feel safe", and had staff that were "patient", "open-minded, kind and understanding".

Parents expressed different views, however, about whether the "right fit" constituted a focus on fostering academic skills or one that provided a more "nurturing environment". Some parents emphasised the quality of education and the importance of academic support so that their child "would make as much progress as he can", "to get him thinking, learning, growing", e.g., "I also want him to be stimulated, not just a babysitting service, but to actually learn something". Others, however, were wary of schools that seemed "to push people a bit too much", placing excessive focus on achieving high grades, e.g., "if that's what's causing the anxiety with him, then we don't want him in that environment"; "his mental state and mental wellbeing have to come first". Some parents wanted schools that also promoted life skills and the ability to live and travel independently, e.g., "basic skills like hygiene, and being able to follow a routine and to be able to think ahead and think for himself".

Many parents also preferred a school that would help prepare their child for life outside of school, one that would "leave him as equipped to deal with the world as possible". Some parents were adamant that such a school was an inclusive, mainstream school: "... because I wouldn't want him to be in a bubble. Because when he leaves the school he's going to be in the outside world, with everyday

people, mainstream people”; “I definitely want him to be integrated with the rest of society, and not to be excluded. I don’t want it to be a special school, just for special people with special needs”. Parents also stressed that for inclusion to be successful, teachers, teaching assistants, and fellow (non-autistic) students needed to be acutely aware about autism, e.g., “my dream school would be that everybody is aware what autism is, so that he’s not misunderstood”, although some perceived such specialist training of staff and one-to-one support to be more characteristic of special schools. In fact, for one set of parents – of the only child to transition to the special secondary school – their decision was grounded in their perception that the school “would have better supervision of him”, would better “cater for his needs” and “understand him better, his autism”.

The burden of decision-making. Despite having often very clear ideas of the right secondary environment for their child, all parents spoke of the enormity of the decision with which they were faced in deciding on a school placement, e.g., “It’s a huge, huge decision. It’s like getting married”. Some described it as a “terrifying process”, that they were in “panic mode”, worried about whether they had made “the right decision”, e.g., “I don’t want the next six, seven years to be my fault”. Some parents also emphasised that the process of choosing a school for their child with autism was very different from doing so for non-autistic children, e.g., “Just like normal parents get anxious, but you get *really* anxious about it”. Another parent noted, “My mum took us to secondary schools and said ‘which one do you want to go for?’ I just picked one that all my friends were going to. But it’s not as simple as that for [our son].”

Grasping at straws for information. This doubt and uncertainty expressed by some parents was further compounded by the perceived lack of information and support in making these decisions. One parent said, “I wanted someone to say to me, ‘Where do the autistic kids go in the borough? What’s the best school for the autistic kids?’ But no-one will talk to you.” While some parents felt well supported and informed, e.g., “they [SEN departments] were fantastic. They calmed us down, they spoke to us, they answered all our questions, and even thought of things we didn’t think to ask”, others “felt a bit lost” and expressed concern at how professionals were unable or unwilling to share information about

the most appropriate place to send a child with autism, e.g., “I wanted more support, someone to say [which school to send him to] – but they don’t”. Others still were dissatisfied with the lack of appropriate staff during school open days or evenings.

Consequently, parents relied on a whole host of different sources of information to make their decisions, e.g., “I pretty much spoke to everyone I could”; “I asked my relatives, I asked teachers, I asked parents. It was just a hard decision to make”. All parents reported gaining advice from other parents (“on the grapevine”; see Lilley, 2015; Ball & Vincent, 1998). They also visited the schools to talk to teachers and SEN staff and to “get a feel” for the environment. Some parents received support from the parent partnership service (n=2), whose staff were able to ask questions on the parents’ behalf during these visits, while others learned about what schools offered through transition events and the authority’s school prospectus.

Only two parents reported directly seeking the views and perspectives of their children during the decision making process. For one family, the child accompanied the parent on school visits and played a central role in school choice. She described how, in one school, “he completely shut down”, while in the other, “he was a nice, calm, relaxed, happy child, asking questions, listening, being nose-y. It just seemed to work, something clicked for him. That was it.” The second mother reported a conflict between what her son wanted and what she felt was best: “He is sad. He wants to be with everyone else. He says, ‘Mum, I miss my friend’ ... but he doesn’t understand. It’s not great education, not enough one-to-one”. She felt that she had given in to her son’s preferred choice but was extremely worried about it.

Parents also highlighted one practical factor, which played a major role in their decisions: the location of the school. Parents were worried about sending their child to schools that were far away from home, e.g., “because we don’t have the confidence that he will manage to travel by himself”, and instead preferred schools that were local, assuming it also provided the right environment for their child. One parent also commented that she did not want her child to feel excluded by transport issues,

e.g., “I didn’t want a special school bus to pick him up because I didn’t want him to be excluded from the rest of the kids where they might say, ‘oh, you’ve got a disability’”.

Importance of developing relationships with schools. With the exception of one parent, all parents had opted to send their child to a mainstream secondary school (see Table 1). Several parents reported the excellent transition work with the children themselves, once the child’s placement had been accepted. This work included school visits and implementing buddy systems, ensuring that children were prepared “so that when he goes, it won’t be such a culture shock”. This transition planning and preparation made them feel assured that school staff were interested in and aware of their children’s needs. Parents further described this relationship with schools to be “key in any child’s development or progress.” They emphasised the need for ongoing effective parent-school partnerships, e.g., “If you work alongside the teachers, you’ve got no problems ... working as a team together”. One parent extended this relationship to include the young person: “there’s got to be a relationship between all three of us, otherwise it’s not going to work”.

Semi-structured interviews with parent advisors

The parent advisors provided a detailed account of how they supported young people, their parents and schools through the process of transition. We identified five overarching themes.

The matching process. The advisors described how they worked at building relationships with young people and their parents: “getting to know them and trying to get as close a match as possible between what the school offers and what the child’s interests and needs are”. There was recognition that the advisors have a detailed overview of the local provision and used this knowledge to encourage parents to look at different schools, as many parents were unsure about what features of a school would ultimately be most important for their child, e.g., “it’s got a really good rating but it still might not be the most appropriate place for the young person”. Implicit in this theme was the knowledge that “not every child that is on the autistic spectrum will need the same kind of support; they need their own individualised package”.

The parent advisors also described the various stages in “facilitating the matching process”, or managing the transition. This began with the annual Year 5 transition event for Special Educational Needs Coordinators (SENCOs) from both primary and secondary schools, which provided a forum in which to “talk about a child and whether they think they can meet their needs”. They valued honesty in both describing the child’s needs and the school’s ability to meet them, e.g., “they’re not always completely honest – you need honesty”. They recognised that transition is more than “just working out what level the child is working at – that doesn’t really help in terms of understanding the needs of the young person” but a process that they facilitated, including helping schools review the support defined in the child’s statement and considering “the ways the school will implement that support”. Some secondary schools provided students with daylong transition experiences prior to their transfer, while others offered a gradual, supported transition process once they had started at the new school, including starting with lessons in the style of primary-school teaching, and the provision of ‘nurture’ groups.

Empowering parents. Parent advisors clearly described that they felt that it was their role to empower parents. They explained how they provide guidance and support for parents, e.g., “if the helping hand is the right one, then they’ll go off and sort the rest of it out themselves”, not to tell them what to do: their job was to “take a lead from the parent, not to direct them”. Once this process is established, parents could then use them as a “sounding board” to discuss potential secondary placements.

Getting children involved. The advisors also firmly believed that it was important to capture the young person’s views and engage them in the decision-making process, especially in light of the new legislation. Yet they were also acutely aware that the views of parents and the child “are not always going to be the same”. They felt that parents “usually made a lot of choices for the young person, who may not be able to make an informed choice” but that this often led to the advisors “not getting enough information from the young person” and “losing some of the young person’s interests along the way”. The advisors wanted to deliver a service where “we’d take the young person and the parents

to look around”, just like they would for children without autism. Some advisors recounted positive experiences of involving the child: “He wrote this really articulate letter about how he felt about the school and the things he wanted. It matched up with some of the mum’s, and then we found the perfect fit”. There was general acknowledgement that young people with autism need to have the same rights and experiences as their peers and that, if consulted, “most of them would want to go to the same school as their friends”.

The role of the SENCO. The advisors also highlighted the importance of the secondary school SENCO, who is meant to agree the transition plan and ensure that it is implemented. The advisors felt that the transition process for autistic children was most likely to be successful when the SENCO is “within the [school’s] management structure, so therefore has some power and influence over what actually happens”. Instead, more often than not, the SENCO was not “given the support and backing from their senior management team to allow them to get on with the job”.

The school’s ethos. Finally, the advisors felt that the success of children’s secondary-school placements was critically dependent on the school’s ethos – their inclusive attitudes and their flexibility in responding to the child’s needs. They emphasised the necessity of a whole-school approach: “It starts with the board of governors and the headteachers, their SEN policy. It can’t just be a piece of paper, it’s got to form part of everything, and how they work in the school”. They described how inclusive schools embedded this positive, flexible, responsive ethos through the entire staff group, e.g., “the dinner ladies know, the playground supervisors know”. Less flexible schools insisted on “the young person fitting into the school”, which often meant that, even with the best transition plans, placements in these schools were unlikely to be successful, e.g., “if the school’s not going to embrace it, it’s just not going to work”.

Semi-structured interviews with school professionals

The school professionals interviewed represented a range of provisions that reflect the spectrum of autistic children’s needs. Nevertheless, we identified five common overarching themes.

Individualised responses to children's needs. Many of the respondents stressed the need to address the individual needs of the child, e.g., “we do tend to think very individually really, rather than ‘oh this is an autistic child, therefore we are going to need A, B, C and D’”. Staff within the autism-specific provision described “an almost individually tailored curriculum” whilst other staff adopted “a differentiated and personal approach” to the curriculum, where possible.

Challenges within the school environment. All of the staff working within mainstream secondary schools noted the contextual challenges and demands placed upon children: “the physical environment, the ability of the child to settle within that environment, the curriculum, the groupings, the numbers of students ... understanding their day, and any changes that are going to be occurring”. There was also a sense that accommodating these changes is part of the learning process and that “pupils do need to get used to working with more than one person”. In response to these challenges, many schools *provided a safe space*, “a place that they know they can go to if things are a bit tough”. Sometimes this safe space was in the form of a tutor room, “a room where they can feel calm, it’s theirs and there they can focus on their learning”, which helped them cope with the demands of their new learning environment.

Varied levels of parental engagement at transition. When discussing parental participation during transition, the informants described a diverse range of experiences. One school noted that few parents visit their school prior to their child’s transition, “maybe 10%”. Parents were perceived to choose another school on the basis of reputation alone “because it’s got a reputation of having very good behaviour, being very calm, and having very high standards” but school staff felt that “parents often underestimate their children’s disabilities” assuming that the placement would somehow make the difference. For another school, once “word was out” in the community about their successful provision for children with autism, applications increased dramatically, leading school staff to acknowledge the difficulties in meeting this demand, e.g., “desperate parents who want to send their child to us, and I know it’s not going to happen”.

While some parents were perceived to be well informed and to participate actively in the transition process, others were said to find it much more challenging, e.g., “we live in a borough in

which parents aren't necessarily very savvy – they don't know the right processes". They spoke about cultural and linguistic barriers for some parents, e.g., "we don't have any information for Bangladeshi parents", and differences in the way that some communities view autism, e.g., "there is a lot of stigma attached". To address these issues, the respondents highlighted the need for advocacy, emphasising "the importance of parents really knowing a school before they choose it". They said that they advised parents to visit at least three schools before making a choice and that in making a choice they should "really emphasise the needs of the child". School professionals were also keen to engage with families at transition because "the way that things work at home, really feeds into how they're going to work in school". But they also noted that, as children progress through the school system, invariably the degree of contact with parents declines.

The limits to inclusion. Finally, there were a variety of views regarding the various schools' abilities to include children with autism. Some schools were clear about the types of profiles for which they could cater: "we would be more skilled dealing with pupils who are high functioning than those who aren't verbal. I think we would struggle to include them". Others felt they would not be able to cater for those displaying challenging behaviour: "the non-verbal, less communicative, more violent. I have a feeling they'd probably get caught in the general disciplinary culture, and probably end up losing their place. They'd end up being excluded". Staff from the special school were "reluctant to take children, on entry who are on the national curriculum levels" but nevertheless recognised the need to be flexible and responsive to children with complex learning, emotional or behavioural needs, e.g., "if it's really impossible for them to go to mainstream, we will consider them".

Semi-structured interviews with students with autism

Students provided a striking contrast to the other participant groups, in terms of their perspective and priorities. We identified two main themes.

Prominence of social relationships. In discussions about their current and future school, there was a clear emphasis on social relationships – positive and negative – for all students with autism. Many mentioned playtime and playing with friends, with some saying that they were excited about making

new friends at secondary school. Yet they also reported the difficulties associated with making and keeping friends, e.g. “my best friend is not being that much of a friend really”. One student reporting feeling worried if his friends were absent from school, “I feel worried if my friends are not in”, while another was preoccupied about a boy who did not want to be friends, “he was shy with me”. The students also expressed an overwhelming apprehension about interacting with others at their new school and whether they would have friends: “I might be shy about meeting new people”; “I’m worried if I don’t have friends”; “I’m really worried when I meet the big children”. When talking about the kind of relationships he wanted, one student drew the distinction between the kindness shown to new students and true lasting friendships, e.g., “not like all being kind, but proper buds stuff, like when you bash your fists together”.

Most of the students were anxious about bullying. Some talked about direct experience of bullying in their current school: “bullying, silly stuff, sometimes”; “people fight me and saying rude words to me”. One student gave detailed descriptions of why this took place and how it could be prevented through better discipline and structured play opportunities: “bigger rules, not to break the rules, more teachers, more security systems to keep the school safe from bullying”; “children were bored [at my primary school], that’s the reason why people [were] bullying”. Others were concerned that bullying might happen at their new school, particularly about being mocked by the older students.

Anxiety towards learning. Students demonstrated an acute awareness of the importance of learning. Although some students talked about the subjects they liked and excelled at (“I’m excited to do drumming”; “I’m really good at maths”), the majority of comments about learning involved negative feelings, including a dislike of particular subjects, e.g., “I don’t like doing work”, but also a sense of failure and inadequacy: “I’m not really good at literacy or science”; “if I was really smart, I’d want to know really hard stuff”. Some students were anxious about the prospect of not achieving academically when they moved on to secondary school: “I don’t know whether I’m going to be able to keep up, because I’m already in the lowest set”; “the thing I’m worried about is hard work”. These worries were tied to their hopes and aspirations after secondary school, e.g., “My Mum didn’t get to go to college, so

she'd be proud of me, if I went"; "I'd like to stay for sixth form and then I'll find a university, maybe Cambridge".

Discussion

This study examined the factors influencing parents' decision-making processes about their autistic child's secondary-school placement, within the context of the perspectives of other interested parties – the young people themselves, local authority advisors and school professionals. The results clearly demonstrate the complexity of the school-placement decisions for parents and the potential challenges associated with navigating the educational system for their child with autism.

The burden of the decision-making process weighed heavily on the parents in this study, who emphasised that such decisions were fraught with anxiety and uncertainty. This finding is consistent with previous UK research, which has repeatedly found that parents of both children with SEN (Rogers, 2007; Bagley, Woods, & Woods, 2001) and children with autism (Plant & Sanders, 2007; Tissot, 2011; Tissot & Evans, 2006) report the process of choosing a secondary school unduly stressful. Current legislation for children with SEN and disabilities (DfE, 2014) has sought to address these concerns by requiring that local authorities provide greater transparency and information sharing with parents, and that parents have greater choice and control in educational decision-making. Whether such legislation allays parents' concerns remains to be seen but the lack of acknowledgement of parental stress by the professionals (advisors and school professionals) in this study suggests that this burden may be borne primarily by parents without sufficient strategic support.

There were mixed responses regarding whether parents *felt* they had sufficient advice and support to make decisions about their child's secondary-school placement. While some parents felt that schools and professionals failed to provide specific information about suitable secondary schools, others reported feeling fully supported and informed. Parent advisors and school professionals, however, felt that there were many support structures and sources of information available to guide parents' decisions. This discrepancy between parents and professionals' perceptions fits with previous research on school placements (e.g., Waddington & Reed, 2006) and highlights whether the

information schools and local authorities currently provide for parents is accessible and useful. Indeed, Byrne (2013) noted that some parents, particularly those with English as an additional language, may have difficulty in having their voices heard in the professionally-dominated discourse around SEN and school placement. In line with this view, several professionals admitted that the support systems currently in place might not always effectively reflect parents' cultural, linguistic and social needs, which meant that parents were often ill-equipped to explore the available options and therefore make fully informed decisions. These findings stress the need for more effective communication between parents and professionals at all stages of the decision-making process, especially for those embedded within culturally- and socially-diverse communities, or communities with distinctive cultural, social and economic challenges such as may have affected some of the families in the current study (O'Hara & Martin, 2003; see also Jindal-Snape & Foggie, 2008; Tissot, 2011).

With regards to the factors necessary for a successful placement in secondary school, parents, advisors and school professionals were in broad agreement that children with autism should benefit from a nurturing, flexible and inclusive environment that emphasised both academic and life skills. Nevertheless, there were subtle differences between parents and professionals in terms of their priorities when choosing or advising on the best placement for autistic children. While parents often focused on their child's personal development, professionals gave greater attention towards functional and systemic factors, such as the challenges and demands of the secondary school environment and the school's cultures and attitudes towards inclusion. These differences are largely consistent with Bagley and Woods' (1998) framework on the value perspectives underpinning parental choice and educational decision-making. They suggested that parents of children with SEN adopted an intrinsic-personal/social perspective during educational decisions, that is, they understood and valued the child as a person, including their likes, dislikes and sensitivities, and wanted him/her to attend a school where they would feel safe and secure and develop fully within a stimulating environment. School professionals instead encompassed an instrumental-academic perspective, in which successful school placements were framed predominantly in terms of examination results. The partially distinct (yet

complementary) perspectives of our sample of parents and professionals are perhaps unsurprising in this context. Caution is warranted, however, in ensuring that one perspective is not overlooked at the expense of the other during the decision-making process – an issue that could be mitigated in part via clear and accessible communication channels and effective home-school partnerships (see Charman et al., 2011).

Another perspective that is at risk of being ignored is that of young people themselves. The students interviewed in the current study clearly demonstrated their ability to share their views about the impending transition to secondary school. Yet only 2 of the 6 students were directly involved in their choice of secondary school. School professionals focused more on parent than on pupil participation and, while parent advisors believed in the importance of involving young people, they suggested that the structures were not yet in place to enable this to happen consistently. Thus, despite numerous calls (e.g., Calder, Hill, & Pellicano, 2013; Parsons & Lewis, 2010) and legislative changes (DfE, 1996, 2014; Special Educational Needs and Disabilities Act, 2001) emphasising the need to listen to the views of students with autism about their own education, there was disappointingly little acknowledgement of these views in our research (see also Pellicano et al., 2014). More work needs to be done to ensure that these young people are involved in key educational decisions-making processes, including choosing a secondary school, in line with the revised SEN Code of Practice (DfE, 2014).

Yet how are decisions made when the child's choices and preferences *conflict* with those of their parents and other adults? Perhaps the most striking difference across our respondents was the sentiments expressed by young people and adults. Young people with autism were concerned mainly with friendships – just like typically developing young people (Reay & Lucey, 2000), as well as potential bullying and difficulties forming new relationships in their new secondary school. Their concerns are not surprising given that we know that social relationships – positive and negative – are a real issue for many young people with autism. Roulstone and Lindsay (2012) also reported that, when asked about their school experiences, young people with speech, language and communication needs (including autism) spoke a great deal about friendship and were concerned with bullying and social acceptance.

Young people with autism in mainstream settings often experience social isolation, bullying and loneliness (Bauminger & Kasari, 2000; Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001; Reid & Batten, 2006) and are more likely to suffer bullying than other students with SEN (Humphrey & Lewis, 2008; Reid & Batten, 2006). Despite this knowledge, young people's social relationships for the most part were not the focus of attention of their parents, the parent advisors or school professionals when considering a secondary school.

These findings raise important issues regarding both the involvement of young people in decisions about secondary-school placements and how parents weight this potentially conflicting information (when it is elicited) alongside the multitude of other factors discussed herein. Should parents prioritise the child's views and perspectives, in this case, the importance of their friendships and social wellbeing, like one of the families in our study? Or should parents prioritise their own or others' perspectives, selecting, for example, the secondary school with the most inclusive ethos or the more experienced staff? Such decisions are likely to be made within the context of the needs of individual children – their cognitive ability, their social competence and the severity of other autistic features (e.g., sensory sensitivities). The diverging perspectives among young people and the adults supporting them serve to emphasise the enormity of the decisions faced by parents but, unfortunately, do not offer any ways to resolve such discrepancies.

Indeed, there is very little research on the most effective placements for children with autism, which could help guide parents as they make these decisions (Charman et al., 2011; Parsons et al., 2011). Interestingly, in one relevant study, Rowley et al. (2012) found that students with autism with higher levels of social competence were *more* susceptible to bullying and victimization in mainstream secondary schools than those with autism with lower levels of social ability. The authors suggested that this difference might arise from children with higher levels of social competence being more likely to experience social situations with little or no support. Choosing a secondary school solely based on factors such as staff training and experience of autism may well result in removing a child from a familiar peer group and make them more vulnerable to bullying and social isolation.

In sum, our findings show that choosing a secondary school for children with autism is complex and multifactorial and that weighing the different sources of information available is in no way straightforward. It could, of course, be argued that our study is limited by virtue of it being focused on a limited number of individuals from one particular London local education authority, rendering it possible that the issues raised are idiosyncratic to this context. Yet, the facts that there is parity with findings from other studies with parents in Australia (Lilley, 2014; see also Kidd & Kaczmarek, 2010) and the USA (Kasari et al., 1999), that the study was not confounded by potential differences at a systemic level (e.g., distinct services or strategies operating in different authorities) and that the level of agreement across adult participants and with previous research (e.g., Byrne, 2013) with regards to the key factors for choosing a secondary school for students with autism all warrant confidence in our findings.

The new legislation in England offers some hope towards potentially reducing at least some of the stress and uncertainty for parents (DfE, 2014) in that it clearly states that parents should have greater choice and control when choosing a secondary-school for their child and that young people should be actively involved in this decision. Future research is necessary to determine whether this new legislative context improves the decision-making process for parents of autistic children and further to examine the factors underpinning a successful transition to secondary school using a longitudinal design.

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