

# The views of young people with an autism spectrum disorder on their experience of transition to secondary school

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## **Abstract**

The experience of transition from primary to secondary school is regarded as being particularly challenging for children who have a diagnosis of an autism spectrum disorder (ASD). The research in this area has identified that additional support during this period has been beneficial, however the dominant voice has been given to the parents and professionals. This qualitative exploratory study offers an opportunity for others to gain a greater understanding of the transition process through the constructs and perceptions of the child with an ASD. It also served to gain information around the development and use of skills that are associated with self-advocacy.

The study involved five Year 7 children who had joined one of two mainstream secondary schools within a local authority in England. The data was gathered through the use of semi-structured interviews and analysed using inductive thematic analysis.

The findings of the study indicated that a sense of belonging was valued by the participants and stressed the importance of having positive relationships. Whilst there were some signs that the children were able to express their needs to others, there was an assumption that the adults may take on the role as advocate. Relationships with peers were a perceived area of difficulty, with some children also reporting experiences of being bullied in both the primary and secondary settings. These difficulties were attributed to having an ASD or feeling they were different to their peers. There were also indications that the interaction of the systems around the child were pivotal to the success of the process of transition.

The implications of this study suggest that there could be a role for educational psychologists in supporting the schools, families and the children with ASD. It is possible that working at a systems level could improve the development of skills that would enhance the ability to self-advocate; thus increasing self-awareness, resiliency and a sense of belonging.

**Keywords:** *Autism spectrum disorder, transition, self-advocacy, mainstream education*

THE VIEWS OF YOUNG PEOPLE WITH AN AUTISM SPECTRUM  
DISORDER ON THEIR EXPERIENCE OF TRANSITION TO  
SECONDARY SCHOOL

Student Declaration

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Declaration

I declare that while registered as a research degree student at UEL, I have not been a registered or enrolled student for another award of this university or of any other academic or professional institution

I declare that no material contained in the thesis has been used in any other submission for an academic award

I declare that my research required ethical approval from the University Ethics Committee (UREC) and confirmation of approval is embedded within the thesis.

Susan Ackerley

Signature: ..... Date: 28th April 2017

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## List of Abbreviations

- ADHD:** Attention Deficit Hyperactivity Disorder
- AET:** Autism Educational Trust
- APA:** American Psychological Association
- ASD:** Autism Spectrum Disorder
- BPS:** British Psychological Society
- DCD:** Development Coordination Disorder
- DCSF:** Department for Children Schools and Families
- DfE:** Department for Education
- DfES:** Department for Education and Skills
- DSM-V:** Diagnostic and Statistical Manual (5th edition)
- EHCP:** Education, Health and Care Plan
- EP:** Educational Psychologist
- EPS:** Educational Psychology Service
- HFA:** High Functioning Autism
- IEP:** Individual Education Plan
- LA:** Local Authority
- NAS:** National Autistic Society
- Ofsted:** Office for Standards in Education
- PATH:** Planning Alternative Tomorrows of Hope
- PDA:** Pathological Demand Avoidance
- PDD-NOS:** Pervasive Developmental Disorder –not otherwise specified
- SEND:** Special Educational Needs and Disability
- SENDCo:** Special Educational Needs and Disability Co-ordinator
- TA:** Teaching assistant
- TEP:** Trainee Educational Psychologist
- UNESCO:** United Nations Educational and Cultural Organisation

## **Chapter 1: Introduction**

### **1.1 Overview of the Chapter**

This chapter sets the context in which the current research has been carried out, hence explaining the rationale for the study. It begins by defining the key concepts relevant to this study, before outlining the national and Local Authority context, which highlighted the need to pursue this area of research. In addition to this, the author recognises her position within the study and how this has served to inform the development of the research. Finally the summary identifies how undertaking the current study could contribute to the knowledge relevant to children with ASD who make their transition to secondary education.

### **1.2 Definitions of Terminology of the Key Concepts**

**1.2.1: Autism Spectrum Disorder (ASD):** The author has selected the term ASD to use in this study primarily because it is currently the preferred diagnostic term used by the Diagnostic and Statistical Manual of Mental Disorders, version five (DSM-V)(American Psychiatric Association, 2013); this is now the collective term used and encompasses terms such as: autism; autism spectrum condition; Asperger syndrome; pathological demand avoidance (PDA); pervasive developmental disorder- not otherwise specified (PDD-NOS); and high-functioning autism (HFA) which often reflects the diagnostic tool being used at the time. It is also acknowledged that the range of difficulties experienced can be affected by sensory processing differences and the levels of anxiety experienced by the individual.

ASD can be defined as a lifelong neurodevelopmental condition that affects how a person communicates with, and relates to other people. This in turn can influence and impact on how they experience the world around them. A diagnosis is given when a person has deficits within the social interaction domain, which includes delays in language and social communication. They will also present with repetitive or restricted behaviours, thus making the process of change more challenging than it would for the neurotypically developing population (National Autistic Society (NAS), 2016; Autism Education Trust (AET), 2016; American Psychiatric Association, (APA) 2013).

**1.2.2: Transition:** The term transition can be applied to any situation where there is change involved, however for the purpose of this study the term will apply to the process of moving from primary to secondary education. Whilst transition is perceived as being an area that children might find difficult, it can be particularly challenging for a child with an ASD, who by nature of the neurological differences associated with an ASD diagnosis, can find change difficult to manage and may not have the necessary skills to be able to fully participate in the process (Lohaus et al., 2004, Foulder-Hughes & Prior, 2014).

**1.2.3: Self-advocacy:** Self-advocacy is a term that has its origins in disability theory; it is also a concept that is defined according to the social constructs. However most definitions agree that it involves: understanding one's own disability and being aware of the associated strengths and limitations; effectively communicating your needs and desires; knowledge of one's rights (Cummings, Maddux, & Casey, 2000; Test, Fowler, Wood, Brewer & Eddy, 2005). Dryden, Desmaris and Arsenault (2014) identified that teaching self-advocacy skills increased the ability to stay safe, their self-advocacy knowledge, confidence

and behaviour. It was also found to assist the individual with a SEND in developing a sense of empowerment that can increase their levels of resiliency (Goodley, 2005).

### **1.3 The National Context and Background to the Research**

**1.3.1 Educational Provision for Pupils with an ASD:** The Children and Families Act (2014) aimed to raise the aspirational outcomes for all children and families; ultimately this is determined by the ability to access appropriate educational provision. In order to achieve this, the child or young person with a SEND and their family are expected to be central to the decision making process around provision, support and transition; this should consider information supplied by professionals working with the child.

There is also an expectation that all schools are inclusive in their practice; this is in line with the international educational policy drawn up following the Salamanca Statement (UNESCO, 1994). Mainstream schools are required to make reasonable adjustments to enable children with SEND to be included in school life (Department for education (DfE), 2014).

The latest figures issued by the Department for Education (DfE, 2016) state that 70% of children with an ASD are currently educated in mainstream settings. They also stated that nationally 25.9% of pupils with a Statement or Education Health and Care Plan (EHCP) in January 2016 had their primary need recorded as ASD, with an additional 4.7% of students receiving SEND support having an ASD. However, it is difficult to determine from these statistics how many of the

pupils are making progress in an inclusive mainstream system that provides appropriate support as opposed to those who are being educated in a more specialist educational setting.

The NAS indicate that while the difficulties associated with ASD can create challenges for the child, they can be successfully supported within the mainstream provision, however this is reliant on a level of understanding and commitment to giving an appropriate level of support that is determined by the needs of the individual. In practice this can prove difficult to achieve with the NAS indicating that children with an ASD are six times more likely to experience bullying than their non-ASD peers. Bancroft (2012) reported that 63% of young people with autism have been bullied at school, evidencing that this rises to 75% for secondary school age pupils. Humphrey and Lewis (2008) also found that pupils on the autism spectrum are twenty times more likely to be excluded than their non-ASD or 'neurotypically' developing peers. These statistics serve to increase parents' anxiety and concerns which may lead them to question the ability of mainstream schools to meet their child's needs (Tobin et al., 2012).

It may be argued that information shared using social media and on-line forums, such as the NAS community and Mumsnet, which often debate about whether children with an ASD can be successful in a mainstream secondary school, can also influence perceptions on the desired choice of educational provision. The majority of views expressed by the parents indicate that there may be a preference for specialist provision or mainstream provision that has a specialist unit attached to the school. Following the implementation of the Children and

Families Act (DfE, 2014) and the SEND Code of Practice (DfE, 2015), there is a requirement to have the child and his/her parents at the heart of decision making with regard to transitions and school choices; it could be argued that, for many, the available specialist provision within a local authority is limited, with many local authorities reporting that demand is exceeding the capacity of available places within the authority. The demise of specialist provision may have been influenced by the inclusion agenda that was driven by the Warnock Report (1978), which indicated that specialist provision should be available for children with the most complex needs (2%) and the remaining 18% of children and young people on the special needs registers should be accommodated within mainstream provision, thus signalling the reduction of specialist provision. The subsequent Education Act (1996) enabled parents to appeal against decisions made by the local authority, including school placement, this highlighted the complexities around inclusion which often led to disputes and costly tribunals between local authorities, parents and schools regarding the educational provision for a child with identified additional needs. In 2005, Baroness Warnock acknowledged that for many children with an additional need in a mainstream school, there was often a lack understanding from staff about how best to support them, alongside an increased risk of bullying, which could lead to the child feeling isolated without a sense of belonging within their school, thus indicating that whilst integration could be observed, inclusion was still not being realised.

The introduction of the free school programme was promoted as an opportunity for parents, teachers, charities and businesses to establish schools that could

offer additional provision to that being offered within a local authority. New School Network (2015) state that the free school programme created 2000 places in specialist provision for children with ASD. These new schools have often been established by groups of parents and charities such as the NAS and Ambitious about Autism. It is possible that this is a reflection of the negative experiences of families in maintaining a mainstream placement for these students. Whilst there have been a range of views around the efficacy of provision offered in secondary education, there also appears to be a lack of information that monitors what form of education is being accessed by pupils on the autism spectrum during the secondary phase of their schooling. Barnard et al. (2002) reported that there are discrepancies between the number of pupils diagnosed with an ASD in primary education and those in secondary education. Whilst some of these pupils could move into specialist provision, Barnard et al. (2002) propose that there could be a significant number of children who are missing out on secondary education, calling for more research to establish what is happening at this stage.

It appears that the decisions around secondary provision are often based on evidence gained from adults. Greene and Hill (2010) indicate that there is an assumption made by the adults that they have a greater understanding about what is best for the individual and how events will impact on them. The author also suggests that power differential has its roots in the socio-political arena where it has often been accepted that the child, particularly the child with additional needs, does not have the capacity or permission to directly contribute to the decision making process about factors that would have a direct impact on

them. The SEND Code of Practice (2015) indicates that the child can provide useful insights that can assist in improving the support that may be provided.

### **1.3.2 Involving Children and Young People in Transition Planning:**

Removing Barriers to Achievement (DfES, 2004) makes reference to the importance of carefully managed transitions for children with SEND, with all the stakeholders contributing to the process. Evangelou et al.'s report (2008) indicated that 1 in 10 parents would have liked the staff at their child's primary school to listen to what their child had to say about transition and to incorporate their views into a transition package.

Whilst there have been several studies that have included children on the autism spectrum (e.g. Lewis & Porter, 2004; Whitehurst, 2007; Ware, 2004, and others), there is little research that is purely concerned with eliciting the views of children and young people with an ASD. It could be argued that children with an ASD may find it difficult to effectively communicate their needs as they should be equipped with the knowledge and self-awareness that could lead to informed choices, as well as the means to effectively communicate this to others in order to request and access provision which leads to a successful, inclusive educational experience. Parents are reported to be more attuned to their child's emotional state, however Fortuna (2014) also indicated that the anxiety and worry for the parents to achieve an appropriate level of support can be reflected onto the child, having an impact on the wellbeing of their child, thus diminishing his/her ability to develop the skills necessary to self-advocate. Tobin et al. (2012) suggested that this role was taken following an identification of need or a

diagnosis and could be seen as a reflection of the perceived difficulties that the diagnosis presented and the perceived potential outcomes.

The shift towards a person-centred approach and encouraging children to advocate for themselves wherever possible, requires practitioners to develop tools that enable children with SEND, including ASD, to present information about themselves giving their perspective on what they would like future provision to look like. The process of gathering a child's perspective and enabling them to participate in the decision making process requires the adults to create a forum that adopts a method of communication that the child is familiar with. This ultimately needs to take into account the individual's receptive and expressive language skills to avoid contributing to the anxiety levels of the child. There are a number of resources that have been developed to encourage the involvement of children and young people; for example, through person centred reviews, PATHs, one page profile (Sanderson, Mathiesen, & Erwin, 2006). The visual element of the tools mentioned may make them appropriate to use to support the child with an ASD to communicate more effectively, enabling them to take an active role in the process of transition. This could promote the development and role of self-advocacy during this period.

Research in the area of self-advocacy indicates that the skills could be beneficial in supporting pupils with an ASD through the transition process, with the added bonus of developing self-advocacy to support life in the wider community (Dryden, Desmaris and Arsenault, 2014).

## **1.4 The Local Context and Background to the Research**

### **1.4.1 Educational Provision for Pupils with an ASD**

Within the local authority where this research has taken place, there are a range of settings where pupils with an ASD can access education. In line with the national strategy, the majority of pupils are typically educated within a mainstream provision; some of which have a specialist support unit attached, offering a range of different packages. These are provided as a permanent placement, with the expectation that pupils will continue to access their mainstream education, wherever possible. In addition to this there are a number of pupils who attend specialist provision both in county and some out of county provision. Unfortunately it has not been possible to access information that identifies the specific numbers of pupils with an ASD attending each of the educational settings, as data within the Local Authority does not separate the different classifications of need in terms of a diagnosis. However, colleagues within the authority acknowledge that the number of requests for specialist provision for pupils with an ASD exceed the number of available places and that this can often lead to out of county placement, home education and SEND Tribunal appeals. It appears that transitions to the secondary setting are a period of heightened emotions where parents have great anxieties around the capacity of some schools to be able to support the development of their child.

In September 2017 a free school is scheduled to open, that will cater specifically for pupils with an ASD who are deemed to have the cognitive ability to access a mainstream curriculum. The publicity around the opening of such a

school has inevitably raised the expectations of the parents with a child that has an ASD; indicating that they will be better supported in such a specialist school and arguably suggesting that the available mainstream provision might not be the most appropriate for a child with an ASD. This has the potential to create tensions, possibly barriers, between parents, schools and the local authority in providing a placement that is perceived by all parties to meet the needs of the child, particularly as the pupil admission capacity at the new school is limited.

#### **1.4.2 Transition between primary and secondary schools**

From the researcher's discussions with SENDCos in schools, within the local authority, it appears that schools generally engage all the children in some transition activities with enhanced packages being developed when there is a perceived need for additional support. For students with an ASD there is also a specialist support team who can be accessed to provide support for transition, which may include signposting schools to their Autism Spectrum Transition Pack, which can serve to collate information from the adults that support the child. It also provides generic ASD information intended to assist the inclusion of the child into a mainstream secondary school setting. The information can be used to present a 'pen portrait' of the student identifying their strengths and needs. This requires schools, in collaboration with the parents, to identify what support the child will need to through the development of a transition package.

For the majority of the students that have been identified, they are invited to attend additional visits to familiarise themselves with the school and meet key

members of staff. Some may also be issued with photographs or visual supports to assist the process of transition.

The consensus from the secondary school SENDCos was that the nature of the support was generated through communications with parents and/or primary school staff, with the adults assuming the role of advocate for the child. This suggested that there is a risk of the child's voice being marginalised during the transition process.

### **1.5 Researcher's Position**

This area of interest has evolved from the experiences gained by the author in her role as an outreach teacher working with schools to support children and young people with a diagnosis of an ASD in mainstream schools. It was through working with stakeholders during the process of transition that it became apparent that the child's voice was often being marginalised and the decisions made were usually based on the perceptions of the adults who had taken on the role as advocate for the child. For some of the children, particularly if they were viewed as having more challenging needs, this could result in a period of conflict arising from what the parents felt should be offered as support for their child and what the school perceived that they could offer to accommodate an individual's needs. It appeared at the time that the views held were influenced the outcomes and experiences of previous transition packages that had been provided for other pupils with an ASD; parental anxiety generated from the difficulties that had been observed in previous transitions; and information being shared between the primary and the secondary school.

Despite efforts being made to ascertain the views of the child, the author felt that the child could often give the impression of being disempowered, apparently lacking the capacity to self-advocate; for some it appeared that they had developed a dependency on having an advocate. Seligman (1972) used the term 'learned helplessness' to describe this state, whereby the child had felt unable to contribute to the situation and affect any positive change. Whilst there were some successful transitions, there were also occasions when the school placement became vulnerable or indeed broke down. This could be accompanied by a deterioration in the child's mental health which caused additional stress to the child. Comments made by the children at this time often referred to them feeling that the support had not given them the knowledge or tools to succeed; most commonly this was linked to not being heard or listened to. This prompted an interest into furthering the author's understanding into the journey of transition for a child with an ASD transitioning to their secondary school.

It is acknowledged that during the process of gathering the data from the participants, the author has used her previous experience in relating to pupils with an ASD to create an environment where the participants are comfortable, thus acting as an 'instrument' that has facilitated the collection of rich data used in this qualitative study. However this does not deny that there will have inevitably been some power imbalance between the researcher and the participants during the interview process. As a practitioner researcher it would be naive to think that the children's contributions were not influenced by the fact

that I was an adult gathering their views or that they were aware from the information given to them about the study that they would be working with a Trainee Educational Psychologist (TEP), which in turn may have influenced some of the responses.

The author also acknowledges that her position and beliefs may have influenced the nature of the interviews. Whilst there is a belief that there were no pre-conceptions about what the data may produce, in terms of what the experience of transition had been for each of the participants, the researcher was interested in determining whether there is evidence of the participants demonstrating that they have developed skills that have enabled them to contribute to the transition process.

## **1.6 Research Rationale**

Within the local authority, the Principal Educational Psychologist has recognised that “a significant number of children with ASD encounter problems when they move to high school, leading to school refusal/avoidance and then to not leaving the home.” (Personal correspondence, 24.08.16) There appears to be limited information that determined whether this issue could be linked to the child’s experience of transition; as perceived by the child, the parents or professionals. It may be argued that difficulties that arise during the transition process may contribute to a lack of confidence in an ability to support a child and subsequently the child and their family feeling that they are not accessing appropriate support. The transition to secondary school is regarded as being particularly difficult for children with an ASD, however, there is little research

that identifies what this experience entails from the child's perspective. Whilst it is recognised that the child with an ASD profile has communication difficulties, this should not be a reason for excluding their views. The current research aim was to utilise the researcher's experience and appropriate communication tools to enable the participants to tell their stories.

It is hoped that the qualitative nature of this research served to give a rich picture that represents the children's stories about their transition. Secondly, the research hoped to identify if there is a role for self-advocacy to be taught to pupils with an ASD whilst at their primary school as a tool that could be used to facilitate a greater understanding of the child's needs. This could influence the perceptions held by the adults supporting children with an ASD and inform future practice with regard to the transition from primary to secondary education.

## **Chapter 2: Literature Review**

### **2.1 Overview of the chapter**

This chapter considers the ways that children with an ASD can be successfully supported to manage their transition from primary to secondary school whilst considering the role of self-advocacy. This reflects the directive towards person-centred approaches that has emanated from the changes in legislation since the Children and Families Act 2014 and the guidance given in the SEND Code of Practice (2015). The chapter starts with outlining the details of the four systematic literature searches in the following areas; ASD and transition; transition and self-advocacy; ASD and self-advocacy; ASD, transition and self-advocacy. Following this the key studies from these areas are critically evaluated with the implications from these findings being used to inform the focus of the current research.

### **2.2 The Key Areas of Research**

#### **2.2.1 Systematic Literature Search**

A systematic literature search was carried out by means of the search engine EBSCO Host to identify what literature was available in this area using the following databases.

- Academic Search Complete
- British Education Index Child Development & Adolescent Studies
- Education Research Complete
- Education Resource Information Centre

- PsycARTICLES
- PsychINFO
- Teacher Reference Centre

The thesaurus function was used to identify any synonyms and/or related terms for each of the key search terms, for example, autism spectrum disorder, autism spectrum condition, Asperger\* Syndrome and neurodevelopmental disorder; Boolean logic was used to incorporate these terms to avoid excluding articles that used different terminology. The limiters applied were for all articles to be published between 1996 and 2016 and for them to be written in English.

With the above taken into consideration, the following criteria were used for the systematic literature review:

- Autism\* and transition or transfer
- Transition or transfer and self –advocacy or person centred
- Autism\* and self-advocacy or person centred
- Autism\*, transition and self-advocacy

In total 212 articles were found, with the titles and abstracts being reviewed before identifying the 10 articles that met the inclusion criteria for the critical analysis. The appendices 1, 2, 3 and 4 describe the full list of the literature searches used, together with full details of the inclusion and exclusion criteria.

The final 10 key references reviewed in this study are detailed in appendix 5.

Following the description of the criteria being used and identification of the articles reviewed, the next subchapters proceed to the exploration and analysis of the 10 articles targeted.

The current study has aimed to present the voice of the child with an ASD, during the process of transition; therefore the order of the reviewed papers commence with the papers that have sought the views of children and young people.

### **2.2.2 ASD and Transition to Secondary School**

As discussed in the previous chapter, it has been acknowledged that the transition to secondary school exposes children to a range of demands. Tsuzuki (2012) suggested that the children experience both an ecological and a developmental transition, which coincides with their biological, cognitive and interpersonal changes. He further suggests that during this time some children may have a negative experience that could have long lasting implications on their emotional wellbeing. Whilst there are a number of studies that relate predominantly to the transition experiences of 'neurotypical' children as a means of gaining an understanding of the academic attainment 'dips' (Evangelou et al, 2008); there are few studies that specifically relate to the experiences of pupils with an ASD transitioning to secondary school and indeed the author identified four studies for the purpose of this analysis. These studies span over qualitative and quantitative analysis and have been undertaken between 2011 and 2015. The studies investigated the transition of children from primary to secondary education using sample sizes of between 6-28 participants. They are explored in greater depth below.

Dann (2011) conducted a qualitative study that explored the experiences of six children, each having a diagnosis of an ASD and a statement of special

educational needs. Data was collected from the children, their parents and key school staff, the first phase being when the students were in their final term of primary school and the second phase was following the first term spent in their secondary school. Three of the pupils went on to attend mainstream secondary schools (two having small SEN bases incorporated within the school) and three pupils attended a specialist ASD unit which was attached to a mainstream school. Data was gathered from the parents using individual semi-structured interviews, which had the same format for the pre-transition interviews and the post transition interviews. When working with the children, Dann (2011) used a technique called 'talking mats' which aimed to facilitate a clearer understanding of the question being posed and the concepts being used during the interviews, thus promoting the validity of the data. Dann (2011) used focus groups with the school staff aiming to elicit a richer set of data to triangulate with the information gathered from the parents and the children. Although the study has great clarity related to the steps followed, the trustworthiness of the study risks being compromised by the apparent conflicting information regarding the epistemological position and the analytic process reportedly using thematic analysis (for instance, it appears that the transition experiences of the pupils are somewhat marginalised in response to the views of the adult respondents). Despite this, Dann (2011) reports there to be high inter-rater reliability scores for all the data gathered from the interviews, with the themes being evidenced with direct quotations. The findings indicated an 'overwhelming positivity' in the responses given by the participants from schools with an SEN base or the school with a specialist unit for ASD, argued by the assumption that this provided a space that was perceived as safe and familiar for the students. The

experiences of the participant who attended a school with neither of these provision expressed a more negative experience.

Dann (2011) identified twenty one factors that were seen to help or hinder the transition experience, with participants valuing additional visits, opportunities to build a relationship with key staff, meeting other students, information sharing prior to starting at the secondary school, e.g. timetable, maps of the school, etc. were all seen as positive aspects. Dann (2011) acknowledged that the sample size is small and this could create issues for transferability of her findings, however there is richness and depth of the data gathered from the qualitative design. The voice of the parents appear to be privileged over the voice of the child, this could be a result of the quality of the data or the interpretation of the researcher. Dann (2011) indicated that her findings are not dissimilar to those of other studies with participants who do not have a diagnosed ASD, this could suggest that there is some commonality around the experiences and the factors that promote a positive transition for all students.

A similar study was undertaken by Hannah and Topping (2013) who also used a qualitative design that looked at the perspectives of children and those of their parents in the Scottish education system. The researchers used purposive sampling that recruited nine male pupils with an ASD who would be transitioning from a mainstream primary school to a mainstream secondary school. Their study drew on resiliency theory and the influence of the eco-systems involved, particularly looking at the risk and protective factors that would impact on the transition process. The study was retrospective which entailed participants reflecting on the transition process - this suggests that the

data gathered could have been influenced by the poor recall and any discussions held during the process. The findings of the data, using content analysis, indicated that there were distinct differences in the perceptions held by parents and their children; for example, children valued being able to meet others with an ASD diagnosis and knowing what was happening; whereas parents prioritised having communication and information from the schools. However, there were some similarities with all participants (parents and children) reporting that their pre-conceived anxieties (e.g. getting lost; being bullied; etc.) were generally less than they had anticipated. A successful transition was perceived, by parents, as resulting in peer acceptance and friendship groups (Dillon & Underwood, 2005). These findings mirrored previous research (Johnstone & Patrone, 2003; Jindal-Snape et al., 2006) indicating successful transition for children with an ASD benefits from participation in activities to develop skills to support the process and create a sense of belonging. It has also been recognised that the needs of students with an ASD point towards a package that targets where they need support rather than a generic SEND package (Jindal-Snape et al., 2006). The authors draw on other studies (Gilligan, 2000) to argue that preparation for significant, potentially challenging, events such as moving school is seen as fulfilling a protective function through developing an individual's self-efficacy and resilience.

Mandy et al. (2015) argued that perceptions around the difficulties children with an ASD experience during transition are based primarily on anecdotal evidence, indeed the researchers had themselves undertaken such a study with Tobin in 2012. Following this study Mandy et al. (2015) perceived that the major ecological shifts between primary and secondary education systems identified by Coffey

(2013) made demands on the social, intellectual and organisational capacity that lead to increased difficulties around the time of transition. In an attempt to address this they sought to identify changes in the levels of psychopathology, adaptive functioning and peer victimisation prior to transitioning to the secondary school and during their second term at the secondary school. The researchers aimed to deliver empirical evidence that clarified whether the transition to secondary school escalated the aforementioned behaviours or not. The quantitative study gathered data from 28 pupils, parents and key staff indicated that there was some correlation between the views and perceptions of the parents and the teachers; however these did not always correspond with the data gathered from the children. For example parents and teachers indicated high levels of pathology in the child using the Strengths and Difficulties Questionnaire (SDQ) whereas the responses given by the children using the Becks Youth Inventory- II (BYI-II) indicated that the proportion of children fell within the expected range for the general population. In terms of adaptive functioning the parents indicated that the high levels remained the same whereas the secondary school teachers reported a worsening of behaviour from that presented by the primary school teachers. It is unclear whether this represents behavioural changes in response to the environment or that the responses made by the primary school teachers reflect a perception that reflects the amount of time that they have spent with the child throughout the school day, or indeed, if the students with ASD have low awareness of their emotional wellbeing and hence under-report symptoms. Observations made by the researchers speculated that these needs may not be recognised, often going unmet within the secondary school environment. Interestingly the researchers did not include the child's perspectives around the

areas of adaptive functioning. The parents and child saw a decrease in peer victimisation which included name calling and being socially excluded, following the transition to secondary school, this had been highlighted as an area of concern by participants in the previous study undertaken with Tobin et al. (2012). The researchers believe that this may be through proactive measures taken by the school. Mandy et al. (2015) accept that there are limitations to their study and that the findings are not generalizable due to the sampling strategy. The study was primarily concerned with pupils with an ASD, all but three were in receipt of additional support, via school action, school action plus, or a statement of SEN. The researchers did not use a control group and therefore the results could also be representative of the experiences of pupils who do not have an ASD. However, over half the participants were said to have at least one additional mental health need that had been identified by a mental health clinician, which is a factor to consider in terms of data collection and its subsequent analysis. Additionally, the validity of the data might have been strengthened if the researchers had been able to gather post transition data for all their participants. The study was focused on the ecological shift during the process of transition and the students were recruited from a number of different schools with a range of transitional experiences that will have been reflected in the data. Whilst the researchers identified that pastoral support in the secondary schools had been classified as 'good' or 'outstanding' in OFSTED terms, there is no indication given about what support had been given to the children transitioning to their schools. The researchers also acknowledged that by using solely quantitative data they were unable to gather data that could have given a more holistic view about the ways in which the ecosystems interact during the transition process. Mandy et al.

(2015) suggest that this would require a mixed methodology, inductive approach using qualitative techniques to generate hypotheses about transition that could then be explored using deductive quantitative methods. The researchers also indicate that this may be a way of developing a manualised transition package that could be used by practitioners to support children through the transition process. This appears to conflict with the views held by others that a generic package is unlikely to support the needs of the individual and that transition support should adopt a person-centred approach (Jindal-Snape, 2006). It also does not reflect the findings of the earlier study undertaken with Tobin et al. (2012) that used qualitative methodology, concluding that the anxiety levels of the parents influenced the perceptions around the success of the transition process for their child and indicated that there was a role for professionals, such as EPs, to support parents in managing their anxieties around transition.

In the final study analysed in this section, Foulder-Hughes and Prior (2014) used semi-structured interviews to generate themes that could be conveyed to influence future research about the transition experiences for pupils with an ASD or a Developmental Co-ordination Disorder (DCD), which is understood can also be a co-existing condition with pupils with an ASD (Siaperas et al., 2012). The researchers identified that the speed and range of detail in the verbal responses given by the participants could be an influential factor in the collection of the data. It is unclear from the article what prompts were used to ensure that the questions and concepts were fully understood by the participants. The interviews took place before the students started at the secondary school which produced two main themes: worries and suggested support. Foulder-Hughes and Prior (2014)

highlighted that the participants were able to identify solutions to some of the concerns, suggesting that this represented a creative thought process. This may also demonstrate a sense of self-awareness that recognises their individual strengths and limitations, alongside the capacity to communicate how these could be resolved. It may also be evidence of some pre-teaching around these issues e.g. an older peer may be able to support them or the use of a map could support them in getting to the correct place. There is no evidence that identifies whether the suggestions were valued by parents and school staff or indeed implemented. However, the study has indicated that children with a diagnosis of an ASD and/or a DCD were starting to develop the ability to self-advocate in a 1:1 environment.

Overall, the studies analysed in this section suggest that children with an ASD require additional support to enable them to have a successful transition. Whilst there appears no criteria that indicates what this entails, success seems to be assumed if the placement has been maintained. All the studies analysed included the views of the child, however these have often been marginalised by the views of the parents or the staff. The rich data gathered from the qualitative studies represent individual perspectives that have generated some generic themes, Dann (2011) and Hannah and Topping (2013) highlight that preparation and communication of key facts and information are beneficial. Generally the participants found that some of their anxieties e.g. peer victimisation was not as great as they had anticipated (Mandy et al (2015). Foulder, Hughes and Prior (2014) also indicated that there was evidence to suggest that the children were able to identify worries, communicate them and access support to resolve any issues.

All of the studies expressed the need for further research into this area to advance the understanding about the process of transition to secondary school with a focus on a child centred approach. The next section considers the role of self-advocacy during the process of transition.

### **2.2.3 Self-advocacy and Transition**

The area of self-advocacy and transition has been a topic of interest for research for the last two decades, this may have been fuelled by the promotion of human rights and Equality for All agenda. Most of this research is centred on the post-secondary education transitions (Merchant & Gajar, 1997; Walker & Test, 2011) with repeated calls for research into the use of self-advocacy in primary transitions Lancaster, Schumaker& Deschler, 2002).

Merlone and Moran (2008) conducted a study in the USA which evaluated a ten-week transition programme that was designed to support a class of 10-11 year olds with learning difficulties. The areas covered in the programme included developing an awareness of the special education system, specific disabilities and learning styles, coping strategies, and self- advocacy skills. This was followed by an individual meeting with a counsellor to review their file and develop their Individualised Education Plans (IEPs).

The evaluations from the programme indicated that they valued being given information about learning disabilities and having celebrities with a learning difficulty identified. Merlone and Moran (2008) highlighted that the participants

felt that it was important to receive positive comments about having a learning disability. Following the intervention the children reported feeling more positive about having a learning disability; more comfortable with their learning style; able to reframe derogatory comments made about attending special education classes; an increased confidence to ask questions when they were confused; they also had reduced concerns that their opportunities to go to college or pursue a career path of their choice would be limited by their disability. The findings were based on self-reporting by participants which can be described as being a person centred approach that gives an insight into the perspectives of the participants. Unfortunately Melone and Moran (2008) have not identified the number of participants involved in the study, furthermore the views of the students may not be shared or reflected by the wider population as they were all recruited from the same class in one US school. The limitations of the study indicate that no conclusions can be made regarding the impact of being taught self-advocacy skills or whether these skills were maintained or developed post-transition.

Kotzer and Margalit (2007) recruited 374 secondary school students from seventh to ninth grade (aged 12 -15 years) from a range of middle schools in Israel; meaning that some had recently transitioned whilst others were preparing for their onward transition to the high school. The study examined the effect of an e-self-advocacy programme on the students' self-perceptions of their competence pre and post transition. The researchers used three groups that were matched by age and gender with the two comparison groups being: students with a learning difficulty who did not participate in the intervention; and

those without learning difficulties. The intervention aimed to promote self-advocacy through the teaching of: self-awareness; insights into their strengths, competence and difficulties; and the ability to communicate their difficulties in order to attain appropriate accommodations/support. The programme also facilitated opportunities for peer discussions in the classroom as well as having access to the course counsellors via the internet.

The findings indicated that higher levels of competence were reported by students with a learning difficulty who had accessed the intervention compared with student with learning difficulties who had not experienced the intervention. The researchers also noted that the most gains were with students from the eighth grade which they attributed to them being the most settled group. The implications may indicate that teaching self-advocacy around the time of transition may not be the most appropriate time as the levels of anxiety at this time may limit the efficacy of such a programme.

By including a comparison group Kotzer and Margalit (2008) could strengthen their claims that the development of self-advocacy had led to a perceived increase in the levels of competence in the participants. Whilst this is a positive outcome, it is unclear as to how this translates into other areas of success for the student, moreover the researchers do not specify how the students used the self-advocacy skills to enable them to feel more competent.

The two studies discussed highlighted that participants benefited from the explicit teaching and promotion of self-advocacy skills. However Kotzer and

Margalit (2008) indicate that the efficacy of such a programme may be limited at times of increased anxiety, for example transition. The available research undertaken in the USA and Israel may reflect some cultural differences, it is unclear how the participants were able to use self-advocacy and whether these findings could be replicated in different situations, e.g. in the UK education system.

The studies were undertaken with pupils with a range of learning disabilities, Barnard-Brak and Fearon (2012) indicated that self-advocacy is particularly valuable to the ASD population. The next section will consider the concept of self-advocacy in relation to people with an ASD.

#### **2.2.4 Self-advocacy and ASD**

The self-advocacy movement for people with an ASD is reported to have its origins in Sweden. Nirje (1972) put forward the concept of 'normalisation principles', representing a means by which people with an ASD could voice their views and contribute to discussion around accommodations that could be made. This was perceived as a new way of thinking as prior to this it had been perceived as necessary to advocate for people with an ASD; this was often through support groups that had been initiated by parents.

A study undertaken by Rosqvist et al. (2014) explored the relationship between advocates and self-advocates; the study references to situation in Sweden, however its authors suggest that the issues are still valid in the broader context too. Rosqvist et al. (2014) used critical discourse analysis of 238 texts that were

produced by people who identified with being an advocate for the autistic community and autistic people who identified as being self-advocates. Their findings suggest that there are two positions: one being as an integrationist (reformist) and the other as a separatist. The study indicates that the advocates tend to lie in the integrationist 'camp' and seeks to make changes to society to enable autistic people to be fully integrated into a neurotypical (non ASD) community, with the changes being negotiated with the members of the autistic community. Conversely the discourse of self-advocates is reported to be focused on valuing their sense of identity within the autistic community. It is through this membership that they feel that they can be open about their diagnosis and maintain a sense of identity. Rosqvist et al. (2014) implied that this could be described as a different classification of advocacy, which they termed 'autistic advocacy'. This presents a dilemma as to whether the concept of self-advocacy is another area of difference and if the promotion of self-advocacy is an extension of advocacy, i.e. the parents and staff influencing whether the person with an ASD should be encouraged to resolve how they can be included into a social neurotypical community or whether they should be campaigning for the community to change to accommodate the needs of the person with an ASD. Rosqvist et al.'s (2014) study findings are based on the analysis of texts, some of which are media reports; it could be suggested that a written text may result in a different analysis to information gathered from a face-face interview, where clarification of a discourse could be achieved 'in situ'.

Research undertaken by Carter et al. (2013) questioned 68 parents, of young people with a learning disability and/or an ASD aged between 19-21 years old.

All the young people had attended specialist provision in the USA. The parents were asked to rate their views of self-determination skills; choice making; decision making; problem solving; goals setting; self-advocacy; self-management; and self-awareness. They concluded that 90.9% of the parents felt that self-advocacy was important with 83.6% claiming that their child had difficulty self-advocating. They found that the parents who defined their child's disability as less severe, attributed a higher level of skills in self-advocacy to their child. Whereas, those who rated their child's disability as being severe felt that their child was unable to self-advocate and therefore adopted a role as advocate for their child. Carter et al. (2013) recognised that their research findings are limited to the views of solely the parents or caregivers as they were often the constant person in the young person's life, advising that the perspective of the young person could be explored in later research. The quantitative nature of the data does not give additional information that could be used to enhance and explain the findings, for example had the young people participated in any programme to promote self-determination skills or did the young person have the skills to communicate. This may suggest that the study may have been enhanced by the inclusion of qualitative data into the design of the research. Despite this the researchers conclude by suggesting that there is a need for the implementation of explicit teaching around the development of self-determination skills (which includes self-advocacy skills) and that this could be initiated at an earlier educational stage to enable a person with a learning disability and/or an ASD to be central to the decision making process throughout their secondary education and onward transition into adulthood. It could also be argued that whilst the ability to communicate is a significant

factor, it is the self-advocacy that is the enabling factor. Barnard-Brak and Fearon (2012) indicated that the development of IEPs was improved when the child or young person had developed skills in; self-awareness, recognition of their strength and limitations, aspirational views, etc., which ensures that a child centred approach is being used.

The majority of studies reference to self-advocacy being regarded as a life skill, which is usually developed through experiencing life and maturation; it also reflects the interactional experiences within families, at school and with peers (Vaccaro, Daly-Cano and Newman, 2015).

In the final study, Dryden, Desmaris and Arsenault (2014) used a quasi-experimental design to evaluate the outcomes of a 10 week intervention programme that promoted safety and self-advocacy skills, comparing the outcomes to participants who were currently on a waiting list for the programme. The participants had a range of learning needs and disabilities including ASD, with 11 of the 57 participants being described as having an ASD. The programme focused on developing self-advocacy knowledge, personal safety, confidence and social behaviour. The researchers found their results encouraging, particularly in developing the capacity to say 'stop' to potentially abusive behaviours from others which has previously been highlighted as a concern expressed by parents and children with an ASD. The findings relate to self-reporting from the participants about how likely they were to respond to a situation rather than how they responded in a situation which could have different implications. Dryden, Desmaris and Arsenault (2014) acknowledge that

it may be more beneficial to group participants with specific needs or disabilities and tailor the programme to their needs, they also add the caveat that the analyses used may not have been suitable for the range of needs within the participant groups. It is unclear whether this also refers to problems to problems associated with the data collection, for example; it is possible that the communication difficulties typically experienced by participants with an ASD may lead to them interpreting questionnaires differently to other participants. In summary, there are few studies that focus on self-advocacy and ASD. Rosqvist et al.'s (2014) study provides an alternative perspective on the role of self-advocacy, suggesting that self-advocacy can be used to promote an ASD identity from within an ASD community or that it can be used to bring accommodation for their needs within a social neurotypical community. They also indicate that this could be a result of influences from key figures such as parents and educators. This point was also suggested by Carter et al (2013) who found that parents and caregivers valued self-advocacy skills but felt that their children had not developed these skills. Whilst there is much evidence to suggest that self-advocacy can contribute to enhancing the ability to participate and contribute to decision making processes, such as IEPs, it could be suggested that the advocates are key factors in determining how the self-advocacy skills are developed and used. There are programmes that promote self-advocacy, however Dryden, Desmaris and Arsenault (2014) have indicated that this is an area that requires further research suggesting that the programmes should take into account the specific needs of the targeted group. This also questions whether self-advocacy skills should be taught and revisited to enable children with an ASD to generalise the concept to enable them to be

able to request resources that could lead to a positive educational experience. It appears that these are strategies that could also be employed by children transitioning to their secondary school, this will be considered in the next section.

### **2.2.5 Self-advocacy, ASD and transition**

When using all three search terms, only one paper was returned. Ciccantelli's (2011) study examined the post-secondary transition, to gain an understanding about the essential features that created a successful transition. The study highlighted the legislative requirements that have secured rights for disabled people and their families which Ciccantelli (2011) infers has significance for colleges and higher education in giving equal access to students with an ASD. The context of the study is that approximately half of the students with a disability (of which ASD was the largest group) were no longer attending the course after the first year, furthermore for the 80% of students that were living independently, 20% continued to do so after the first year (Baer et al. 2010). These statistics were seen as significantly higher to those of their non-disabled peers. Ciccantelli (2011) chose a qualitative case study design for her research aimed at developing grounded theory from the data gathered from 9 participants (3 young people with an ASD, 3 parents and 3 staff). The researcher claimed a constructivist position however the analysis indicated that the findings were predominantly her interpretation of the data with member checking undertaken solely with the parent group. The study concluded that the parents of the students assumed an advocates position, which the student was comfortable with. However this conflicted with the preferred role desired by the college, which encouraged the student to self-advocate. It was apparent to the

researcher that there was a need for the students to be autonomous in order to participate in the decision making, that could enable them to be successful in requesting the necessary accommodations to maintain their position at the college. The study was small and this limited its generalisability, however it raises questions about whether the teaching of self-advocacy could challenge the position of parents and staff who identify with the position of advocate as the expressed views may conflict.

Whilst this study reflects a post-secondary school experiences it is possible that this is also common to the primary-secondary transition phase. It appears that despite legislative changes (USA) the adults still retain the role as an advocate role.

### **2.3 Conclusions, Implications and Development of Research Questions**

Four systematic literature searches were carried out to critically analyse the available research in the areas pertinent to this study; they are ASD, transition and self-advocacy. The implications of this will now be considered in the context of the current research and explicit links will be made to the development of the research questions addressed in the present study.

In general there has been little research carried out into understanding the transition process from primary to secondary education from the perspective of a child with an ASD. When considering how successful a transition process has been, the voice of the parents and school staff seem to have been prioritised over the voice of the child. Hill (2010) goes further in suggesting that even when

the views of the child have been elicited they are often triangulated into the views of the staff and parents resulting in a published article that gives precedence to the adults' perspectives. These views can often translate into strategies or policies pertaining to be good practice. It is unclear whether some of this is partly due to the traditional research methods being used whereby the participant with an ASD may not have theory of mind and subsequently expects the researcher to have the same knowledge of their experiences as they do; or that they find it difficult to organise information in order to give an appropriate response due to impairments in their executive functioning skills (Beresford et al., 2004). In recent years there have been moves to include the use of visual materials to counteract this effect and develop methods that fully involve participants with additional needs, such as ASD (Hill et al., 2016). In light of this, the author considered appropriate to formulate the first research question of the current study as:

**What are the experiences of the journey of transition for a child with an ASD transitioning to secondary school?**

Additionally, whilst there appears to be some common agreed themes that professional and families have adopted into their practice, e.g. planned transition experiences; there are still areas that may benefit from further exploration. The area of using self-advocacy strategies during the transition to secondary school, with children who have an ASD is one such area. There is good evidence base to support the role of self-advocacy with people with a SEND, however the research has generally been undertaken with a small number of participants who are in the latter stages of their secondary school.

Given the nature of communication difficulties associated with an ASD, the role of the researchers and their relationships with the participants could influence the data gathering. This could also explain why the views of parents have also been explored to further develop the 'bigger picture'. The perspectives of parents and children have featured in studies that are underpinned by ecosystems theory (Hannah and Topping, 2013; Tobin et al., 2012) In Dann's study (2011) she alluded to the students using some self-advocacy skills to identify what they would like from their transition which may indicate that some of these skills may be emerging without direct teaching in this area. Therefore the second research question is:

**What has been the role of advocacy or self-advocacy during their transition to secondary school?**

Having explored the literature available in the area and formulated the research questions, the next chapter will proceed to detailing the methodology used in the study.

## **CHAPTER THREE Methodology**

### **3.1 Overview of Chapter**

This chapter begins with presenting the conceptual, theoretical and epistemological framework that has driven this research. Following this, the design of the study is outlined, with an insight into the ethical considerations pertinent to this study. This includes identifying the procedures that have been used for the data collection and the methods of analysis. Finally the chapter considers the credibility and trustworthiness of the research.

### **3.2 Conceptual, Theoretical and Epistemological Framework**

The area of research is often driven by the desire to gain more knowledge and understanding of a selected process or concept. However, Willig (2008) advises that the researcher should be clear about the objectives of their research and how they aim to achieve this. Within this study the researcher acknowledges that decisions are also influenced by her beliefs about what the knowledge represents; what is 'knowable', and how this knowledge can be generated. It is this 'basic belief system or worldview' (Guba & Lincoln, 2011) that determines the paradigm from which the researcher develops his/her methodological approach and research design. Guba and Lincoln (2011) suggested five paradigms, each associated with their own ontology, epistemology and methodology (table 3.1). Ontology refers to the assumptions made about the nature of reality; whereas, epistemology infers the assumptions that are made about the relationship and interaction between the researcher's knowledge and the role of the participants. There are methods that are commonly used with the

different paradigms, however, researchers use a range of techniques to gather and analyse data.

<b>Paradigm</b>	<b>Ontology</b>	<b>Epistemology</b>	<b>Methods</b>
Positivist	Realism. There is a reality that is knowable	Objectivist. The researcher can, and should, avoid any bias or influence on the outcome. The results are true representing a definitive view of an event.	Generally uses quantitative approaches and controlled experiments.
Post- positivist	Critical realism. There is a reality, but it is not absolute	Modified objectivist. The aim is objectivity, but accept that this is not possible, therefore results are 'probably' true. The researcher observes and manipulates in a dispassionate/objective manner	Primarily uses quantitative but may also use qualitative methods. Interventionist and decontextualised.
Constructionist	Relativist. All truth is constructed by humans and is situated within a historical moment and social context. Multiple meanings can exist of the same data.	Researcher and participants are interconnected and co-construct the knowledge/meanings.	Generally qualitative with an emphasis on dialectical and contextual factors within the research. Therefore hermeneutical i.e.generates an interpretation of the meanings presented.
Transformative	Varied may include Critical theorists, participatory	The distinction between researcher and researched breaks down. Advocates for marginalised groups and has an action	Can be qualitative, or quantitative or using mixed methods. Works with individuals or

	action researchers.	agenda linked to political and social agendas e.g. oppression.	groups to empower them to challenges issues that are important to them. Uses variety of methods aimed to generate social, cultural or political change.
Pragmatic	Varied. Pragmatists are more interested in 'what works' than identifying what the 'truth' is. The assumption is made that all individuals have their own unique interpretation of reality.	Accepts that there are numerous viewpoints and works to ameliorate those perspectives through pluralistic means	Focuses on a real world problem and uses a method that they identify as appropriate including the use of mixed methods matched to the questions being asked in the research. Moves towards creating evidence to support a change in practice.

**Table 3.1** Research paradigms (created from Guba & Lincoln, 2011; Cresswell, 2014; Mertens 2015).

The author used the research paradigms above as a framework in justifying the process of developing the conceptual framework for this study. The ontological and epistemological position of the researcher is also clarified, as this has informed the methodological decision making.

### **3.2.1 Ontological Position**

The aim of the current study was to gain an understanding of how children with and ASD experience the process of transition from primary to secondary school. It is recognised that these experiences are unique to the individual child as there are a number of variables, e.g. different schools, individual needs, etc. The researcher also believed that the experiences of each child are enmeshed with the perceptions and constructs that have been shaped through interactions with members of their family and the systems that they engaged with, e.g. the schools, clubs etc. Therefore, this research is underpinned by a relativist paradigm. This ontological position or 'world view' recognises that there are multiple knowledges and that gaining an understanding of the different constructions of these knowledges helps to recognise the complexities of social phenomenon within a context (Willig, 2008). Thus it supports the view that there is no absolute truth and that 'truth' is contextual. It also recognises that the reality is not fixed and responds to changes created through life experiences and the language that is used to shape perceptions and develop concepts. With regard to the terms ASD, self-advocacy and transition, it is evident that the language and constructs associated with each term can influence the perceptions and interactional experiences of various stakeholders, which can lead to a range of interpretations of these concepts. For example, children with an ASD will have been exposed to a discourse and experiences that reflects the adults', and possibly other children's, perceptions of the diagnosis, which will influence and contribute to, how the child views themselves and the perception that they hold around their diagnosis and self-identity. The process of transition to secondary

school could also be portrayed as being positive or negative depending on the experiences and knowledge of the stakeholders. These constructs can be viewed as fluid, meaning that they may change as a result of interactions and experiences during the process.

The current research offers an exploration into how the interplay of the different constructs can affect the individuals' experiences of transitioning to a secondary school. In line with the relativist ontology and social constructionist epistemology (which is explained in the following section) held by the author, the study focused on the construction of the perceptions and concepts that are presented in the views expressed by each participant. Mertens (2015) suggested that the social constructionist paradigm moves away from pre-determining what concepts will be prioritised by the researcher and instead allows the concepts of importance to emerge from the participants during the research. The author has collaborated with the participants to represent the 'voice of the child' in an effort to co-construct an understanding of their transition process so that it can be shared to inform future practice in this area. The relationship between the researcher and the participants is explored further through the epistemology of this study, which is informed by the ontological position that has been outlined above.

### **3.2.2 Epistemology and Theory**

Research positioned within the social constructionist paradigm starts by identifying the social phenomenon that is to be explored. It is suggested that the

experience of transition is unique to the individual and could be interpreted using approaches such as; symbolic interactionism and double hermeneutics. Symbolic interactionism recognises that people make sense of the world around them through their interactions with others. This is not a fixed interpretation and is shaped through the ongoing interactions with others. Gray (2009) suggests that researchers should engage with participants by attempting to understand an action or an event from the perspective of the individual, which could include one-to-one interactions and observations in the field setting.

Hermeneutics is an approach to the analysis of data that emphasises how prior understandings and prejudices shape the interpretive process (Denzin and Lincoln, 2011). It also assumes that the 'reality' is socially constructed, indicating that the interpretations should be prioritised over explanations or descriptions of activities. In the context of this study, this could be viewed as understanding that the participants are presenting their interpretations of the transition process. Another layer of interpretation is undertaken during the data analysis, which is likely to be influenced by the knowledge and self-understanding of the researcher. This represents a double hermeneutic (Giddens, 1987) which serves to add meaning to the findings.

At this juncture the researcher has acknowledged that the design of the study rejects the view that there is an objective reality that can be determined, thus recognising that the participant's views will be unique to them. There is also an assumption that the interactive process between the researcher and the participants will be influential in the process of data collection and analysis. Mertens (2015) argues that the 'research is a product of the values of the researchers and cannot be independent of them' (Mertens, 2015, p.170).

Therefore the researcher does not claim objectivity in this research, however Guba and Lincoln (2011) suggest that this notion should be replaced by confirmability; whereby the interpretation and outcomes from the data are explicitly linked to the raw data. Within this study the participants were the 'knowers' and the researcher elicited their views by adopting a 'would-be-knower' position during the data gathering process. The interpretation of this data has been reliant on the collaboration between the researcher and the participants to create a shared meaning of the data. This has been an inductive process, whereby the researcher used the analysis of the data to generate an additional understanding of the concepts associated with the key terms used in this research.

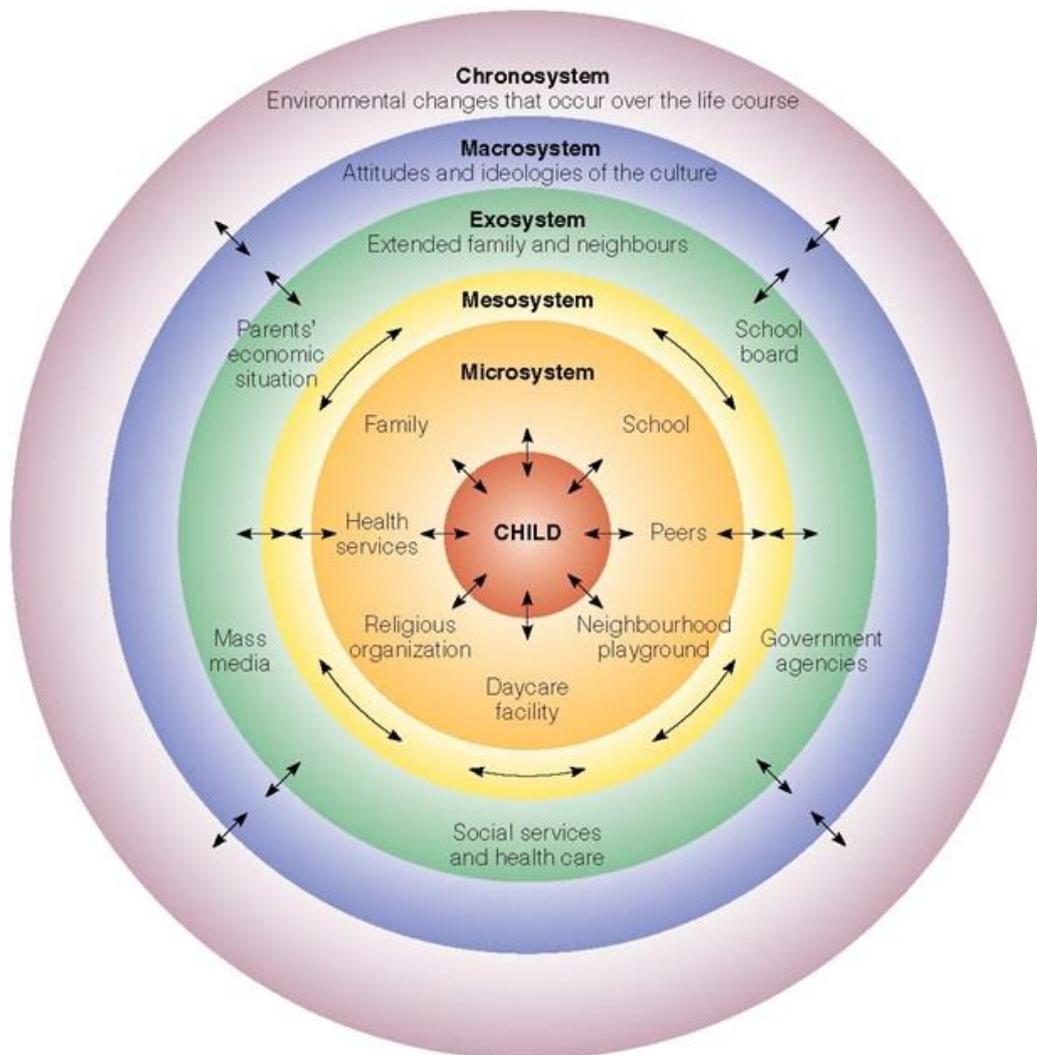
The research has drawn on the person construct psychology (PCP) theory that was developed by Kelly in the 1950s. Fundamentally Kelly (1955) suggested that people needed to be able to predict events by using constructs that have been built through previous experiences and interactions, however each of these is unique to the individual (Carver & Scheier, 2000). Positive psychology moves away from the deficit model that has been central to many of the traditional mainstream branches of psychology; with the emphasis of the approaches used in positive psychology being focused on building on success with the view to developing emotional wellbeing and resiliency (Seligman and Csikszentmihalyi, 2000; Seligman, 2002).

Transition from primary to secondary schools can prove to be a traumatic event for some children (Jindal-Snape and Miller, 2008) and therefore resiliency can

offer a framework through which transition can be conceptualised. When considering resiliency theory as a means of explanation for why some children are more able to manage a successful transition than others, it ultimately identifies features that are child centred in the context of environmental and protective factors that may be seen as influential. (Newman and Blackman, 2002). Resiliency incorporates the principles of self-advocacy theory that are interwoven throughout this research, serving to give priority to the voice of the child to determine a greater understanding of the experiences of transition, which could also influence the social constructs held by others. This includes challenging some of the constructs held by society around disabilities such as ASD and the promotion of self-advocacy within marginalised groups. The constructs held by the participants, in this study, could serve to inform the constructs held by professionals, and possibly parents, which in turn may be used to inform the process of transition.

Fox et al. (2007) argue that no knowledge is individually constructed, suggesting that that a shared meaning of a concept arises from a social construction. Bronfenbrenner (1979) recognised that the beliefs and values held by individuals is influenced by the interplay between different systems. The ecological model of child development (Bronfenbrenner, 1979) offers a framework which acknowledges that the reciprocal interactions between the multiple systems that a child experiences, thus informing the child's development. This model (Figure 1.1) illustrates complexity of the inter-relationships and systems with which a child interacts. It could be argued that the process of transition should be considered using this model as a framework

to guide an understanding around the many factors that could influence the child's experience of transition from primary to secondary school.



**Figure 1.1:** Bronfenbrenner's ecological system of child development (Rhodes, 2013)

### 3.3 Purpose of the Research

There is little published research that focuses specifically on the child's perspective of their experiences during primary to secondary school transitions

for pupils with an ASD. Therefore the main purpose of the study has been to develop the understanding and increase the knowledge around how a child with an ASD experiences transition. In addition to this the researcher has been curious to establish whether pupils with such a profile have demonstrated using any skills that could be associated with the ability to self-advocate. Polit, Beck and Hungler (2001) indicate that in areas where there is limited information available, the purpose of the study should adopt an exploratory approach, where new findings can be utilised to inform future research or practice (Robson, 2011).

The purpose of the research has influenced the design of the study which is outlined in the next section.

### **3.4 Research Design**

The systematic literature review reinforced the researcher's belief that the ASD child's voice has often marginalised in studies that claim to present findings that include the perceptions of the child (Dann, 2011). The United Nations Convention on the Rights of the Child (1989) required that adults need to facilitate giving all children, regardless of any additional needs or disabilities, the opportunity to have their views and feelings incorporated into decision making. It is reasonable to suggest that this should also be represented in research studies. However as Shier (2001) indicated, the right for children and young people to be central to discussions around issues that could influence decision making is often disregarded. There are challenges associated with eliciting the views of children and young people especially if they present with

communication difficulties or differences. Therefore the current study has been mindful in confronting these issues and has incorporated measures that have enabled the participants' views to be gathered to ensure that they can be central to this study.

The majority of the research designs, used in previous research around the area of transition for children and young people with an ASD, were either qualitative designs or they used mixed methods, i.e. a combination of qualitative and quantitative methods; with the qualitative data being used to give a greater understanding to the quantitative results. However the exploratory purpose of this study was to gain an understanding of the transition process from the child's perspective rather than to evaluate an existing transition system.

The social constructionist position held by the researcher determined that a qualitative research design was appropriate to capture the data for this study (Mertens, 2015). Qualitative research is now an established paradigm that sits within the mainstream of psychological research, offering a methodology that can generate a greater understanding of the research area. The design offered flexibility to explore concepts and perceptions when the opportunity arose. Cresswell (2014) argued that this is particularly relevant in developing an understanding of a phenomenon from a viewpoint of which there is limited research, with Willig (2008) adding that this is a means to gaining a rich understanding of the participants' experiences. Qualitative research acknowledges that personal accounts are subjective, however they are seen as providing a 'positive step towards a deeper understanding of social phenomena

and their dynamics' (Attride-Stirling, 2001, p.385). Camic, Rhodes and Yardley (2003) explain that this gives researchers the opportunity to engage with participants to explore concepts and to create new understandings for others.

### **3.4.1 Research Techniques**

Within qualitative research there are a range of techniques that can be employed to produce rich data sets. When considering which method to use, the researcher needs to identify which techniques would be most appropriate in relation to the research questions; needs of participants; time available and the purpose of the study. As a practitioner researcher, the author found it essential to create an initial framework that looked at the feasibility of the study within the constraints of the time available (see Gantt chart in appendix 6).

Following this, decisions were made about the tools that could be used to produce the rich data to answer the research questions, thus gaining insight into the experiences of transition from the perspectives of the individuals. Interviews were selected as being a means of connecting events in a meaningful way and offering an insight into the lived experiences of the participants (Hinchman & Hinchman, 1997). Interviews are commonly used in qualitative research, often as a way to qualify some of the responses given through a questionnaire that may have had a quantitative element.

Westcott and Littleton (2005) highlight that the idea of being actively listened to can be novel for many children, with many associating interactions with

professionals, such as EPs, with when something is wrong. This has been taken into account when considering an appropriate tool to support the elicitation of the participants' views. The interview is often used to develop a relationship between the participant and the researcher, in this study it aimed to minimise the potential power imbalance that may have arisen as a result of the researcher's perceived role.

### **3.4.2 Interviews to Elicit the Views of Individuals**

Interviews are a common tool used in social research (Robson, 2011) to generate rich sets of data. The aim of the current study has been to gather the views of the child and therefore it was important to use open ended questions that encouraged a free flowing set of responses. The researcher also wanted to structure the questions in order to produce sets of data that was reflective of the journey that the participants had encountered through the transition process (appendix 7). Robson (2011) suggested that a semi-structured interview could serve as a means of guiding the participant to respond to broad themed questions that could be adapted by the researcher during the interview, through the use of prompts or probes. This could be seen as a move away from more traditional qualitative methods, such as questionnaires and standardised structured interviews that use pre-constructed questions in an attempt to increase the perceived validity of such a technique. These techniques have criticised for assuming that the results are fully representative of the respondents' views rather than being an interpretation of the responses to the questions that have been posed. Houtkopp-Steenstra (2000) argued that results should be considered in the context of the interview situation with a recognition

that the results are a product of the techniques employed. Kelleet (2010) indicated that the researcher should seek to implement tools that serve to 'engender accurate accounts' (Kelleet, 2010, p. 69), the flexibility of the semi-structured interview created opportunity for the researcher to enter into a fluid dialogue that explored the concepts and perspectives that were being expressed. Thus the interviewer in this study viewed the semi-structured interview as a medium that enabled participants to communicate their views in a meaningful way to others.

In recognition of some of the social communication difficulties experienced by this cohort of children, the interviewer has been mindful of using the language of the participants as suggested by Farr (1982). However at times it was also necessary to negotiate a shared meaning of the language that is used to ensure that there was no ambiguity or misrepresentation during the data analysis. This is an essential aspect of qualitative interviewing and acknowledges that the subjectivity of these interviews can create the fluidity to explore the multiple and often conflicting perspectives that emerge from the interviews (Warren, 2001). The interview guide was designed to encourage the participants to respond to open, expansive questions. The researcher was conscious in avoiding posing leading questions that could influence the responses given by the participants, as well as phrasing questions using clear, succinct language that aimed to avoid ambiguity. The set of questions (appendix 7) acted as an aide memoire for the researcher which enabled the managing of the expectations in gathering rich data, whilst remaining focused on the research questions in this study. At times it was necessary to use prompts to encourage

the participants to articulate their views and expand on their responses. Robson (2011) advocated the use of phrases such as 'anything more?' or 'what do you think about this?', which were used at appropriate times throughout the interviews.

The use of visual supports is common in schools and in the home to assist pupils with an ASD in their communication with others and to understand what the expectations of a task is. In this study the author made available visuals, to support the participants in the processing of the information being given to them and to act as prompts to maintain their focus and engagement (appendix 13). The researcher adopted a reflexive approach to encourage the critical analysis of the procedure, striving to privilege the voice of the child. In order to achieve this, the researcher was mindful of techniques suggested by Robson (2011) who highlights that interviewers should be active listeners, pose clear straight forward questions, avoiding giving cues e.g. emphasis on certain words and leading questions, which may lead to responses that are aimed at pleasing the researcher. He also added that an effective interviewer should appear to be enjoying the process and create an environment that is conducive to developing a fluid dialogue.

Mertens (2015) argues that whilst the interview can be a positive tool to us to elicit a range and depth of information that some other methods don't, there are also risks that the amount of data can be difficult to analyse and compare. Therefore the researcher needs to ensure that the data is collected and stored in a format that allows for robust analysis. In order capture a true account of the

interviews, each of them were recorded using a digital audio recorder. In addition the researcher also made observational and contextual notes to support the analysis of the data.

### **3.5 Participants**

The study was undertaken in a LA where the researcher was on placement, with the participants being recruited from two secondary schools, one with an urban catchment area and the other one having a catchment that included rural areas. The 2011 census figures (available from the Office of National Statistics, year) indicate that diversity within this LA is less than many other areas in England; with 92.4% describing themselves as white British, compared to 79.8% as a national figure.

In order to answer the research questions the following criteria were used when selecting the participants:

- All participants had a medical diagnosis of an ASD
- All participants attended a mainstream secondary school in the LA where the research took place.
- All participants were in year 7 at the time at the interview.

Within the LA where the study was undertaken there are a number of specialist units attached to a mainstream school, where pupils have an individualised learning plan that can result in being supported in the specialist unit for much of the curriculum particularly following their transition from primary school. It was felt that this type of experience would not be typical of a pupil transitioning to a

mainstream placement and consequently schools that had a specialist unit attached acted as an exclusion criteria.

Purposive sampling was used as the aim of the research was to gain fresh perspectives around the experience of transition; Collins and Solomos (2010) add that by recruiting participants that fulfilled the criteria it could also produce a greater depth of information pertinent to the research questions. This could also be described as a convenience sampling as the recruitment of participants depended on the engagement of the secondary school SENDCos, who were invited to identify pupils, before contact was made through the parents/carers. Whilst this form of sampling may be criticised for not being representative of all pupils who met the criteria, Teddie and Yu (2007) state that this form of sampling adds to the richness and value of the data gathered which is unique to the context of the study. The researcher acknowledges that the findings will not be generalizable beyond the context of the current study. However Guba and Lincoln (2011) dispute that this is a potential weakness to a study, suggesting that this could be said of all research and their results, as are only indicative of the given context and the time of the study.

In order to recruit the participants the researcher initially contacted colleagues within the EPS to schools within the LA to inform of any potential participants that met the criteria given. This prompted the researcher to contact individual schools directly to confirm that they had pupils who fulfilled the research criteria, additional information outlining the nature and purpose of the study was also shared with the school which included a request for potential participants to be

identified by the head or the SENDCo allowing pupils to be withdrawn from lessons and facilitate the data gathering interview (appendix 8). Following this the school sent information sheets to the parents of potential participants (appendix 9) this informed them of the expectations of the study; they were also given contact details to ensure that they were able to ask for further information or clarification, prior to giving their consent for their child to be a participant in the study. Whilst there is no legal requirement to gain consent from the child participant, the researcher strongly believes that there is a moral duty informed consent to be given by the participants, particularly as this study is focused on giving the child a voice. Each participant was given a modified information sheet to explain the processes involved in the study and a consent form (appendix 10 a & b). These forms were gathered by the school and the researcher met with the staff from each school prior to the interviews taking place to ensure that there was informed consent for the participation in the study. Table 3.2 summarises the participants' details, with names presented being pseudonyms chosen by each participant, therefore maintaining anonymity and confidentiality.

<b>Participant</b>	<b>SEN status</b>	<b>Diagnosis</b>	<b>Gender</b>
Robert	EHCP	ASD & ADHD*	Male
Charlie	SEN support	Asperger Syndrome	Male
Ed	SEN Support	ASD	Male
Petal	EHCP	Asperger Syndrome	Female
John	EHCP	ASD	Male

- ADHD *Attention Deficit Hyperactivity Disorder*

**Table 3.2** Participant details

It is worth noting that the researcher was unable to establish exact numbers of pupils with a diagnosed ASD who were on role in mainstream secondary schools within this LA, as these pupils are often included in the numbers of pupils that are categorised as having additional/special educational needs or a disability.

The researcher experienced difficulty in recruiting participants, with concerns that data gathered from the five participants would not be sufficient, However the interviews produced a rich set of data for analysis, thus supporting the view of Baker et al. (2012) that it is not the number of participants, it is the quality of the data that is gathered that serves to answer the research questions within the theoretical frameworks and design of the study. In light of this the researcher believed that the number of interviews used were sufficient to develop meaningful themes and interpretations.

### **3.6 Ethical Considerations**

All research that involves people has the potential for impacting on participants in a negative or harmful way. Therefore safeguards were put in place to ensure that the research is conducted in an ethical manner with the researcher initially seeking ethical approval before the study commenced. This included consideration being given to; gaining informed consent; anonymity and confidentiality; the right to withdraw from the research; acknowledgement of any exclusion criteria; and any special consideration to protect vulnerable groups.

### **3.6.1 Protection from harm**

The researcher has been guided by the British Psychological Society (BPS) Code for Human research Ethics (2010), the Health and Care Professions Council (HCPC) Standards of Conduct, Performance and Ethics (2012) and the University Ethics Guidelines. Furthermore the research has been granted ethical approval from the ethics committee at the University of East London (appendix 11). Permission to carry out the research has also been approved by the local authority's research governance board.

The process of applying for permission and ethical approval provided a stance from which the researcher could contemplate the risks associated with human research. At the core of the research it aimed to respect the dignity and autonomy of participants, whilst accepting social responsibility and adopting scientific values. Moreover, the researcher hoped that the study could benefit the participants through developing tools that they could use or others could use to support them in communicating their views in a form that reflected their communication styles.

The researcher also recognised that there was a risk that the process of eliciting the views could evoke difficult emotions or responses that the participants may have associated with the experiences of transition. As an experienced practitioner in working with ASD children, the author took steps to safeguard the child, thus minimising the risk of emotional harm. This included creating an environment that they were comfortable to be in, adopting a non-confrontational

approach and enabling the participants to indicate if they needed to halt the process. The researcher ensured that all the participants were debriefed before returning to their school activities. In the unlikely event that this was not managed within the interview, the researcher had a contingency plan that involved signposting the parents of the participant towards accessing emotional support from local service, i.e. CAMHS Tier 2 or 3.

Consideration was also given to assessing the risk of potential harm for the researcher. The nature of the research posed minimal risk as the data collection was carried out within the participants' schools, with the knowledge of staff at the schools. The researcher was also familiar with the safeguarding policies and health and safety procedures.

### **3.6.2 Consent**

In accordance with the requirements of the BPS (2010) informed consent was given by all participants prior to any data collection taking place. The consent forms already mentioned (Appendix 9b and 10b) included highlighting to the participants that they had the right to withdraw from the study up until the point where the findings were included in the write up of the study. This was reiterated with participants at the time of the data collection interviews. The parents were also advised that they could withdraw their child's data during this period.

### **3.6.3 Anonymity and confidentiality**

The interviews and data collection took place in participants' schools, in a room with just the researcher and the participant being present. This was established that the information was being treated as confidential, however the participants were informed that any information that could put themselves or others at risk of harm would be passed on to the safeguarding officer for that school.

Following the data collection, every effort was made to anonymise information through using pseudonyms for the participants from the point of data transcription and neither the schools or the LA have been identified during the data analysis and the report writing. This information was shared with the participants before the data collection. Robson (2011) suggests that if a participant felt that they were going to be identified they may be less likely to share pertinent pieces of information. However, the researcher is aware that the data collection, in this study, has taken place within the participants' schools, which makes it possible to identify that a child has participated in the study within the context of their school, for example each participant was withdrawn from a lesson to participate in the study. It is possible that some of the participants may also have wanted recognition of their participation in the study and chose to divulge this to others.

### **3.6.4 Data Protection**

All information gathered has been stored securely digitally in an encrypted file in adherence to the UEL and local authority's data protection policy and procedure. All paper based information, such as the consent forms, have been scanned to enable

it to be stored electronically before being shredded in a confidential shredding facility in the LA. The participants were made aware that the information pertaining to the data collection will be kept three years to allow for the publication of the study.

### 3.7 Procedures

The study involved a number of stages that are outlined in table 3.3.

<b>Date</b>	<b>State of Research</b>	<b>Activity</b>
November 2015	Recruitment	Initial interest from schools via EPs.  Research area outlined with the SENDCos
May-October 2016	Recruitment	More schools contacted as the previously identified schools did not have any pupils with an ASD transitioning.  Head teacher information sent.  Consent for facilitation of the research requested.
September-October 2016	Research preparation	Design and make visual tools to support the

		elicitation of the child's views.
October – November 2016	Recruitment	Parental consent sought
November 2016	Data collection	Participants interviewed after giving consent.  Semi- structured interviews undertaken in schools where the participants attended
November-December 2016	Transcription of data	Verbatim transcriptions of the interviews produced
December 2016	Data analysis	Data analysed to generate codes and themes.

**Table 3.3** The chronology of research procedures in this study.

Researcher bias can be an issue for all research that involves people (Robson, 2011). Fox et al. (2007) state that there is an increased risk of researcher bias when research is conducted within the researcher's workplace. This study has

been undertaken to gain an understanding around the experiences of students with an ASD at the time of transition, within the LA that the researcher was on placement. In this study the researcher had made initial contact with the staff at the schools to recruit participants, however the participants were not known to the researcher prior to the day of the interviews being carried out.

Bias could also arise from the interviewer asking leading questions in order to validate their thoughts around a topic of interest. As this study has been an exploratory design it has been particularly important to minimise researcher bias and elicit the views of the participants. Thus, the researcher has attempted to maintain a neutral stance, by avoiding showing any approval or disapproval to responses given. A research diary was also kept, allowing for detailed records of the research process to be maintained, particularly following the data collection. This has allowed the researcher to reflect on any personal biases that may have arisen during the process. The data analysis was undertaken using full sets of data (transcriptions of audio recordings of all the interviews), the findings being checked by a research supervisor and through peer supervision. This ensured that the process was transparent and open to scrutiny. Throughout the study the researcher accessed regular supervision to ensure that the research was being undertaken in a manner that complied with ethical guidelines. ensuring that the study would have credibility and trustworthiness, as expected of a doctoral thesis.

### **3.8 Study**

The study comprised of five Year 7 pupils, that were recruited from two schools within a local authority in England. Following the confirmation that a school was willing to facilitate the recruitment of participants and provide a suitable area for the interviews to take place, the researcher was able to proceed with the data collection for the study.

### **3.9 Data Collection**

The data was gathered from individual interviews that were conducted during the second half of the Autumn term following the transition to secondary school (September 2016). This allowed the participants to have become accustomed to their secondary school, whilst still being able to reflect on the experience of the transition process. One school SENDCo expressed that the children had become anxious about the interviews, therefore it was agreed that the researcher would meet with them prior to the individual interviews. This enabled the researcher to develop a relationship with them, which may appeared to promote a more relaxed approach to the interviews. As a researcher it provided an insight into the range of communication levels of the individual children which led to some adaptations being made to the language used in the interviews. For example one participant took longer to process information and needed to have time to process the questions that were being asked.

The interviews were carried out in a quiet room, one that the children were familiar with, in an attempt to reduce any anxiety around the event. Prior to starting the interviews, the researcher clarified how the process would be

conducted, ensuring that the participants still consented to participating in the study. The SENDCo's from the schools had indicated that all the participants were verbal, however the researcher has had experience of children with ASD not being able to effectively communicate when anxiety levels are raised; therefore she ensured that the participants were given the tools to use if verbal communication became too difficult. This included having available a laminated card with a STOP sign and a visual representation indicating that they could leave the room at any point and the interview would cease. However these were not used by any of the participants. The children were also reassured that there were no correct or incorrect responses to the questions.

The interviews used open and broad questions to explore the participants' experiences of their transition to the secondary school. The researcher was able to conduct the interviews in a flexible manner to ensure that the participants were able to comprehend the questions and give their responses (Robson, 2011). The questions were also presented individually on laminated strips to enable the children to refer to the written question if necessary. In addition to this the researcher used a visualisation of the journey of transition that was used a reference point (appendix 13). Practically, the visual tool displayed the journey from the primary school to the secondary school, with reference being made to the time that events may have happened using a calendar. There was also drawings of people which were non-specific gender, aimed to support the participants when responding to questions that related to people that had been involved in their journeys. The use of thought and speech bubbles acted as prompts that could also be used in the process. At times

during the data collection the visuals acted as a means of maintaining focus and engagement in the interviews. Four out of the five participants used the visual materials, often to clarify a piece of information, thus enhancing a shared understanding. This in turn supported the researcher in creating an interpretation that was representative of the views of the participants.

One participant had been anxious and attended the interview with a teaching assistant (TA) who regularly supported him. He found it particularly difficult to provide detailed responses to open questions that required him to reflect on his transition experience. This interview required a differentiated approach which drew on the researcher's previous experiences in interviewing children (Greene & Hogan, 2005), which initially offered some closed question and choices with the aim of developing more fluid responses in later questions. He was also given short breaks, with the researcher taking time to re-focus him to enable him to share his experiences, thus ensuring the purpose and the underlying principles of the study were upheld.

### **3.10 Data Analysis**

Following the verbatim transcription of the recorded interviews, the researcher carried out rigorous analysis of the data. Qualitative research produces a substantial amount of data that ultimately needs to be analysed to produce an interpretation of the findings in a format that can be communicated to the reader. Robson (2011) suggests that there are three common approaches that can be used:

- Quasi- statistical approach that convert the qualitative data into a quantitative format e.g, content analysis
- Thematic coding approach where parts of the text are coded and labelled. Labels are then grouped together and themes are created.
- Grounded theory approach is a version of thematic coding with the codes representing the researcher's interpretation of the meaning or patterns in the data, thus generating a theory 'grounded' in the data.

There are also other analytic strategies that are being used that identify how the language is constructed and used e.g. discourse and narrative analysis (Wertz et al., 2011).

In determining which method of analysis to use in this study, the researcher considered adopting a narrative approach, Hiles and Cermack (2008) argue that such a method offers an inclusive and pluralistic approach, allowing researchers to draw on analyses that are helpful in answering their research questions. It was felt that for this study, the focus was on generating the 'picture' of the process of transition, rather than determining how and why the experiences served to create a narrative or a story around the event. Due to this specific research interest, and the related research questions, it was considered that thematic analysis would be an appropriate method to use for this study.

### **3.10.1 Thematic analysis**

For the purpose of this study an inductive thematic analysis was used as it was an approach that could be applied to most qualitative designs. Braun and Clarke (2006) define thematic analysis as 'a method for identifying, analysing

and reporting patterns (themes) within data' (p.6). The results can be interpreted and easily communicated to a wide audience and was seen as being appropriate to make the findings of the study accessible to the participants (Robson, 2011). By using inductive thematic analysis (Crowe, Inder & Porter, 2015) it provides an interpretation of the participants' responses, whilst still valuing their perspectives, experiences and contextual insights that will be influential in the proposed research.

There are criticisms that some research reports to be using using thematic analysis yet they do not evidence the procedure that has been followed, with little attempt being made at interpreting the findings (Boyatzis, 1998). In order to avoid this criticism being levelled at the current study, the researcher used the six stage model outlined by Braun and Clarke (2006):

#### *Phase 1- Familiarisation with the data*

The researcher was able to listen to the recordings of the interviews and read the transcripts of the interviews.

#### *Phase 2-Generating initial codes*

The researcher listed initial areas of interest that emerge from the data, before defining a suitable code. This is the first stage of analysis and starts to organise the data into meaningful groups (Tuckett, 2005). Units are then indexed, charted and mapped into analytic categories and given provisional definitions, the inductive thematic analysis results in several key themes that are data driven.

### Phase 3 –*Searching for themes*

The codes have been grouped to generate a thematic map with a view to identifying relationships between the themes.

### Phase 4 –*Reviewing themes*

At this stage the themes are clearly defined and supported with evidence from extracts of the data.

### Phase 5 –*Defining and naming themes*

The themes are labelled and individually analysed to produce the final thematic map that represents the interpretation of the views of the participants.

### Phase 6 –*Producing the report*

The findings are written up in a coherent manner that evidences the themes with sufficient data.

The use of additional memo writing also supported the analytic process and served to record themes and anomalies about the data. This included adding descriptions about the non-verbal responses, which served to give a context to the verbatim transcripts that were analysed.

The reflective diary documented the experiences of the researcher reflecting on the evolving feelings and beliefs throughout the research. In keeping such a

diary the researcher has been able to demonstrate a transparency about the study (Ortlipp, 2008). It has also enabled a critical self-reflection of the study to inform the discussion of the findings in chapter 5.

### **3.11 Credibility and Trustworthiness of the Research**

Qualitative researchers do not claim to produce studies that can be measured as having reliability or generalisability, they acknowledge their subjectivity and therefore accept that the research is evaluated by its credibility and trustworthiness. Stiles (1999) defines this as:

“How well can readers trust the methods to have adequately exposed the investigator’s ideas to empirical observations and how well can they trust the interpretations to improve people’s understanding of the phenomena that was investigated.” (Stiles, 1999, p.100).

Yardley (2000) suggests that this is essential if the findings of a study can have a practical application or benefit for an identified group of people. The aspect of credibility and trustworthiness will now be discussed within the context of the current study.

The research design means that this research cannot be re-created to replicate. This is a piece of research that considers a phenomenon in the context of when it took place. The findings are not generalizable, but this does not mean that there is not trustworthiness in the findings (Robson, 2011). There are several ways that the researcher can demonstrate trustworthiness, initially the researcher can demonstrate that there has been a prolonged commitment to developing an understanding across the area of ASD which has involved developing and evaluating interventions with children and young people in a

variety of contexts. In the current study, the researcher carried out all the interviews and became immersed in the data through repeated listening of the audio recordings and reading of the transcripts. This commitment to the data is evident of increased descriptive validity (Robson, 2011).

Another element of trustworthiness is the rigour that is applied to complete the data collection and analysis process (Yardley, 2000). The researcher was able to facilitate interviews that lasted between 35 and 55 minutes. During this time the researcher was able summarise and clarify what was being said to determine that the interpretation was one shared with the participants. This 'member checking' serves to strengthen the credibility of the research and is viewed as an important quality control process in qualitative research (Harper and Cole, 2012).

The development of an audit trail from data collection to analysis (example in appendix 14 and complete set of data analysis is available on the CD attached) are evidence that the researcher has been transparent in detailing the procedures that have been utilised (Robson, 2011). In this study the use of a peer support group and the researcher's supervisor to ensure that the analysis was trustworthy. This also minimised the risk of researcher bias that could have resulted from being directly involved with the participants. This ensured that there was coherence and transparency in that there was a consensus on how the data was interpreted. The use of thematic analysis applies a coding system that identifies themes and patterns that have emerged from the data, this was checked by a peer and research supervisor who were familiar with thematic

analysis to ascertain the credibility of the data analysis. (Elliott et al. 1999)

These findings are qualified through the use of quotes from the raw data (Yardley, 2008). In addition to this, measures have been taken to ensure that there is a clear understanding and rationale that illustrates how the findings have been reached, these include a research journal that contains a record of the research activities and reflections of the process; the raw data in audio format and transcripts; and details of the coding system and subsequent data analysis process.

### **3.11.1 Reflexivity**

Fox et al. (2007) argues that a practitioner researcher cannot be identified as being objective and that to maintain integrity and trustworthiness, the researcher has to be reflexive. This can be defined as the ability to analyse how the beliefs and values of the researcher influence the research (Finlay, 2002). The author of this study has acknowledged that the motivation for this study was an attempt to give children with ASD a voice in the decision making process around transition. This originates in the belief held that the child's voice is usually marginalised with adults' views being prioritised. However there has been a conscious effort through constant reflections throughout the research process to acknowledge the role that the researcher has played in developing the constructs represented in the findings.

The researcher remained reflexive when determining what codes were applied and that the analysis of the data did not represent the researcher's views. To ensure that the codes reflected the contents of transcripts, they were checked

by another psychologist. The reflexivity has enabled the researcher to consider some alternative interpretations of the data.

### **3.12 Summary**

This has been a small scale study that has incorporated the theoretical frameworks associated with a social constructionist's 'world view'. The overarching framework is that of ecological systems theory which considers how the development of a child is influenced by the experiences and interactions with others. The study has considered the personal constructs that have emanated from these interactions which in turn have played a part in determining whether a child has been able to develop skills that demonstrate that they have a sense of resiliency, self-determination and ultimately the ability to self-advocate.

The exploratory design of this study and the use of semi-structured interviewing techniques, has enabled the researcher to elicit the views of children with a diagnosis of an ASD, an underrepresented voice in research. The next chapter shares the findings of the study following the use of inductive thematic analysis, whereby themes have emerged from the raw data.

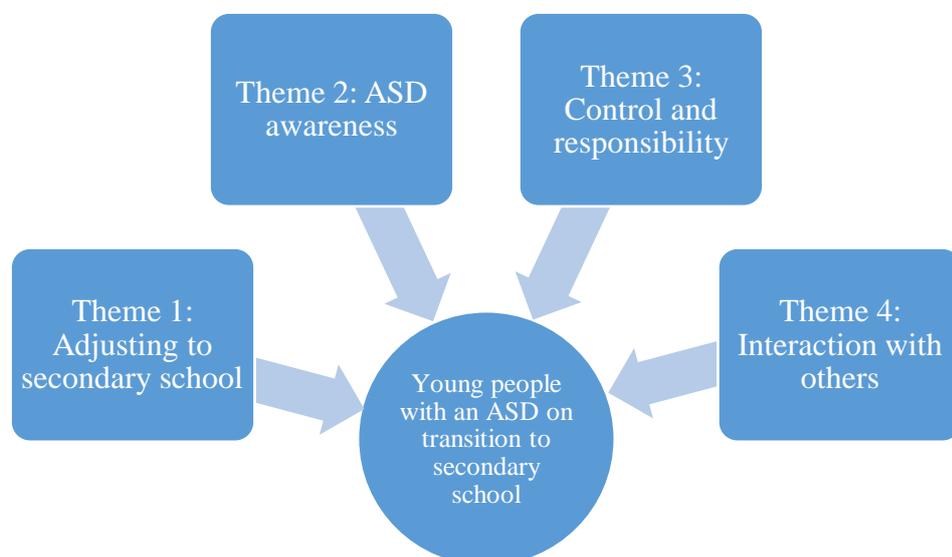
## Chapter 4: Findings

### 4.1 Overview of Chapter

The previous chapter detailed the methodology and the techniques that were used to elicit the data and analysis for this study. This chapter aims to provide an overview of the findings that have emerged following the process of thematic analysis. Thematic maps are used to provide a visualisation of the themes and subthemes that were developed using an inductive thematic analysis. In order to illustrate this further, contextual quotes and extracts, from the interviews with the participants, are used to offer a narrative that aims to support the interpretation of the data analysis.

### 4.2 Themes and Subthemes

The inductive thematic analysis process generated four themes (see fig. 4.1) and seventeen subthemes (appendix 12).

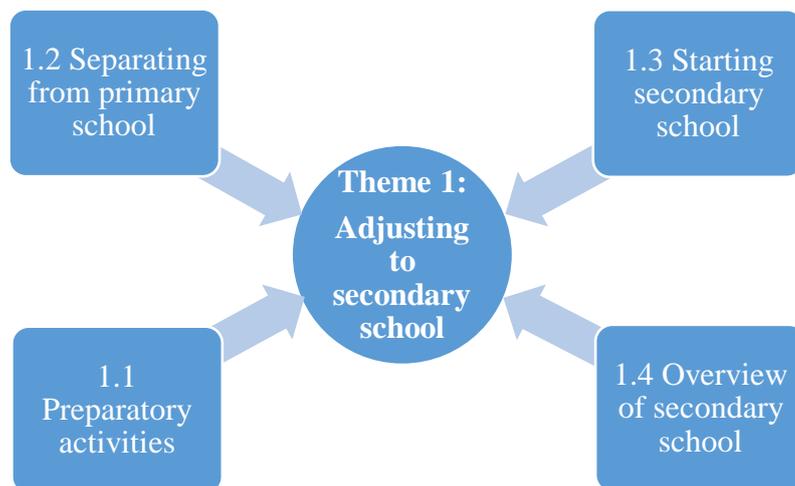


**Figure 4.1** Thematic map illustrating the four themes

The themes emerged by analysing the responses given by children with an ASD about their experiences of the transition from primary to secondary school. These themes are expanded subthemes and described in the following sections.

### 4.3 Theme 1: Adjusting to Secondary School

This theme encompassed the process of transition within the context of how it served in the adjustment to secondary school (see fig. 4.2). This included: preparing for the transition; leaving primary school and the experiences of secondary school.



**Figure 4.2** Thematic map illustrating the subthemes attached to theme 1

#### 4. 3.1 Subtheme 1.1 Preparatory Activities

The information provided by the participants suggests that the experience of transition had been an anxious period for them. There was also an

acknowledgement that their parents were also finding the transition process a worrying concept. Two of the participants indicated that these apprehensions were evident prior to the transition to secondary school, these appear to have been related to concerns stemming from their child's ASD diagnosis and associated needs. For some participants this was perceived as an area of tension when the decision about secondary school had to be made. One participant indicated that this had been resolved following a discussion with key staff at the secondary school, though without effective communication between parents and the secondary schools prior to completing the school preference form.

Researcher: *“So then when it came to umm coming to this school, how did you get the information about this school?”*

Participant: *“The information...my mum was handling a lot of the stuff and she had offered me two schools to go to... I wanted to go to X because all my friends were going and it was fun and it looked fun. My mum wasn't really fond about this decision, she wanted me to go to X and she was really scared, she was panicking, I think sometimes crying when I wasn't there. In the end when she met one of the people who helps out with Autism and Asperger's she just...got back together again. She felt so good about her decision about letting me decide what school I wanted to go to ....”*

(Petal, lines 299-311)

Another parent appeared to be concerned that the secondary school may not be equipped with the information that would ensure support for their child's needs. The parents seemed to be acting on advice of the outside agency (a local ASD charity), who supplied them with a transition booklet to complete with their child, rather than to work with the secondary school. This personal profile of the child was developed as a means to confer information to the secondary school with the aim for the school to implement the appropriate support.

Researcher: *“So what sort of things were in that booklet?”*

Participant: *“Like how do I feel and how do they know if I get sad and stuff and if I’m...and how they can help me if I’m...well how they can help me come...how they can see if what’s the matter with me or if I am angry, frustrated...where do I live and how am I and who are my friends who are coming to this school and who my friends are right now and all sorts of stuff what would help me. ...”*

*“...So then I gave it in to the school.”*

(John, lines 305 – 313 & 320)

Following the decisions being made about attending secondary school, it appears that children were involved with secondary school staff visiting the primary school and additional visits to the secondary school. Some participants visited with their parents or went with a group of peers that were perceived as needing additional support in the transition process. All of the participants had accessed additional transition activities at the secondary school before participating in the transition days with all the incoming Year seven pupils. The majority of the participants indicated that this had been a positive experience, however they also expressed having experience some conflicting emotions.

*“Well when I came on the transition day I was really excited because...even though I was really nervous moving up to Secondary school, at the same time I was really excited to see what it was like. I honestly thought it would be much bigger but no...it was pretty small...but I was fine with that. It was a pretty nice place anyway...pretty big as I have seen...bigger than my school I think...old school.”*

(Petal, lines 324-330)

The transition and transfer days were viewed as an opportunity for the children to familiarise themselves with the layout of the school and to build relationships with staff members and other peers.

*“Umm basically I was looking round the school umm teachers chatted to me and told me umm the sort of things you will be doing when you move up to high school and the main transition days were where the whole of Year 6 were there.”*

(Charlie, lines 249-253)

Gathering information about the secondary school was seen as helpful, with reference being made to information being given by family members and from activities undertaken at primary school.

Researcher: *“And...what do you think helped or didn't help...you to be how you are in school today?”*

Participant: *“Well it helped because the Year 6 teachers told me a bit about the school and err some people there that have older brothers and sisters there told me a bit about the school as well and umm some fun things you do and umm and also when I went on my transition days they told me the exact locker I will be in as well so...”*

(Charlie, lines 383- 391)

Most of the participants indicated that they had benefited from being given detailed information about the secondary school, which they shared with their parents.

*“They gave a sheet what had all the teachers' names, where everything is and then the parents and their children looked at it and seen where everything is and it showed all the teachers, the head teacher, every single teacher.”*

(John, lines 345 – 349)

The emphasis that was being placed on supporting the transition to secondary school may have contributed to some pupils finding certain aspects of primary

school challenging. One participant suggested that following the transition days, he needed support in re-engaging with activities in his primary school.

Researcher: *“And how did you feel after you had done two transition days?”*

Participant: *“The two err, after I did that, I was umm I kind of forgot where to go umm in Middle School. I kind of forgot where I was going because I have like really bad memory, so umm I just walked around. I asked some people who were in my lessons like, ‘Where do we go, I forgot and they were like, ‘Oh go to blah-di-blah-blah class 15’, something like that”*  
(Ed, lines 289 -297)

Following the preparation for the transfer to secondary school, most of the participants expressed that they were looking forward to the move, indicating that they had found the process helpful. However, one participant thought that the preparation activities had little impact on the transition process, stating that;

*“It didn’t really make a difference”*

(Robert, line 345)

#### **4.3.2 Subtheme 1.2: Separating from Primary School**

Whilst one of the participants did not know how he felt about leaving his primary school, the remaining participants experienced a range of emotions. They expressed sadness at leaving some of their friends and the staff members with whom they had positive relationships with.

*“I felt a little bit sad leaving the school because I had so much fun in Year 6 and that some people even cried and I felt a little bit sad that I had to leave the school because it was fun stuff but I thought, well there is going to be even ‘funner’ stuff there (secondary school) and then when I went into there I thought, wow and then I thought...”*

(John, lines 385 – 391)

*“Well how I said goodbye to everybody was just last moments, because the last day it was really, really, really emotional. ... I didn’t really care about High school at that point because I was too busy crying over what I was leaving behind.”*

(Petal, lines 462 -476)

Some participants viewed the summer holidays as a separation from the primary school and a time to relax, before preparing for the start at secondary school. This was also a period when the participants were apprehensive about starting at the secondary school.

*“Well I was feeling umm I sort of felt a bit nervous and sort of did... because err a side of me was thinking, ‘Oh I don’t know where to go’, ‘I might not know where to go’, ‘I might have forgot’, but then the other side of me was saying, ‘That’s what them extra transition days were for, to help you umm do things and know where to go.’”*

(Charlie, lines 297 -303)

It was evident that the parents played a key role in supporting their children in managing their emotional wellbeing. Whilst some participants saw the summer as a period when school was forgotten, some parents saw this as a time to reassure their child about the transition to secondary school.

*“Well, over the summer my parents have been getting things ready. They have been telling me that everything is going to be fine and that when I went on holiday I got a bit worried and my parents told me that and then I was okay and then when I got home I was okay.”*

(John, lines 403 -408)

*“ They umm...they just helped me and told me that everything will be okay...you will love high school, it will be nice, you get to do loads of fun lessons, fun Science experiments like...they are telling me all the good things about it...and what my family done to help me was...they mentioned it each day just so I wouldn’t forget and just...I could get a rough feeling of it when I go. So they mentioned something about the school each day.”*

(Charlie, lines 335 -343)

### 4.3.3 Subtheme 1.3: Starting Secondary School

Whilst most of the participants acknowledged that their secondary school was bigger, this was also identified as being a factor that they had anticipated finding difficult. However, it was interesting to note that, following the transition this was not perceived as being an issue by any of the participants.

Researcher: *"How was it different to your primary school?"*

Participant: *"Erm bigger."*

Researcher: *"Just bigger...yes. How much bigger was it?"*

Participant: *"A lot."*

Researcher: *"A lot bigger...okay...and how did that...what did that make you feel?"*

Participant: *"Nothing."*

(Robert, lines 54 -59)

Some participants reported that they had also anticipated having difficulties associated with homework, particularly as they were aware that non-completion could lead to a detention.

Researcher: *"What things do you think were difficult, or was there anything that was difficult?"*

Participant: *"I think what was a bit difficult, was that I was worrying about umm the homework err if any got set without me knowing and err worrying what date it was going to be due and all that sort of things."*

(Charlie, lines 485-490)

Most aspects of the expanded range of activities and subjects at secondary school was welcomed by all the participants, with some of them indicating that

drama was a new curricular area for them. Familiar subjects such as science and technology are being taught as separate subjects rather than through a topic based approach. Some of the participants had experienced or looked forward to being able to undertake experiments which they seemed to relate to being 'proper' science.

*"... we are actually doing Science."*

(Robert, line 260)

One of the positive aspects of moving to secondary school appeared to be that this reflected another stage of their development which was evidenced by the different expectations and increased responsibilities. This included being responsible for arriving at the correct lessons with the appropriate equipment. In addition to this it was reflected through being trusted in the social times at school.

*"... we actually get plates and it's like being at home that was nice because it's like you are treating us as actual elegant people ... its nice how the High school people are trusting us with actual plates. If we drop them they smash but they are trusting us because we are older children...its nice...it's like being at home."*

(Petal, lines 373 –380)

#### **4.3.4 Subtheme 1.4: Overview of Secondary School**

The participants gave a variety of reflective views on their current perceptions of secondary school. After being in the school for half a term, all of the participants indicated that generally the experience had been positive; with the exception of bullying, which is expanded further in Theme 4.

*“Umm...school is alright umm I sometimes get bullied, I sometimes don't...it depends where I am and when umm when I am...like where I am when it happens...and umm some lessons can be fun but then umm some lessons can be boring...but most of them are fun.”*

(Ed, lines 6 – 11)

*“Quite good...not a lot...nothing bad...well I had...every lesson has been great. Yesterday Drama has been good and today in lots of the lessons, everything good as well...and all the others last...for the last two months I've enjoyed it.”*

(John, lines 9-13)

*“Some lessons are pretty hard for me, yes, like Maths and Geography but I am getting there.”*

(Petal, lines 107 – 108)

Three participants initially accessed a smaller group that was regarded as a more nurturing environment for a majority of their lessons, which they felt had assisted with their adjustment to the secondary school. One pupil reflected on the experience;

*“Umm well I have moved up now because the school thought umm I had settled in now and umm if I didn't have done...if that didn't have happened to me umm and I just went up and not on that xxxx group, I wouldn't have settled in very well and umm...if that weren't for that I probably wouldn't have settled in now...I still wouldn't be settled probably.”*

(Charlie, lines 27-34)

There was recognition from two of the participants that their school was smaller than the average secondary school with one of them suggesting that the smaller environment was more suited to the needs of a pupil with an ASD.

*“I feel happy at this school...but if I went like...because this isn't like a normal average high school size...if I went to a bigger high school...because umm people that are autistic don't like big places...like a lot of noise and all that umm this is just a nice small school...its easier for me to settle into.”*

In preparation for the transition, visits to the school and transition days were seen as being a beneficial experience for all the participants, serving to familiarise the children with the setting and develop relationships with the staff who would be supporting and teaching them. This served as being positive for both participants and their parents. In addition to this, participants also found that information cascaded through activities and given to them by their parents was helpful throughout the process.

#### **4.3.5 Overview of Theme 1: Adjusting to Secondary School**

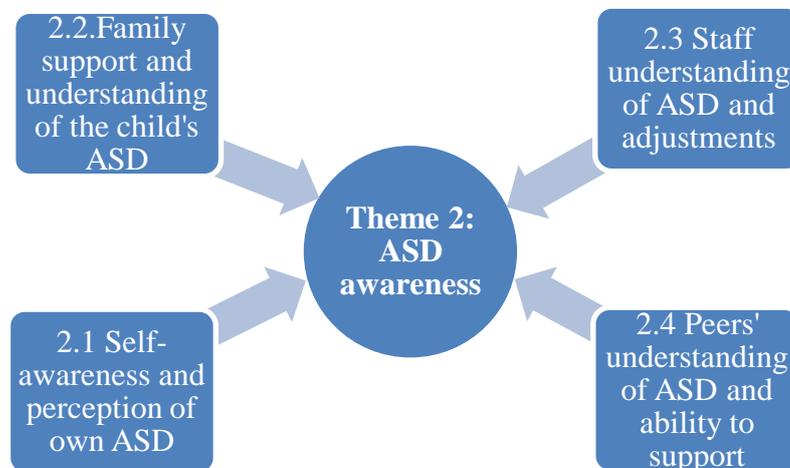
It appeared that most of the participants found the separation from primary school an emotionally challenging period, with the summer holiday being identified as a time where anxiety levels were fluctuating. The children identified their parents as the people that they went to for support and who encouraged them to focus on the positive aspects of secondary school, giving them reassurance that they would be supported in managing any difficult event, if it was needed.

It is important to note that the adjustment to secondary school caused some anxiety for most of the participants; however the move to secondary school was generally viewed as being much better than they had anticipated it to be, with all of the participants being satisfied or happy with their secondary schools after transition. Some of the students felt that being in a smaller environment was conducive to enabling them to settle into the routines of the secondary school.

The content and arrangement of the lessons at the secondary school were greeted with some enthusiasm, with reflections that being taught individual subjects enhanced the learning experience.

#### 4.4 Theme 2: ASD Awareness

Theme two details the awareness and understanding of ASD, from the perspective of the participant and their interpretation of the impact of the understanding and awareness demonstrated by others (see Figure 4.3). It encompasses four subthemes, which are described in the sections below.



**Figure 4.3** Thematic map illustrating the subthemes attached to theme 2

##### 4.4.1 Subtheme 2.1 Self-awareness and Perception of own ASD

All of the participants were aware that they had a diagnosis of an ASD, this was confirmed with them when completing the consent forms prior to the interviews. Whilst one participant made no reference to having an ASD during the interview, it was evident that the other participants associated having a diagnosis with areas of difficulty that they had or were experiencing. The

individual perceptions of what the diagnosis meant to them was varied and at times was presented as being different to what others may perceive as being reflective of an ASD. One boy describes his autism as;

*“Well, it means that there is things that...in my body that...well there’s things that I want to do but I don’t want to do, like click my finger...well sometimes it keeps crack. One time I scratched and clicked my fingers, because I keep thinking about something is on it and stuff and I have had a lot of twitches. Some twitches go but then new ones come and then when those new ones have gone the old ones come back in.”*

(John, lines 137 -145)

Some of the participants referenced to previously experiencing more difficulties, indicating that it was their autism that had “improved”. They also made comparisons to difficulties that others with a diagnosis of an ASD may have. This appeared to be based more around behavioural responses.

*“Umm...well...I am autistic and I do get in moods, like I have already said, and I put my head down like I have said. My autism is a lot better than it was umm but I don’t act too much or not as bad as some other autistic people, because my autism isn’t bad, bad.”*

(Ed, lines 467 – 471)

The discourse around having a diagnosis was problem based, however there was a recognition that there is a spectrum of needs associated with a diagnosis of an ASD.

*“I am not the only one, I know there is some other people around the world that have autism and they are not...and they have probably more problems than I do but... I know that we are both the same mostly because we both have the same thing, just different problems.”*

(Petal, lines 177 -181)

The ASD diagnosis was often viewed as the cause of the difficulties that the participants were experiencing. This was often used as a reason for behaviours that would usually have been regarded as unacceptable or inappropriate if they were exhibited by neurotypical students, with one of the participants demonstrating that the expectation was that there should be differential treatment when there is a shared knowledge of a diagnosis.

*“...I did get kicked out of the lesson one time...the teacher said I was going to get the detention but then I told her I am autistic...I can't help it. She fully understood and she got rid of my detention.”*

(Ed, lines 71 – 75)

Whilst the diagnostic label was seen as a means of explaining some of the behaviours and difficulties to others, the participants reported that having a diagnosis could also be emotionally challenging, which may impact on their mental health and emotional wellbeing.

*“ ... sometimes I get upset and cry and wish I never ever had it...and sometimes it bugs me and sometimes I just forget all about it.”*

(John, lines 133 -135)

*“ ... it's really hard to be pretty different ...”*

(Petal, line 92)

#### **4.4.2 Subtheme 2.2 Family Support and Understanding of the Child's ASD**

All of the participants indicated that they were given support by family members, particularly their parents, who they felt understood them. Some of the participants reported that their parents had shared information about ASD with them and that they had benefited from knowing more about the condition.

*“Well I think...knowing that I am not the only one with autism its making me feel pretty happy now that I am not really the only one. Because if I was the only one then everyone would just be looking at me and I would be pretty confused.”*

(Petal, lines 171-174)

There was also an indication that some parents were cautious about what information was shared with their child, aiming to reassure the child through the explanations that they were offered.

*Participant: “my umm family umm help me because they sat me down and told me all about umm what autism is about and it explains things why I have outbursts sometimes umm people bully me more and I don’t have as much friends as other children do.”*

*Researcher: “And so how did that help you? When you said mum sat you down and did that?”*

*Participant: “ ... because I knew all about it and that if you have got something wrong with you err you deserve to know about it really. But my mum didn’t really want to tell me at a younger age because she didn’t want to make me like feel like I had some sort of really bad illness, but it turns out it’s not.”*

(Charlie, lines 510 – 524)

It appeared important for the participants to feel supported by people who they perceived to have an understanding of ASD. This was often associated with the person having previous experience or links to others with an ASD.

*“ ... my mum has helped me the most umm...because also my sister is autistic ...”*

(Ed, lines 92 – 93)

*“Umm sometimes my stepdad...because he used...I think he used to...I think he sometimes teaches at this school...I don’t really know ... he teaches naughty children and autistic children and umm he gets my autism as well.”*

(Ed, lines 104 -108)

#### 4.4.3 Subtheme 2.3 Staff Understanding of ASD and Adjustments

The participants indicated that their success at school was often associated with how they were supported by the staff. Difficulties at school were often attributed to a perceived lack of knowledge or understanding about the participant's ASD.

*“Mr A, he weren't quite nice to me ... saying my autism would grow out but it's still here today. So mum got fed up that she made me move to Mr H's class and then I was happier there, calmer there and Mr H helped me ...”*

(John, lines 513 -523)

*“ ... sometimes when the teacher is speaking I can't really look at someone directly, I always look around a bit and umm once the teacher told me to umm look at the teachers, like most teachers done that, and my mum went into the school about it and said he can't help it because of his autism and then they told all the teachers that teach me that I can't help it and all that and then they err stopped telling me off for doing that.”*

(Charlie, lines 493 – 502)

Staff demonstrated that they had an understanding of ASD through activities that were seen as contributing to the participants having a positive experience of transition.

Participant: *“... one of my teachers, umm she was my Year 6 teacher and she umm she always understood err my autism ... Yes, she helped me a lot.”*

Researcher: *“And what did they do that got you ready for going to high school?”*

Participant: *“Umm...they umm always err well they always did fire drills umm at least once a month...just to see what happened, and we were always ready.”*

(Ed, lines 382 – 397)

A further indication of staff having an awareness of ASD was reflected in the perceptions of how the teachers engaged with the participants. There was also

some expectation that the staff should make adjustments to accommodate their needs that were accepted as being different to other students.

Participant: *“Well there’s a lot of teachers that understand autism and umm...well they like treat you like an autistic err child...not like a regular child...because autistic children are very different.”*

Researcher: *“So how...in what ways do they treat you differently?”*

Participant: *“Umm...they be nice to me, they umm wait for me to talk...and if they are talking and if I am about to talk they like stop and then they let me talk.”*

Researcher: *“Okay. Are they not nice to the other children?”*

Participant: *“Mmm...I mean they do that but not umm...they don’t do as much as...well they do it more with me.”*

(Ed, lines 46 – 57)

Some of the participants accessed a differentiated curriculum in a small group environment, which was seen as supporting the needs of students with an ASD.

*“Because they were very supportive, so it was... like different to all the other things that everyone else does...because you are in a smaller group and umm there is not as much children in there so it’s nice and peaceful because people that are autistic don’t like lots of noises.”*

(Charlie, lines 119-125)

#### **4.4.4 Subtheme 2.4 Peers’ Understanding of ASD and Ability to Support**

There was some indication that some participants had disclosed their diagnosis to their peers, suggesting that the peers had been accepting of some of the behaviours that may have identified the participant as being different. For some of the participants the peer support had been established in the primary school.

*“...because my friends knew that I am autistic. They have seen that I had twitches and stuff and they are okay with it.”*

(John, lines 217 – 219)

However, there were also signs that the peers were also seeking a better understanding of some of the behaviours being presented by the child with an ASD, with the possibility that there was an increased awareness of the differences as the students had grown older.

*“... there’s one friend whose little sister said why?...why?...she said that I am weird because of my twitches and stuff, so I got really stressed and angry and I said, ‘Well go tell your sister that I have autism and see how she likes it if you had autism’ and I said that to her...you see because if she...because I thought, well she wouldn’t like it if she was me so I told him to say that to his little sister and he didn’t bother.”*

(John, lines 221 – 229)

For one participant, it also appeared that some of the difficulties that they experienced with peer interactions was associated with the characteristics of his autism, making him a target for bullying.

*“... they picked on me because when I used to have the bad autism at the time umm I used to get really angry but now I have learnt how to control that.”*

(Charlie, lines 83-86)

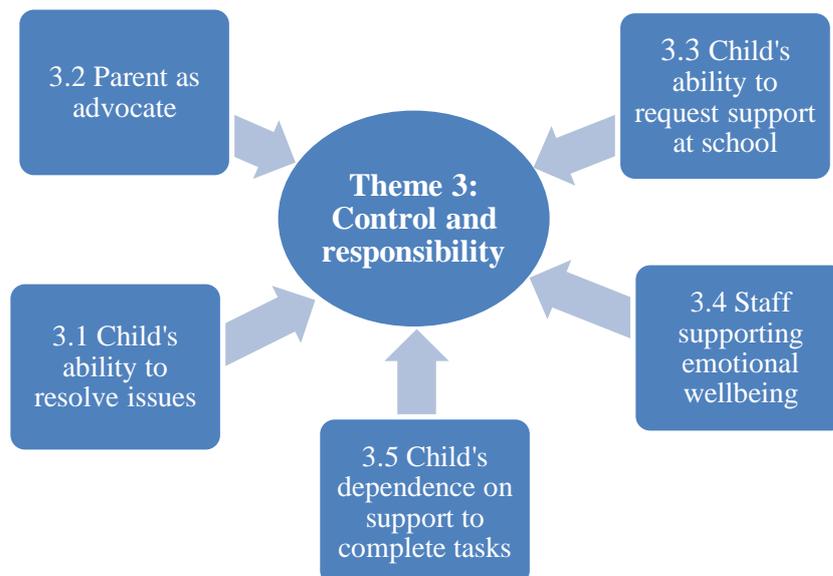
#### **4.4.5 Theme 2 Overview**

Most of the participants could offer an understanding of their ASD, this was commonly associated with a sense of being different and experiencing difficulties as a result of their diagnosis. Parents played a role in sharing an understanding of ASD with their child and the schools. There was a perception that following the knowledge of an ASD being disclosed, participants could expect to be given access to preferential treatment that in some ways was different to how neurotypical (non-ASD) students would expect to be treated; such as, not being given detentions.

In terms of peer awareness, there were indications that the traits that the participants found difficult to manage, were tolerated or accepted by their friends in the knowledge that they were seen as part of the ASD. However the participants also expressed that having an ASD could also make them vulnerable to bullying and could present them with challenges to their emotional wellbeing.

#### 4.5 Theme 3: Control and Responsibility

Throughout the transition process there are a multitude of changes; theme three is concerned with identifying the roles that the different stakeholders played during this process, with an emphasis on identifying the locus of control and responsibility within these roles. (see Figure 4.4)



**Figure 4.4** Thematic map illustrating the subthemes attached to theme 3

#### 4.5.1 Subtheme 3.1 Child's ability to resolve issues

Throughout the interviews each of the participants gave examples of how they had resolved an issue, demonstrating that there were some areas of difficulty that they could positively influence. The issues raised varied enormously, for one participant describing break time issue;

*"There was tons of seagulls that were dive-bombing me. I had to go inside and wait until the end of break and lunch because I was just getting dive-bombed."*

(Ed, lines 308 – 311)

For another child, homework was identified as being problematic and she was able to activate support from people who she felt had the appropriate skills or knowledge to assist her into complete the task.

*"Well my friends live close by me and they know how I do Maths and things, so I ask if they could come round my house and we could have a study party or something. Do all our homework together and...yes, that's what really happens. If they can't really go, I'll go and find whatever teacher that I am struggling in the subject with and ask them about things and they'll normally explain it to me and...yes."*

(Petal, lines 112 – 118)

Most of the participants indicated that peer interactions could present them with challenges with a certain sense of helplessness when this area was discussed. However for one participant he had developed a strategy that he found resolved a difficult situation in the classroom.

*"... I do sometimes sit next to people who I don't like who are my enemies and I just ignore them. If they say 'Hi' I say 'Hi'...I don't want to be rude to them...and if they are rude to me I will go to a teacher and tell them that they are being rude to me, and I will ask to move to umm a different spot."*

(Ed, lines 484 – 490)

Another example of being able to improve the learning experience was indicated by a participant who had become aware of strategies that supported him in accessing the input being given by teachers.

*“ ... when I have got something to move...like to fiddle with...I usually fiddle with my pen and listen.”*

(John, lines 583 – 585)

One participant identified with being an ‘agent of change’, however he was not able to express how he managed to do this.

Researcher: *“And who helps you then? Do any of the other adults in school maybe help you...or is it your friends...or do you just think really hard and work it out?”*

Participant: *“Just work it out.”*

(Robert, lines 478 – 480)

#### **4.5.2 Subtheme 3.2 Parent as Advocates**

Whilst the participants had been able to resolve some issues, they also identified times where they were given additional support. The participants were able to demonstrate that at times there was some reliance on their parents to act as advocates to ensure that they were supported in school.

*“ When I was moving up...through up...up there...up to primary school, my parents said that we are going to get all this sorted for you and one time my parents went to Autism XXXX , ‘I am going to see if there is anything to make it better because I am now going to High school.”*

(John, lines 484 – 489)

Many of the participants indicated that their parents resolved certain issues for them, particularly when they were perceived as being school related. Many of the participants indicated that a dialogue between the parents and staff at the schools would resolve the issue.

*“And umm she has helped me through everything and if I am getting bullied she always comes to school, tells the teachers and the teachers tell their parents to tell them to stop it and...yes, my mum’s always just been there for me.”*

(Ed, lines 98-102)

For some participants, it appeared that the parents presented themselves as the advocate, creating an expectation that they would take responsibility for remedying a situation. This was perceived as being reassuring by the participants.

*“ ... my mum she just says what she usually says, ‘if you get bullied come tell me and I will sort it out.’”*

(Ed, lines 164 – 166)

Parents were also reported to liaise with the school about creating opportunity for their child, whilst taking into account the needs of the child. These conversations were then relayed to their child.

*“My mum said to the SENCO at this school about me designing stages and things for school play...I would love to do that really because just... I mean acting, yes, acting is pretty cool but it’s tiring”*

(Petal, lines 554 – 557)

#### **4.5.3 Subtheme 3.3 Child’s Ability to Request Support at School**

It was recognised that at times some of the participants may be able to access support whilst they were at school. One participant indicated that if she had a subject or lesson related matter she could initiate support from both teachers and her peers.

*“... if I don’t get the subject, if I am doing homework, I tell my teacher, Miss xxxxx. When I am doing Geography, if I don’t get it I ask my friend M to help me”*

(Petal, lines 19 – 22)

Another participant reported that they could seek support from teachers for issues that took place out of the classroom.

*“... some children, yes they pick on me because I used to get really annoyed and angry, but then I told the teacher and the teacher sorted it out.”*

(Charlie, lines 75 – 77)

The experience of accessing support was generally positive, however one participant indicated that requesting support did not always result in positive outcome for them. However they also distinguished that this can be dependent on their relationship with the teacher, and the perceived understanding of ASD.

Participant: *“... like if I have one of the teachers that doesn’t really understand autism and they tell me umm a question I don’t really get, I usually put up my hand and say, ‘Miss (or sir) I don’t get this’ and they say it again and I say, ‘I don’t get this, can you please try change it’ and they said, ‘I have told you this too...too many times, just figure it out’”*

Researcher: *“Okay...and then how does that make you feel?”*

Participant: *“It just makes me feel frustrated and worried if I get detention.”*

(Ed, lines 229 – 239)

#### 4.5.4 Subtheme 3.4 Adults Supporting Emotional Wellbeing

All except one of the participants indicated that they had experienced a range of emotions that impacted on their emotional wellbeing during the transition process. In all these cases the adults were directly involved in replacing some of the negative thoughts with suggestions of the positive experiences the child could focus on. The participants acknowledged the role that this played in supporting their emotional wellbeing.

Participant: *“Umm...because umm I was thinking err...because my parents made me think of all the positive not all the negative because if I went in really negative err I wouldn’t have as...a much fun day because I would just think everything...everything is going to happen...it’s going to be really bad and like...not fun, but my parents told me all the good things... so I went in thinking I am going to do loads of nice things like Science experiments err cooking.”*

Researcher: *“And how has it been when you think everything is going to be nice and you thought about the good things that might happen?”*

Participant: *“It made me feel happy and it made me feel more confident to go to that school.”*

(Charlie, lines 351 – 364)

Peer interactions were highlighted as an area that could impact on the emotional wellbeing of a child with an ASD. It appeared that some of the participants relied on parental support, to assist them in making sense of the social world and how they could manage it. One participant indicated that guidance given from her mother supported her in being able to manage the social situations in an effective manner, therefore minimising the impact of difficult social interactions.

*“Well she would always give me pep talks and stuff and tell me how I talk to my friends when they annoy me and stuff.”*

(Petal, lines 187 – 188)

For one participant, the decision by his parents to buy him a puppy was regarded as a factor in helping him to manage his emotional wellbeing. His responses indicated that the physical responses to his levels of anxiety were reduced following the arrival of the puppy and the child taking responsibility for the dog's welfare.

*“That’s been making me happy and my parents thought that has been making me happy because all of...more my twitches, because my twitches haven’t been going off since my dog...all lot since my dog came into my house.”*

(John, lines 426 – 429)

For some of the participants, having a teacher with whom they could feel emotionally supported was important. One child who had expressed having a positive relationship with their year six teacher, found that when they were absent (due to ill health) the repercussions were that the child's emotional wellbeing suffered.

*“ ... because our teacher wasn't there I was just feeling depressed so I just wrote everything negative.”*

(Ed, lines 613-615)

#### **4.5.5 Subtheme 3.5 Child's Dependence on Support to Complete Tasks**

The analysis of the data, gathered through the interviews, suggested that for the majority of the participants, there was a sense of dependence on others for support to complete tasks. For some this was the parents, who they relied on to support them in school orientated activities;

*“My mum always looks on the website to see what homework I have and we always do it on the weekends”*

(Ed, lines 183 – 185)

With some of the participants it was evident that they felt that having additional support in the class was perceived as being conducive to their progress at the secondary school. One participant related the fact that they had initially been given a 1:1 support in primary school and that this person had been able to help her to maintain positive relationship with her peers. The participant indicated that there had been some dependency on the support, relating that when this support ceased it had left her feeling;

*“Alone really”*

(Petal, line 296)

The participants who had experience of the small group setting following their move to secondary school indicated that having additional support in the class improved their chances of success within the lesson.

*“And like in each lesson there is always a TA in there to help you umm if you get any stuck, but if you weren’t in Level Up its just a teacher and no TA so...that’s why it’s better in there, because you get extra support.”*

(Charlie, lines 48 – 52)

Several participants expressed an anxiety around having a detention, for one student who accepted that he had to complete the tasks that were given in the lesson, however the perception was that if he had been placed in detention for non-completion of work, that was presented in a lesson, he would be unlikely to complete it if he was not given access to support.

*“I didn’t get umm I have to do it, but like umm none of the...some of the teachers help me with it but because you are in detention you don’t really get help apparently...that’s what I have been told”*

(Ed, lines 247 – 252)

#### **4.5.6 Overview of Theme 3: Control and Responsibility**

Within this theme it was apparent that each participant felt that they were able to resolve an issue. This was usually related to an issue that was not directly linked to the learning content of a lesson, which was often perceived as being the responsibility of the staff in the lessons.

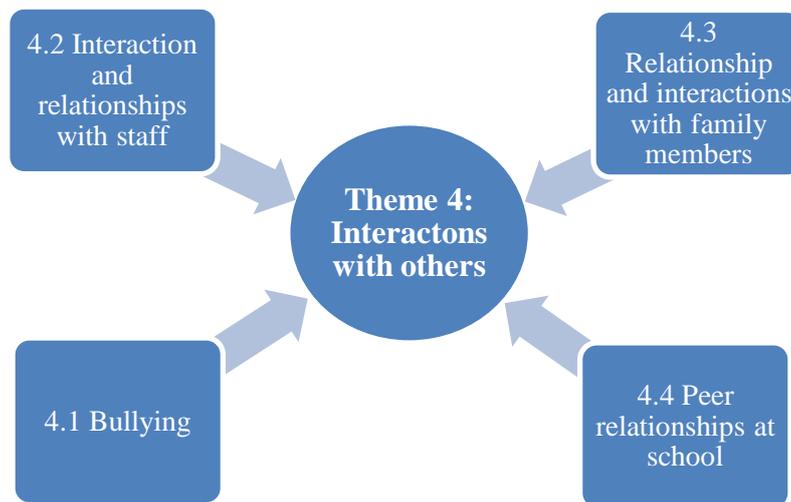
Access to additional support was perceived as contributing to enabling a student to achieve and complete the task that was given in a lesson; whereas not being able to access support was viewed as being a factor that limited successful engagement.

Parents are seen to assume the role of advocates for their child and took responsibility for their inclusion in activities within the school and liaising with staff from the school to ameliorate the difficulties that their child may be exposed to.

Value was placed on having the interactions with adults who they determined as having a positive relationship and who they perceived as being able to support them in developing a positive sense of emotional wellbeing.

#### **4.6 Theme 4: Interaction with Others**

The process of transition involves interactions with a range of people, including peers, family members and staff from the different educational settings. Theme 4 (see Figure 4.5) illustrates the subthemes that have emerged through the analysis of the data in terms of both positive and negative interactions.



**Figure 4.5** Thematic map illustrating the subthemes attached to theme 4

#### **4.6.1 Subtheme: 4.1 Bullying**

Bullying was described, by many of the participants, as being an issue throughout the primary school, which continued to be identified as an area of concern in the secondary school. Whilst it is a concept that can be difficult to define, several examples were given of targeted physical or verbal interactions which served to emotionally and/or physically hurt the some of the participants.

*Participant: "At the moment what's not so good is that every time I go out to play that there is sometimes other years say things about the size I am and some of them sometimes be rude to me and barge...and to others as well."*

Researcher: *“Okay, is there anything else you want to tell me about that?”*

Participant: *“And some of them keep on annoy...and there is two boys from another year who keeps...and they keep annoying me. Because whenever I go and like they see me...sometimes they come and annoy me...because they used to do it in primary school.”*

(John, lines 19-30)

In line with the ethics submission for this study, this specific participant was debriefed and the researcher conveyed the information to a representative from the school. The child had already reported his concerns to the pastoral head and he felt that the issues were in the process of being dealt with.

Several participants suggested that they had been or were vulnerable to being targeted as a result of behaviours that they had associated with their ASD.

*“I used to get quite angry when people used to wind me up, and I got really angry and they absolutely loved it and started laughing and like umm...because they thought that was funny umm they are doing it to me here because they...they remember from when I was at the junior school.”*

*“...they picked on me because then I used to have the bad autism.”*

(Charlie, lines 67 – 73 & 83 - 84)

Bullying was perceived to be carried out by any student, including those who were year group peers, serving to isolate the participants from potential social opportunities.

*“It’s mostly just the children...or the bigger children. Some of them are my year umm are bullying me...umm...they keep err pushing me around. I mostly just get pushed and they just run away. I try chasing but they are always too quick...and one time they kicked a football at me on purpose and it hit my face.”*

(Ed, lines 81- 87)

The effects of being bullied lead to one participant withdrawing from lessons and was impacting on his mental health.

*“Umm...I felt very depressed because I was getting bullied umm...I wasn't turning up to as many...I wasn't turning up lessons, I was turning up to lessons late...because I didn't know where to go umm...I was just feeling very 'depressed' and I err ran away.”*

(Ed, lines 552 -557)

Whilst this was a problem that was commonly reported by the participants, some of them had found that school staff had been able to resolve the issue.

*“I had a chat about my bullying and everything and she sorted it all out for me. ...”*

(Charlie, lines 93 – 95)

#### **4.6.2 Subtheme: 4.2 Interaction and Relationships with Staff**

All of the participants shared a perspective of the interactions that they had had with members of staff, from both the primary and the secondary schools. Some of the participants perceived the role of staff as being responsible for resolving issues, appearing to interact with them for this purpose, with an expectation that the staff should be able to resolve the issue. One participant indicated that he also valued the sense of fairness in resolving issues by staff at the secondary school. However this appeared to be in the context of justice and the use of punishments.

Participant: *“Well whenever I was upset the teachers always sorted it out, but when I was at the junior school they didn't really sort it out properly.”*

Researcher: *“Okay, so you are finding here...”*

Participant: "So it made me quite angry and made me feel more upset and made me *felt...forgotten.*"

Researcher: "*Oh right. So here you feel that...*"

Participant: "*Yes, like whenever something happens the punishment is good.*"

Researcher: "*Okay. So is that...that you feel that it's fair?*"

Participant: "*I feel like it is fair at this school how they punish children.*"  
(Charlie, lines 221 -232)

The organisation within primary schools usually leads to a child interacting with fewer members of staff, which in turn provides greater opportunity for relationships to develop. In high school, the relationships with key adults were highlighted as being influential in determining the ability to manage within the classroom and the wider school community. For some of the children the relationship was described as a friendship that continued beyond the time when they accessed the support in the school.

Researcher: "*Miss D, umm you said that she had helped. So how did she help with you coming...getting ready to go up to High school or going to High school?*"

Participant: "*She, you know, toughened me up umm made me laugh and stuff and I also had some other teachers. I had a 1 to 1 called Miss S...she was really nice as well. She made me stay positive, keep me calm and stuff...that was nice...to sort out my arguments with my friend D. ...I also had a 1 to 1 called Miss G who I am is still friends with now...so is my mum. I am still friends with Miss S...*"

(Petal, lines 276 – 286)

One participant recognised that interactions and the relationships with a key member of staff could influence the school environment.

*“...our Year 6 teacher had to go to the hospital because she wasn’t well. I don’t know why she wasn’t well...no one knew, but umm she was at the hospital most of the time and umm no one was really happy because she always just made people laugh and helped people when they were upset. But umm no one really...no other teachers did that...so everyone was just getting all sad and miserable.”*

(Ed, lines 587- 595)

During the initial stages of the transition to secondary school, relationships with a key adult have not been established, which could impact on the ability to support the student at this time. The findings suggest that when staff are proactive and initiate appropriate support, this is seen as helpful by the participants.

*“So when I went I was the first person there, I got really worried about my friends weren’t there until my friends came and one of the teachers came who...who he knew about my big brother...he knew that what my big brother was called so...and he was friends with my big brother so I just talked to him. I talked to him until my friends came and then I went.”*

(John, lines 262 - 269)

The extract above also suggests that when adults are able to use additional knowledge to engage with the student, it can be regarded as a positive interaction. The connection to another family member suggested that the teacher was a trusted adult. Trust was also identified as a feature in the development of the relationships with supportive adults.

Participant: *“... I always used to go to her and she used to sort it out for me...because she was someone that was really nice and I trusted”*

Researcher: *“Okay, so you had somebody that you trusted. Is there anybody in this school...so that was at junior school...what about this school?”*

Participant: *“I quite trust err my year guidance manager, Miss X, and I quite trust the nurture teacher, Miss XX, she is really nice and umm supportive. ...”*

(Charlie, lines 97 – 105)

#### **4.6.3 Subtheme: 4.3 Relationships and Interactions with Family Members**

All the participants lived with one or both of their parents and whilst societal expectations may be that families should be supportive, the findings identify some of the ways that the participants interacted with their family members.

Each participant indicated that this relationship was supportive in terms of establishing an understanding of the child’s needs and ensuring that the child is accessing support at school. Most of the participants made reference to this being related to having a diagnosis of an ASD and associated difficulties.

*“Mmm...family has helped how...nice and positive they have been to me because I have some family members that have anxiety and depression and things.”*

(Petal, lines 164 – 166)

The participants’ responses suggested that perceived difficulties dominated the interactions that they had with the family, with a focus on what others could do to support their child or their role in creating an environment that promoted their child’s wellbeing. Participants valued their parents’ support in assisting them in reducing school based anxieties around areas such as, homework tasks, peer interactions and ensuring that they had all the necessary equipment for school.

Researcher: *“... So you said that Nan helped you in the summer”*

Participant: *“Yes”*

Researcher: *“And did she...so was that to stop you worrying or to...?”*

Participant: *"Yes, stop me worrying about homework and detentions"*

Researcher: *"Okay. So were you worried about some things?"*

Participant: *"I was worried about detentions and me getting detentions affecting umm how I feel and umm I haven't got a detention yet. My mum always looks on the website to see what homework I have and we always do it on the weekends."*

(Ed, lines 174 – 185)

Several of the participants indicated that they had siblings, with some referring to older siblings for advice and information about the secondary school.

*"Umm...well my brother err he always used to come to this school and his friends did umm and him and his friends said, 'Be careful, don't talk to...or try not to talk to anybody bigger than you and don't say mean stuff to them' and umm they just said, South block, West block, East block where the classes are there and...yes that was about it. My brother and his friends told me basically where to go."*

(Ed, lines 122 - 129)

One participant who had indicated that he preferred to be in his room with little engagement with shared family activities, did not refer to his older sibling during the transition to secondary school.

Researcher: *"... did they come to this school?"*

Participant: *"I think my brother did for...I don't know...a year."*

Researcher: *"Okay...so do they still live at home?"*

Participant: *"Umm yes"*

Researcher: *"Yes? Did they tell you anything about coming to school?"*

Participant: *"No."*

(Robert, lines 204 – 209)

#### 4.6.4 Subtheme: 4.4 Peer Relationships at School

Friendships were considered to be an important factor at school. The participants identified their friends as being supportive partners in the transition from primary to secondary school.

*“ ... So when I went (to secondary school) I was the first person there, I got really worried about my friends weren't there until my friends came ...”*

(John, lines 262 – 264)

There was an acknowledgement that established friendships and newly formed friendships are an important feature of secondary school

Researcher: *“Do you think it was important to have people that you knew in school?”*

Participant: *“It's quite important, because then you know who to talk to and you know umm their personality, but it is good to have new friends.”*

Researcher: *“Okay...have you made new friends?”*

Participant: *“I have made like three or four new friends and they have helped me through school a bit.”*

(Ed, lines 455 – 462)

Maintaining friendships that had been established in primary school was often perceived to be more problematic for them than for their peers.

Researcher: *“So you are saying that friends have been helpful in different things but sometimes it's still a bit tricky?”*

Participant: *“Yes.”*

Researcher: *“And would you say that's the same for everyone or...?”*

Participant: *“Mmm...not always because everyone...most people do really want a best friend and I think I have decided to give up on trying to*

*get that 'best' friend. Because I have a friend called D who I have been friends with for long time, but she doesn't really hang out with me much. So I don't know how I could say that she is my best friend...she is a best friend but I really have multiple best friends. I don't want one particular one...I want multiple really...because if I have one, then others are going to get upset and it's just going to go all wrong."*

(Petal, lines 149-161)

For some participants their perception of the social interactions may be indicative of a lack of resiliency skills.

*"I just get nervous sometimes I...to put my hand up in class sometimes because I worry if I get it wrong and then I get worried if my classmates laugh at me...and like I just don't like that."*

(Charlie, lines 145 – 148)

#### **4.6.5 Overview of Theme 4: Interactions with Others**

All of the participants mentioned the interactions and relationships with others in terms of being supportive or contributing to negative experiences at school. The participants indicated that they had an expectation that the role of adults was to support and resolve any issues that they may have. Peer relationships were often viewed as being the most difficult to manage with some participants experiencing changes to their social groups.

The responses suggested that the participants perceived the relationships with others as a form of protection from interactions that they found difficult or felt unable to manage. Bullying was a term that featured in most of the interviews, with illustrations of physical and emotional bullying being present at both primary and secondary school.

## 4.7 Summary of Findings

Following the analysis of the data available, four themes emerged from the views of children with an ASD, concerning their transition from primary to secondary school:

- Adjusting to secondary school
- ASD awareness
- Control and responsibility
- Interactions with others

The data gathered offered rich descriptions to elaborate on the identified themes and subthemes. It is clear from the evidence that the participants have experienced challenges throughout the process, with some continuing to be confronted with difficult situations. The general view appears to reflect that this group of participants had several resources that they could draw on for support, these tended to be perceived to be in the form of people with whom they had a relationship and the expectation was that the responsibility for resolving the issues would reside with the other person. These relationships were influential in developing an understanding of the expectations of the community within the schools. However this contrasted with the evidence that some students identified that they were able to resolve issues, interestingly some of the examples given were at times where the participant did not have access to immediate adult support. This evidences a continuum of autonomy for these children.

All of the participants had a diagnosed ASD, the perception of their diagnosis was generally seen in negative terms with reference to the problems that they

perceived to accompany the label. The children also gave a sense that some of these difficulties should be viewed as a means of accessing differential treatment or activities. It appeared that the participants identified being treated differently as an indicator of the level of understanding and awareness of ASD by the adult.

The concept of bullying was evident across all the data sets, with some participants identifying that bullying had been experienced throughout their schooling. Importantly the participants also referred to having peer support with some of them indicating having friendship groups.

When the transition was considered as a whole, the process was viewed as a successful process, with all the participants indicated that secondary school was currently a positive experience for them.

These findings are further discussed in the next chapter and are considered in relation to the findings from previous associated studies, as detailed in Chapter 2.

## **Chapter 5 Discussion**

### **5.1 Overview of Chapter**

The findings outlined in chapter four are now be discussed in relation to the research questions with links to theoretical underpinnings of the study and in the context of previous research findings deliberated on in chapter two.

Following this there is a critical review of the research which identifies the strengths and the limitations of this study. This also includes the reflections and the reflexivity of the researcher to ensure that the reader is in possession of all the contextual information pertaining to this research.

### **5.2 A Review of the Research Aim and Key Findings**

The aim of this study was to gain an understanding of how students with an ASD experience the transition from primary to secondary school. The process enabled the participants to share their perspectives on the journey and to have the opportunity of having the dominant voice, in a previously marginalised arena.

The four key themes that emerged from the data, detailed in chapter four were:

- Adjusting to secondary school
- ASD awareness
- Control and responsibility
- Interaction with others

These findings have added to the understanding of students with ASD around transition to secondary school and will serve to inform others about these experiences from the perspective of the student. It is hoped that this study will aid professionals to understand how they can prepare students with an ASD for the journey of transition from primary to secondary school. These are now discussed in relation to the research questions.

### **5.2.1 Review of Research Question One Findings:**

#### ***What are the experiences of the journey of transition for a child with an ASD transitioning to secondary school?***

The rich descriptions of the transition process ensured that the researcher was given access to contextual information around the personal journeys that the children had been on, solely from their perspectives. The experiences demonstrated that the children had all participated in preparatory activities, such as additional visits to the school and building relationships with key staff, indicating that this was common practice in the primary schools. Friendships and relationships with peers were also identified as being influential in making a positive transition from primary to secondary school. The transitioning to the secondary school evoked conflicting emotions, with the most common one being labelled as worry or anxiety about how they thought they would manage in the secondary school setting, alongside excitement about the new curricular areas that they would be accessing. These were all features that were viewed as contributing to a successful transition in previous research focusing on the

primary to secondary school transition practices for ASD students (Dann, 2011; Tobin, 2012; Hannah & Topping, 2013). Dann also highlighted that this is also similar to the findings of studies with participants who do not have an ASD (Evangelou et al., 2008), indicating that all children benefit from preparatory activities that ensure that the student has information about the secondary school prior to starting. Additionally the participants discussed the role that their parents and family members had played in supporting them through the summer holidays.

Previous studies have suggested that parents are attuned to the emotional state of their child (Lewis & Porter, 2004; Whitehurst, 2007; Ware, 2004). However, the current study also indicated that the children were aware of the anxieties being experienced by their parents during the decision making about the placement and when they were liaising with schools to ensure that there was an appropriate level of support. There was evidence suggested that the parents assumed the role of advocate for their child with most of the participants indicating that their parents were the expert and that the relationship between key staff and the parents were influential factors for the successful placement of the child. It was apparent from the responses that the levels of confidence that the parents had in the school's ability to meet their child's need was also transferred to the child. In the current study these were positive, however Fortuna's study (2013) reported that when a parent advocates for a child there is a risk that parental anxiety can be transferred to the child, thus impacting on his/her emotional wellbeing.

The interview responses gave the researcher an insight into the emotional journeys that the participants had taken. This encompassed the initial decision making about which secondary school they would like to attend; the transition activities; leaving their primary school; to starting at the school in the September and beyond. All of the participants had had positive transition days, indicating that alongside the nervousness, they had felt that they knew what to expect when they joined the school. One student related that he had accessed extra days as the school had felt that he would benefit from them, thus suggesting that the secondary school were responding to the needs of individual students. By offering a person centred transition package, it is likely that the school contributed to the participant's confidence in his ability to manage at the secondary school. Jindal-Snape et al.(2006) indicated that a successful transition package created a sense of belonging to the receiving school. Research has long since recognised that a sense of belonging has positive outcomes for engagement and learning attainment ( Finn, 1989). It is likely that most children have experienced a sense of belonging with their primary school, with Anderson et al. (2000) highlighting that this is not developed when they transition to the secondary school. Sancho and Cline (2012) see this as an explanation for the impact on the emotional wellbeing and the attainment dip documented by researchers , for example Galton et al. (2003). However, one participant in this research, Petal, articulated that she had experienced inner turmoil over the developing sense of belonging to the secondary school and the guilt of feeling disloyalty towards her primary school, indicating that she had developed a sense of belonging with her secondary school. Such a finding suggests that transition activities can develop a sense of belonging to the

secondary school, furthermore it also reflects that the separation from the primary school may also need to be addressed.

The recognition of needs and an understanding of ASD was another factor that shaped the experience of transition. It was apparent that the ASD diagnosis for their child had enabled some parents to offer an explanation for a behaviour or an area of difficulty experienced by their child. Within this small group of participants, they identified with a range of features that they attributed to their ASD, these included; anger, 'twitches', sensory needs and mental health issues. The participants expressed concerns about being diagnosed, indicating the stigmatisation that can accompany having and or disclosing a diagnosis. Throughout the interviews it appeared that there was confusion about the term ASD and what this meant for the individual in the context of their unique set of circumstances. Some shared that they were autistic, whereas others defined themselves as having Asperger Syndrome. It appeared that for some they were not aware that these labels were both representative of ASD. This suggests that the participants had a limited understanding about ASD and the meaning that it held for them, this seemed to be influenced by when the child had been given or became aware of the diagnosis. It may also reflect what information the parents were able to access at this time. In the age of internet searches, there are copious amounts of information, some contradictory and others offering a cure. Therefore, there is no wonder that there is a lack of clarity and parents may have concerns about 'making a situation worse'. The Autism Education Trust (AET) suggests that for some children they can be accepting of a diagnosis which offers an explanation around why they may view things

differently to some of their peers. Alternatively, some children may resent being labelled as different others, particularly if there is a culture of homogeneity rather than developing an acceptance of diversity (Critchley, 2016). This infers that it is advisable to support a child in developing their understanding, however the current study suggests that this aspect can be overlooked, maybe partly because adults feel ill equipped to successfully manage this subject.

At times the students expressed some frustration about the apparent disregard given to the difficulties that they may be experiencing. There from was an indication that these 'problems' could be lessened if there was an increased awareness and understanding of ASD. However, an understanding appeared to be associated with being disallowed from activities rather than being enabled to access activities. The AET (2017) have described ASD as being a 'hidden disability', and as such can lead others to be sceptical about whether a difficulty is representative of a person having an ASD or is indicative of a behavioural problem of leading to a child being labelled as 'naughty' or 'disobedient'. The term ASD is commonly used and encompasses a range of difficulties that can be manifested in a variety of ways, thus making it difficult for others to recognise the needs of individuals with an ASD, particularly if the person with a diagnosed ASD does not present in a manner that is congruent with the perceptions held by others. For example, one common held belief is that children with an ASD do not give eye contact, whereas some children with an ASD are able to have appropriate eye contact during conversation. It is possible that such perceptions around ASD are a reflection of images presented by the media, or through personal experiences. However it could also be argued that for some of the

participants they were unclear about their understanding of their ASD or how to communicate their difficulties or needs to others. Despite this most of the participants were able to identify groups of people who they felt accepted and supported them. For some this was family or friends, while others suggested that teachers or key staff took this role. Dillon and Underwood (2005) indicated that parents viewed a transition as being successful when their child was accepted by their school community. The term 'accepted' is one that can generate a range of meanings, in the context of Dillon and Underwood's (2005) study, it appeared to indicate that a child was not made to feel vulnerable as a result of their difficulties. In the current study the participants used the term to reflect a feeling of safety resulting from having support from advocates.

Despite the overall positivity about the secondary school, bullying was perceived as being a long standing issue by the participants; with some indicating that bullying was an unresolved issue at their primary school which continued to be an area of concern at their secondary school. Hannah and Topping (2013) found that the majority of participants in their study felt that the incidence of bullying was less than anticipated, however this raises the question as to whether these participants had been concerned about bullying issues in the primary school and had felt that it would be worse at the secondary school; or if bullying had not been prevalent in the primary school. There is a recognised increase risk of a child with a disability being bullied, with the statistics for children and young people with an ASD being placed as high as 75% (Bancroft, 2012). This is a persistent problem and schools strive to reduce the risk of bullying occurring for all students. In the current study the participants

indicated that they felt that they were vulnerable to being targeted due to their diagnosis, particularly when they did not have a supportive peer network. There were some signs that some of the students in this study were able to access support or demonstrated that they had developed some strategies to manage these situations.

Three of the participants had initially attended a smaller class based nurturing provision, which they revealed had several students who had similar needs to themselves. This suggests that the information gathered by the secondary school during the transition process had acted as a screening tool to identify students who may benefit from additional support. The group appeared to be aimed at supporting learning needs, however, the students commented that their confidence levels had increased as a result of the additional support, thus enabling them to access the mainstream lessons. Merlone and Moran (2008) indicated that such a programme could support the child in viewing their differences in a more positive light to enable them to develop resiliency skills that leave them better equipped to deal with situations that they find challenging. This also demonstrated a humanistic approach such as the hierarchy of needs (Maslow, 1954) whereby the students developed a sense of belonging and positive self-esteem to enable them to engage in the learning (Baumeister & Leary, 1995). The participants referred to being supported by their parents and other family members, in addition to staff in both settings; indicating that this enhanced their emotional wellbeing through this period. Several children expressed their sense of loss on leaving the primary school, with a particular reference to the relationships that they held with key staff (who offered

individual support to the student). However the reinforcement of positive views about the secondary school served to support the child in managing the levels of emotions that common with the process of transition.

In general all of the participants were positive about how they had managed since arriving at their secondary school. Several participants referenced to the support of key members of staff and parents as equipping them with the skills that they have needed to manage the transition. All of the students referenced to being involved in decision making, from the choice of school to attending additional transition meetings, suggesting that they had participated in a person centred approach to their transition. The role of advocacy and self-advocacy during the process will be considered in response to the second research question.

### **5.2.2 Review of Research Question Two Findings:**

#### ***What has been the role of advocacy or self-advocacy during their transition to secondary school?***

The current study found that there was limited evidence of the participants using self-advocacy skills. There are a number of possible explanations why this was the case. Advocacy and self-advocacy could be viewed as a continuum, with the ability of self-advocacy being viewed as developmental life skill (Dryden, Desmaris and Arsenault, 2014). It is accepted that as a child typically develops

they become less dependent on the caregiver to provide everything to ensure that their basic needs are met. There is a gradual expectancy that the child will become more independent with the aim of having the necessary skills to function in adult life. The evidence in this study suggests that the adults were perceived by the children to have the locus of control and responsibility. There was an indication that this could have been associated with the adults' perception of the level of need for the child. The acknowledgement of an ASD diagnosis and how this has been constructed, appeared to influence development of advocacy and self-advocacy in the participants. One participant defined his autism as being 'bad' in the sense that he was not able to manage the difficulties without the support of his parents, which also suggests that he had limited self-determination skills. It is possible that this was reinforced through the perceptions held by his parents around the severity of his needs and their concerns about his ability to manage without their support, creating a sense of dependency (Carter et al. 2013). It also has to be recognised that earlier educational experiences may have influenced their perceptions about the school's ability to effectively support their child. This may have contributed to the assumed need for parents and supporting adults to act as advocates for the child, in the belief that they are best positioned to make decisions on the child's behalf (Green & Hill, 2010; Tobin, 2012; Fortuna, 2013). This overall assumption can prevent adults being able to acknowledge the realities of what their children are capable of understanding and achieving (Smart, 2003). Thus, by taking this position the child may have developed a sense of 'learned helplessness' (Seligman, 1972) and a self-belief that they are unable to

generate change, which in turn may have confirmed the role for the adult to become the advocate.

The indications from this study suggested that by having a diagnosed need, there was an expectation that the onus was on others within the community to make adaptations that would facilitate the inclusion of pupils with an ASD. An example of this was when Charlie's teacher stopped expecting him to give eye contact when they were talking, following the involvement of his mother, or that they should be exempt from detentions. This suggests that an integrationist approach from the advocates (Rosqvist et al., 2014), which serves to develop ways in which adaptations to the environment could be made to integrate the child. However, there were some indications, in this study, to suggest that the participants had acknowledged that they had been encouraged to take more responsibility for themselves, with less reliance on adults to initiate the support. This was aligned to the maturation in their stage of development and the expectations of the secondary school. The students reflected on experiences that they had been able to manage or ask for support. It was accepted that these were often negotiated between the student, the school and the family. However there were also some indicators to suggest that there was a growing self-awareness around how some of the participants' behaviours impacted on their interactions with others and vice versa. The findings suggest that some of the participants were aware that they could resolve some issues for themselves, such as finding a quiet area during break time. They were also able to recognise that certain emotional responses could exacerbate a situation, for example getting angry with peers or adults. This awareness had enabled them

to become agents of change, by developing strategies that they could use independently. Through the development of these strengths, the participants suggested that this had had a positive impact on their emotional wellbeing. An awareness of one's strengths and limitations are key areas of self-advocacy and self-determination, which focuses on the ability to make decisions and communicate effectively to ensure that they are able to have their needs met (Cummings, Maddux, & Casey 2000; Test, Fowler, Wood, Brewer & Eddy, 2005).

Whilst there was some evidence of a child centred approach being adopted, in line with the Children and Families Act (2014) and the SEND Code of Practice (2015), there was limited evidence of the participants' ability to self-advocate, suggesting that the adults have assumed a role as advocate for the child, alongside the expectation from the child that the adults will act as advocates.

### **5.2.3 Summary and Synthesis of Research Questions One and Two**

#### **Findings**

In order to consider the findings of the study as a whole, the following section brings together the previous sections to present a cohesive overview. In the current study the participants shared a predominantly positive experience of their transition with many of the findings replicating those of previous studies. However this was a study aimed at getting the child's perspective on the process, given that there are communication and interaction difficulties associated with having an ASD, this is a voice that has often been marginalised by the dominant discourse of parents and professionals (Hill, 2010). The

responses given in the interviews raised an awareness of the emotional aspect of the transition process, reinforcing Foulder, Hughes and Prior's (2014) suggestions that children with this type of profile are able to identify their worries, communicate them and access support to generate a resolution. Whilst it is hoped that every parent would want to support their child during the transition to secondary school, the findings indicate that having a diagnosis of an ASD added to the anxiety for the parents. Tobin et al. (2012) also came to the conclusion that the anxiety levels of the parents influenced the perceptions held by the child.

The changes that take place during transition can be considered within the framework of Bronfenbrenner's (1978) ecological model of child development. Bronfenbrenner (1999) argues that 'human development takes place through processes of progressively complex reciprocal interaction between an active, evolving biopsychological human organism and ...its' immediate environment' (p.38). Thus suggesting that the influences of these different systems, for example; the home, peers, the school, the SEND policies, the curricular requirements, etc., serve to create a unique journey for each child. This is also a framework in which to consider the role the child's characteristics play in the context of being an ASD child accessing a mainstream educational setting. The views of the children made direct references to experiences that Tobell (2003) refers to as proximal, distal and environmental. It is the synthesis of these that can determine the transition outcomes for individual children. The findings of Makin et al's. (2017) recently published study, also indicated that transition success was predominantly dependent on factors that were determined at a

systems level, arguing that a lack of preparation for the transition contributed to the difficulties experienced by the participants. This included; limited communication between the primary and or secondary schools; relationships between the families; and the schools and identity related issues whereby the staff may have not recognised the individual needs and implemented appropriate support. In the contrast to the reports from participants of the current study, the participants generally reported a negative experience of the transition process. Makin et al. (2017) recognised that in line with other studies (Dillon & Underwood, 2012) the perceived negativity could be attributed to adjusting to the routines of the new setting, thus suggesting that in time this situation would improve. Interestingly these studies included the responses from parents and children, whereas this study solely reflected the views of the children with the findings indicating a more positive view of their secondary schools.

It would appear that the diagnosis of an ASD can be regarded in terms of a pathologised condition that disadvantages an individual, needing different treatment, or it can be considered using the social model of disability, i.e. that ASD is a social construct that is made a disability through barriers created by the inrelationships between the environment and the individuals' responses to this (Shakespeare & Watson, 2001). For the participants of this study the environmental factors will have an impact on how they are able to function, however, this model appears too simplistic to assume that the all biological responses can be eradicated, it appears too idealistic to expect that an environment can be 'all things to all people'. Moreover, in line with disability theorists, such as Siebers (2008), it was evident that the group of students who

had attended the same school had developed their own identity around the diagnosis of an ASD, with each recognising differences alongside similarities of need.

This could also be viewed in terms of Kelley's (1967) covariation model of attribution theory. The majority of the participants attributed many of their difficulties to their ASDs, and their ability to operate within the school environment. Thus, suggesting that the ASD characteristics or internal attributes can be observed in a range of activities which provide external attribution to serve to create a perception or a judgement about that person. When there is a correlation of causality observed this can lead to assumptions being made about that person's functioning. In terms of transition and developing a sense of belonging to the school, attribution theory can give a perspective on why this can be a difficult period for these children. The children in this study were aware that they often found it difficult to interact with peers and adults, however it is not possible to rule out that the perspectives of others has not contributed to this.

Whilst it is important to note that the majority of participants in this study indicated that they were reliant on adults to advocate for them, they also demonstrated that they were beginning to view themselves as being causal agents in their own lives and exhibiting some self determined behaviours (Wehmeyer, 2005), thus suggesting that these skills may have been promoted by the parents and supporting professionals. The shared understanding of a child's needs, have contributed to strategies being implemented that have

reduced the barriers to inclusion within the mainstream school. The self-determination theory proposed by Deci and Ryan (2000) considered the impact of self-determination on motivation and autonomy on students' learning and education, with self-determination being defined as having the capacity to choose and having choices. In order to achieve this the three psychological needs of; competence, relatedness and autonomy have to be met. In terms of transition, competence can be perceived as being capable of meeting the demands of the school environment. Relatedness is the associated with the relationships with others such as parents, teachers and peers, who can create a sense of connectedness and belonging to the school. Finally autonomy, this includes having a self-awareness that facilitates being able to make choices in response to the demands of the environment. Research suggests that if these psychological needs are met, the student will be more motivated to learn, increase their academic performance and it will promote emotional wellbeing (Niemi & Ryan, 2009; Chirkov, 2009). However, at the point of transition from primary to secondary school, the findings from this study indicated that the focus was on having the basic needs of belonging and safety being met rather than academic achievement, these replicated the findings of Ashton's (2008) study.

In this study, most of the participants indicated that they had achieved a level of competence and felt that they were able to manage the daily activities in the secondary school, they also demonstrated that they were developing a sense of relatedness. There was limited evidence of autonomy demonstrated, however all of the participants referenced to being supported by parents, family and staff

members. Parental autonomy has been positively associated with improving educational outcomes for their children, however the majority of studies have been undertaken with neurotypical children (Joussemet, Landry & Koestner, 2008; Grolnick, Ryan & Deci (1991). Parental autonomy is seen as the bridge to a child becoming autonomous. Shea, Millea and Diehl (2013) argued that autonomy supportive teachers who promote developing independence, through structuring activities to enable mastery of skills, have increased the opportunity for the ASD child to become autonomous, thus improving the possibility of self-determinism.

In the interviews, participants alluded to experiences that had led to difficulties that had arisen from a lack of understanding, indicating that sharing information about a diagnosis often created an opportunity to resolve a situation. This included teachers adapting strategies to accommodate the learning styles of the individual, whilst recognising that there was a need to equip the students with appropriate skills to encourage them to engage with their learning. The secondary school environment promotes the development of the student becoming an independent learner, however for a child with an ASD there is a recognition that there is often a need for explicit teaching of these skills. In this study four out of the five participants openly referenced to having an ASD during the interviews and of disclosing this to some friends. Whilst the concept of ASD was varied and often lacked clarity, it appeared that being accepted by their peers could possibly lead to peers becoming advocates for the child in the school community. All of the students who participated in this study had access to additional adult support, with several having had a designated adult offering

individual support during their time at the primary school. It is possible that this could have contributed to the sense of dependency, thus restricting the development of skills to promote autonomy and independence. Using the social model of disability (Oliver, 1983) the development of self-determination and self advocacy could be promoted to increase the access to a mainstream education.

Self-advocacy is one of the skills that is required to be autonomous. The term is used to describe the ability to effectively communicate, in order to make informed decisions and take responsibility for those decisions. This requires the individual to be able to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights (Van Reusen 1998).

An awareness of strengths and limitations is viewed as one of the main concepts associated with self-advocacy. In the current study, some of the participants relayed that during the transition process they had the opportunity to comment on what their interests, likes, strengths and difficulties were, with a view to how they felt they would manage at the secondary school. However, one student indicated that his responses were influenced by how he was feeling at the time of the activity and would have responded differently had the activity been undertaken at a different time. This suggests that whilst the activity was aimed at eliciting the views of the children, it was unclear how or what the information was going to be used. It is possible that the staff may not have had the skills to ensure that the activity was an opportunity for the children to develop self-awareness and self advocacy skills at a time of transition. This is a finding of previous research that recognises that educators valued such development, but felt that they did not have adequate skills to develop this work

(Browder, Wood, Test, Karvonen, & Algozzine, 2001; Mason, Field, Sawilowsky, 2004). Lancaster, Schumaker and Deschler (2002) argued that self-advocacy should be promoted before the primary transition takes place, providing a foundation that could be continued to be built on throughout secondary education and into adult life.

Following the consideration of the findings of the current study the next section offers a critical review of the research process.

### **5.3 Critical Review of the Research**

As a practitioner researcher it is important to acknowledge what the strengths and the limitations of this study are, therefore these are addressed in the following section.

#### **5.3.1 Strengths of the Study**

The qualitative design of the study has produced a rich set of data from participants who have been underrepresented in previous research. This served to generate a deeper understanding of the experiences of transition from the perspective of children with a diagnosis of an ASD. Several studies have incorporated views or responses from children, however, the findings have often marginalised the child's views with the voice of the parents and professional dominating the discourse. (Dann, 2011; Hannah & Topping, 2013). In the current socio-political drive to be person centred, this study demonstrated that children with an ASD are able to present their views, in response to researcher's question, thus offering individual responses that may relate to

broader theoretical constructs (Onwuegbuzie and Leech, 2009). From a social constructionist position, this study offers an insight into the interplay between the systems with which the child has interacted.

The use of semi-structured interviews offered a flexible and adaptable approach to generate understanding (Robson, 2011). It enabled the researcher to build a rapport with the participants and to frame the questions in a manner that reflected the language that they used. The face-to face meetings enabled the researcher to modify the line of enquiry. In this study the purpose was to explore the views of the participants on their experience of the transition process, therefore it was appropriate to follow up on some of the responses given in order to get clarity and develop a shared understanding. One of the participants of this study, Robert, offered limited verbal responses, which meant that his non-verbal communication contributed to the interpretation of the data. The interviewer was able to probe the responses given, which served to explore areas that emerged from the process that may not have been anticipated or fully understood. As this was an exploratory study, it was important not to influence the responses and to avoid the researcher having preconceptions the information that they anticipated. Therefore, there were a small number of pre-set questions (10) which were designed to be open to avoid leading the responses.

In recognition of the social communication needs of the participants, a visual map of the journey (appendix 13) was used to assist the students in eliciting their views. This served as a resource that the interviewer could use to refer to

to ensure that she had a shared understanding with the participants; it also acted as a prompt to guide the student through the transition process. In some cases the visual supports helped to refocus the participants on the questions and give more clarity to the questioning process. For instance, following her interview, one participant, Petal, reflected that

*“Using my mind when I’ve loads of questions in my head is pretty hard; but when I have something in front of me it’s a bit easier to do things. I can point to it and project my mind or thoughts”.*

Qualitative research can be criticised for the lack of clarity in extrapolating the findings from the data set (Thomas & Harden, 2008; Boyatzis, 1998). The inductive thematic analysis approach (Braun & Clarke, 2006) firstly allowed for the themes to emerge from the responses that were given directly by the children. Secondly the process of coding and creating sub themes before the main themes were generated, offered transparency which serves to add to the trustworthiness of the study. This was also given credibility by having the analysis checked by a research supervisor who was knowledgeable in thematic analysis. In addition to this the findings are accompanied by quotes from the raw data to qualify the analysis and interpretation (Yardley, 2008). The analysis also allowed for the findings to be easily interpreted and communicated to others, including the participants.

The role of the participants can also be considered in relation to Hart’s (1992) ‘Ladder of Participation’ (see figure 5.1), which defines the level of participation in the degree to which a person is involved.

**Rung 8.** Youth initiated shared decisions with adults:  
Decision making shared between youth and adult working as equal partners

**Rung 7.** Youth initiated and directed:  
Youth led with little input from adults

**Rung 6.** Adult initiated shared decisions with youth:  
Adult led, decisions shared with youth

**Rung 5.** Consulted and informed:  
Adult led activities, in which youth may be consulted

**Rung 4.** Assigned but informed: Adult led youth understand purpose, decision making process and have a role.

**Rung 3.** Tokenism: adult led activities, youth may be consulted with minimal opportunities for feedback

**Rung 2.** Decoration: Adult led, youth understands purpose, but has no input in how it is planned.

**Rung 1.** Manipulation: adult led activities, youth is directed with no understanding of the purpose



**Figure 5.1:** Ladder of participation (adapted from Hart, 1992)

Hart (1992) argued that children's participation should be reflected by including them in decision making. In many of the earlier studies, previously reviewed in chapter 2, the voice of the child has appeared tokenistic, often being marginalised by the views of adult participants, thus suggesting (using Hart's categorisation) that the child did not take a participatory role. Whilst this study has been initiated and designed by the researcher, it is suggested that the participants were fully informed about the process at the time of giving their consent. It is also argued that the voice of the child is the dominant discourse of the findings of this study which have been shared with the participants. It is argued that the level of participation is aligned with Rung six of Hart's model. Interestingly, following the dissemination of the findings with the participants, there were indications that there was some interest in participation in future studies. It is possible that further studies with an increased level of participation

could provide an alternative perspective on why students with an ASD can often find the mainstream secondary education system so challenging.

Having considered the strengths of the current study, the following section will acknowledge where the limitations of this study lie.

### **5.3.2 Limitations of the Study**

This study employed a qualitative design with a small number of participants. The researcher makes no attempts to claim that the findings constitute an assumed understanding of the experiences and views of transition from all students with an ASD. It is recognised that the study is limited in terms of the statistical generalisability, limitation common to most qualitative studies. The findings have been based on the views gathered from a small number of participants who were recruited from two secondary schools in one local authority. Therefore the interpretations reflect the context of the policy and practice specific to this locality.

The recruitment of participants enforced the criteria for participants to have a neurodevelopmental diagnosis of an ASD and be a year 7 student who has transitioned to a mainstream secondary school. Initial discussions with EP and SENDCo colleagues indicated that the recruitment of participants would not present as an issue, however in practice this became one of the biggest challenges. There is no published data to indicate how many children had an ASD diagnosis or whether they were in mainstream education. Following the publishing of the admission lists and liaison with the primary schools, the

secondary schools reported that this was an unusual cohort with very few students with a diagnosis of an ASD. Out of the schools that responded; three secondary schools claimed that they did not have any pupils with a diagnosis of an ASD; one secondary school had one pupil who met the criteria for the study out of an intake of 240; with the remaining school identifying 6 participants who met the criteria, from an intake of 70, with 4 finally consenting to participate in the study. The reasons for the low numbers have been purely speculative and pose the questions concerning the diagnostic pathway, i.e. number of referrals, diagnostic tool being used, waiting lists, etc. Also have parents selected a school that has a specialist unit attached or have they pursued specialist provision for their child? This is a conundrum that could be another area of research in itself.

The recruitment process for the participants was reliant on the engagement of secondary schools and the support of the SENDCos. It is possible that the relationships between the parent, school and child could have influenced the consensual position of the parent and subsequently the child. It is reasonable to suggest that this may have resulted in recruitment coming from those families who had a positive relationship with the school. One of the schools initially had six participants, two withdrew before the data collection. It is possible that facilitating a meeting with parents may have offered them greater understanding of the purpose of the study. However, it was felt that the data gathered from the participants that had consented was sufficient for the design of this study. It may also have reflected how the study was initially communicated to the

parents or maybe that the parents were not generally interested in their child participating in research.

It is feasible to suggest that some pupils with an ASD may have had a different experience of transition, which may have influenced whether they were comfortable in sharing their views with a person who is unfamiliar to them. This is particularly pertinent for students who have an ASD, who have a social communication difficulty which may be compounded by any associated anxiety following a difficult period of transition. One student had felt apprehensive and requested that a member of staff sat with them during the interview; there is a possibility that this may have limited or indeed biased some of the responses (Green & Hill, 2010). The other participants met as a group, with the researcher, before the individual interviews to ensure that they were comfortable with the process.

The current study used individual, semi-structured interviews with participants to gain a greater insight and to generate a rich set of data (Wilkinson, 2003).

However, following the experience of the pre-meeting with four of the participants who had been nervous about participating in the study, it is possible that the use of focus groups may have added an alternative dimension to the findings. In the meeting with the group, it became apparent that the participants were keen to share their experiences. Initially gathering data via focus group means had been dismissed due to the nature of the social communication and interaction needs of the participants being recruited.

The use of interviews could also be criticised as being influenced by the relationship between the interviewer and the interviewee. It is important to note that the flexibility of interviews that has been highlighted as a strength could be perceived as being a limitation. For this study to be reproduced, it is unlikely that the findings would be replicated, however this could be said of a number of research studies as there are so many variables that cannot be accounted for.

The use of thematic analysis is dependent to some degree on the interpretation of the responses given to the interviewer. However some of the themes could be criticised for the fact that they were extracted from across all of the interviews and does not allow for the continuity of an individual's accounts. This could have impacted on the intended meanings (Boyatzis, 1998) from the participants. However, the researcher has made attempts to counteract this by the use of raw data quotations in the findings.

#### **5.4 Researcher Reflections and Reflexivity**

The social constructionist position taken by the researcher aimed to represent the 'truths' of the participants in a way that enabled them to be seen as the experts in their lives. From the outset of this research journey, there have been a number of challenges and learning points that have reinforced the need to adopt a reflexive approach when undertaking research. However, this has been an interesting journey of discovery particularly in the area of research design and methodology, thus raising the profile of qualitative research for the researcher. The process of carrying out the research has increased the

researcher's critical thinking around published research, which is significant as a TEP who is espousing to deliver evidence based practice.

When contemplating this area of research, there were a number of aspects that were considered, particularly as the participants were all children with a diagnosis of an ASD. Initial assumptions were that the responses may be limited by the communication difficulties. One participant was reluctant to expand his responses requiring the researcher to use many prompts, however the remaining participants were able to give much broader responses. Whilst the researcher has had a significant experience working with children and young people with an ASD and using a range of tools to elicit their views, the participants were all unknown prior to the day of the interviews. The parents and the participants had all been issued with information regarding the nature and the purpose of the study, prior to them giving consent, with four of the participants indicating that they had discussed the study with their parents and teachers from their school. Thus suggesting that the responses could have been influenced by knowledge of the data being used for the study; i.e. the Hawthorne effect (Gillespie, 1991) whereby the knowledge of being studied had an effect on the outcomes. In addition to this one participant reported that he had enjoyed being able to talk about his experience, indicating that he had felt valued that his views could contribute to a better understanding of the experience of transitioning to a secondary school.

In terms of the relationships between the participants and the researcher, there is an acknowledgement that most adults working within a school will usually be

granted a position of authority. Whilst every effort was made to redress this power imbalance in an effort to encourage the children that they were the expert in their experiences; it became clear that this was an unfamiliar experience for most of the participants, with most of the there referring to what others may have said, i.e. parents, teachers or peers. It is possible that if the participants had been recruited by a different process and the interviews had taken place away from the school that the findings may have been different.

As a practitioner who has supported students with an ASD through the transition from primary to secondary school, the researcher is aware that prior experience could have influenced her constructs around this area. It is possible that the interpretations of the findings could reflect some of her construing of the topic and be evidenced in the analysis of the data. However, the analysis and findings were scrutinised by others to minimise any researcher bias. The research diary provided a written record that was reflected on by the researcher, which was shared in supervision of the this study, in an attempt to manage any researcher bias.

The process of undertaking this study has resulted in generating more questions and potential areas for further research, which are detailed in Chapter 6. However, the researcher's initial motivation for training to become an EP was to contribute to supporting positive outcomes for children and young people. In the current socio-political climate where psychological interventions are expected to be evidence based, studies such as this could support the development of interventions and inform the practice of the EP. In recognition of

the impact of the ecological systems around the child, the findings of this study indicate that a systemic approach that enables the child's voice to be heard alongside the development of skills pertaining to self-advocacy could serve to support the inclusion of marginalised groups and enable them to be successful within a mainstream education system.

## **5.5 Summary**

This chapter has discussed the findings of the study in relation to the research questions that were posed, offering an interpretation within the context of previous research and the theoretical underpinnings of the research. The researcher has also offered a critical overview of the study in terms of methodology, which includes the credibility and trustworthiness of this study. In line with maintaining the integrity of being a practitioner researcher, the researcher has demonstrated that she has been reflexive and reflective in her practice. The methodology used in this study has made every effort to be transparent about the research process from start to finish. As with all qualitative research, there are critics that question its validity as a scientific study as its findings cannot be reproducible; however, the researcher would argue that all research involving people can only be representative of one set of data. This study offers a group of children's perspectives on their experiences of transition, with the findings arising from a rigorous analysis process.

## **Chapter 6 Conclusion**

### **6.1 Overview of Chapter**

The final chapter of this study gives a brief overview of the study, before outlining the implications for future research and the implications for EP practice. The distinctive contribution of this study is addressed before concluding with the final summary.

### **6.2 Overview of the Study**

This has been a small scale study to facilitate raising the awareness of the experiences of the primary to secondary school transition, from the perspective of the child with an ASD. The findings have confirmed some of the conclusions from previous research involving the practice of transition. Whilst each participant presented their own view of the experience there were identified commonalities that have been represented through the thematic analysis (as detailed in Chapter 4).

### **6.3 Implications for Future Research**

One of the main aims of this study was to generate a better understanding about the process of transition; despite these insights being limited by the small number of participants. It is anticipated that future research should be conducted with more participants from a more diverse range of schools. Within the LA in which the study was undertaken, there is a common thinking that there is a difference between the numbers of pupils with ASD attending mainstream primary schools and those completing mainstream secondary education. This is also mirrored by findings of the NAS. The data is not

available to indicate whether there are patterns that could be observed with many agencies offering possible hypotheses based on anecdotal evidence; therefore a longitudinal study could track students to identify where or why the 'drop out' may be happening or indeed what is taking place in schools to ensure that the students with an ASD are successful. The indicators from this study suggest that the participants, or others with a similar profile, could be well positioned to work with adults to develop a participatory action research project that may serve to inform future practice in mainstream secondary education.

The findings of this study also indicate that the teaching of self-advocacy or self-determination skills could be beneficial for ASD students and enhance their life long opportunities; several of these suggest that this should start in the primary schools, thus proposing that an intervention to support this could be evaluated for wider use. Within the LA where this research was undertaken, the ZAP anti-bullying programme has been widely delivered with positive outcomes. Many of the skills that are developed are common to self-advocacy. This may be an intervention that could be evaluated for the impact that it could have when implemented as part of the transition process with the involvement of parents.

#### **6.4 Implications for EP Practice**

From experience working as a TEP and the anecdotal evidence gained from EP colleagues, there is a significant proportion of EP time that is allocated to supporting students with an ASD to access appropriate provision. The expectation is that the majority of pupils will be supported to be integrated into a mainstream educational setting which should provide appropriate resources to

meet their needs. Therefore it is paramount that schools are equipped with the expertise to support these students. The EP is well positioned to identify where they may be training needs to be addressed through offering support directly to the schools. This training could be tailored to take into account the interplay of the systems around and within the school communities.

It would appear that the need to support the transition for students with an ASD is being considered by schools and is promoted through specialist services, the NAS and the AET. The onus is on schools to implement transition packages to support the students, however there appears to be a range of approaches that may be dependent on the available resources around the time of transition. EPs often work with groups of schools and are well positioned to support a systemic approach that could co-ordinate the available resources to effectively support pupils during their transition. This may also consider the separation from the primary school and helping the receiving secondary school understand what works for children with ASD.

There appears to be a need to support school staff in increasing their confidence in supporting students to develop self-awareness and self-advocacy skills that could then be used during transition activities. The Children and Families Act (2014) adds a greater emphasis on eliciting the child's voice and use of the person centred approaches. This can often be difficult to achieve if there is a perception that the child is unable to express their views. This study has indicated that the children were able to express themselves, but they may need to be supported in developing skills to ensure that they can do this

effectively. It is possible that such a process could involve parents, teacher and the child to ensure that all parties develop their confidence in developing self-advocacy skills to enable them to become successful adults. EPs could play a role working with schools and families to deliver programmes such as the anti-bullying programme ZAP (Kidscape) to empower the child prior to their transition to secondary school.

Following a diagnosis of an ASD, the child and their families can find it difficult to access information and support. With the phenomenal amount of information available on-line, it becomes difficult to separate fact from fiction. The evidenced based practice of EPs could offer a forum whereby the diagnosis of an ASD can be discussed in view of what this means for an individual to support them in developing a sense of identity.

Finally the current study indicates that there is a role for the EP in supporting schools in developing strategies and interventions that will reduce the risk of bullying in schools. Again this may involve working at a systemic level to ensure that this creates a cultural shift towards acceptance and tolerance of difference, as well as a good understanding of the complex profiles of children with ASD.

### **6.5 Distinctive Contribution**

This study has been solely focused on the views of transition from the perspective of the child, with the aim of giving them the dominant voice. The data gathered revealed that the participants were able to express the emotional journey that they had experienced, rather than simply focus on the transition

activities that they had engaged in. It appeared that it was the relationships and the sense of connectedness was prioritised by the participants.

The study also highlighted that the separation from the primary school was a significant event; which was centred around the ending of the relationships with key staff members. This seems to indicate that the impact of the interplay between the systems involved with students, needs to be considered in relation to developing self-advocacy tools with children to use in developing and enhancing a person centred approach to transition.

## **6.6 Summary**

Transition is recognised as being a difficult period for most children and young people, yet it is an event that all experience. Despite this transition from primary to secondary school, involving ASD is an under researched area, particularly involving children as participants. The findings indicated that the necessity to meet the basic needs of feeling safe and have a sense of belonging is crucial throughout this period. The participants indicated that their ASD diagnosis had an impact on their experience at school, suggesting that when they feel misunderstood or unsupported they are unable to have these basic needs met.

Parents played a key role as advocates for their children, therefore the relationships forged between home and school are pivotal in creating a successful transition for the child. However, most of the children in this study demonstrated that they were able to communicate their needs and valued being

listened to, thus suggesting that they could be encouraged to take a more active role in the transition process.

Whilst the current study was a small scale one, its findings suggested a possible reason why some of the children with a similar profile can find the transition to secondary school difficult. Within the LA where this study took place there appears to be a significant problem in students with an ASD not managing to maintain a successful mainstream placement; with many seeking alternative provision or home education in response to increasing difficulties or school refusal.

The participants in this study currently feel well supported in their educational settings. The challenge for schools is to maintain this and enable such students to maximise their potential alongside their neurotypical peers, equipping them with skills that enable them to lead an independent life, wherever possible. The author of this study suggests that the teaching and development of self-determination and self-advocacy skills, starting in the primary school, could support this process; thus encouraging these students to become agents of change. There is a role for the supporting adults, i.e. parents, professionals and school staff to facilitate the development of these fundamental life skills to maintain the child's emotional wellbeing.

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Table Outlining Systematic Search 1 (accessed 29.07.2016)

*Systematic search 1 for Autistic Spectrum Disorder and Transition*

<b>Key Term</b>	<b>Related Search Terms</b>	<b>Limiters</b>	<b>Narrow</b>	<b>Number of results</b>	<b>Exclusions</b>	<b>Key references found</b>
Autism Spectrum Disorder  Transition	Autism or ASD or Asperger Syndrome or Autistic Spectrum Condition Transition or Transfer	Published within the last 20 years  Peer reviewed journals	Subject age: School age 6-12 years Language: English	176	Not related to Autism Spectrum Disorder 47 Not related to school transition 94 Not related to education 10 Parental views 11 Replication including previous search 6	4

Table Outlining Systematic Search 2 (accessed 29.07.2016)

*Systematic search 2 for Transition and Self-advocacy*

Key Term	Related Search Terms	Limiters	Narrow	Expanders	Number of results	Exclusions	Key references found
Transition Self-advocacy	Transition or Transfer  Self-advocacy or Self-advocate or Person centred	Published within the last 20 years  Peer reviewed journals	Subject age: School age 6-12 years Adolescence 13-17 years Language: English	Apply related words	27	Not related to self-advocacy 3 Not related to transition 5 Not related to education 5 Not related to primary transition 12	2

**Table Outlining Systematic Search 3 (accessed 29.07.2016)***Systematic search 3 for Autistic Spectrum Disorder and self-advocacy*

<b>Key Term</b>	<b>Related Search Terms</b>	<b>Limiters</b>	<b>Narrow</b>	<b>Number of results</b>	<b>Exclusions</b>	<b>Key references found</b>
Autism Spectrum Disorder  Self-Advocacy	Autism or ASD or Asperger Syndrome or Autistic Spectrum Condition  Self-advocacy or Self-advocate or Person centred	Published within the last 20 years  Peer reviewed journals	Subject age: School age 6-12 years Adolescence 13 –17 years Language: English	8	Not related to transition or self – advocacy 2 Not Research 1 Replication including previous searches 2	3

**Table Outlining Systematic Search 4 (accessed 29.07.2016)**

*Systematic search 4 for Autistic Spectrum Disorder and Transition and self- advocacy*

<b>Key Term</b>	<b>Related Search Terms</b>	<b>Limiters</b>	<b>Narrow</b>	<b>Number of results</b>	<b>Exclusions</b>	<b>Key references found</b>
Autism Spectrum Disorder	Autism or ASD or Asperger Syndrome or Autistic Spectrum Condition	Published within the last 20 years  Peer reviewed journals	Language: English	1	None	1
Transition	Transition or Transfer					
Interventions	Strategies or best practice					

### Details of Key Research Identified for Critical Analysis

#### Details of Key Research Identified for Critical Analysis

Number	Research Area	Authors	Date	Research Title and Journal	Methodology
1	ASD & Transition	Hannah, E.F. & Topping, K.J.	2013	The transition from primary to secondary school: perspectives of students with autism spectrum disorder and their parents. <i>International Journal of Special Education</i> , 28(1), 145-160.	Mixed methods Questionnaires Interviews Content analysis 9 pupils ( all male) & 9 parents Purposive sampling
2	ASD & Transition	Foulder-Hughes, L. & Prior, C.	2014	Supporting pupils with DCD and ASD with transition to secondary school. <i>Research in Education</i> No 92	Qualitative Thematic analysis 6 participants ( 5 male, 1 female) Convenience sampling
3	ASD & Transition	Dann, R	2011	Secondary transition experiences for pupils with Autistic Spectrum Conditions (ASCs). <i>Educational Psychology in Practice</i> , Vol. 27(3) p 293-312	Qualitative Interviews ( semi-structured) Focus group interviews Thematic analysis

					6 participants, parents and key staff Purposive sampling
4	ASD & Transition	Mandy, W., Murin, M., Baykaner, O., Staunton, S., Cobb, R., Hellriege, J., Anderson, S. & Skuse, D.	2015	The transition to secondary education for children with autism spectrum disorder. Autism, Vol 20(1), Jan 2016 pp 5-13	Quantitative Longitudinal assessments using standardised questionnaires (SDQ & Becks Youth Inventories) 28 pupils (89% Male 11% female); 26 parents; 20 teachers Purposive sampling
5	Transition & Self-advocacy	Merlone, L. & Moran, D.	2008	Transition Works: Self-awareness and Self-advocacy Skills for Students in the Elementary Learning Center. Teaching Exceptional Children Plus Volume 4, Issue 4, March 2008	Mixed methods
6	Transition & Self-advocacy	Kotzer, E. & Margalit, M.	2007	Perception of competence: risk and protective predictors following an e-self-advocacy intervention for adolescents with learning disabilities. European Journal of Special	Quantitative

				Needs Education, 22(4), 443-457.	
7	ASD& Self-advocacy	Carter, E. W.; Lane, K. L.; Cooney, M.; Weir, K.; Moss, C.K., & Machalicek, W.	2013	Self-Determination among Transition-Age Youth with Autism or Intellectual Disability: Parent Perspectives. Research & Practice for Persons with Severe Disabilities 2013, Vol. 38, No. 3, 129–138	Quantitative Surveys 68parent participants Proportional stratified sampling. Invited participation
8	ASD & Self-advocacy	Rosqvist, H. B., Brownlow, C. & O'Dell, L.	2014	An Association for All'—Notions of the Meaning of Autistic Self-Advocacy Politics within a Parent-Dominated Autistic Movement. Journal of Community & Applied Social Psychology J. Community Appl. Soc. Psychol., 25: 219–231 (2015)	Qualitative Critical discourse analysis 238 papers
9	ASD & Self-advocacy	Dryden, E.M.; Desmaris, J. & Arsenault, L.	2014	Effectiveness of the IMPACT: Ability Program to Improve Safety and Self-Advocacy Skills in High School Students With Disabilities.	Mixed methods  57 participants

				Journal of School Health v84 n12 p793-801 Dec 2014. 9 pp	
10	ASD, Transition & Self-advocacy	Ciccantelli, L.A	2011	College Navigation For Students With Autism Spectrum Disorder: The Need For Advanced Preparation. Global Education Journal, Issue 2, p53-63, 11p	Qualitative, mixed methods, three case studies (Young person, parent & staff for each)

**Gantt Chart outlining initial time scales.**

Activity	Jan 16	Feb 16	Mar 16	April 16	May 16	June 16	July 16	Aug 16	Sept 16	Oct 16	Nov 16	Dec 16	Jan 17	Feb 17	Mar 17	April 17	May 17	June 17
Ethical approval UEL	█	█																
Ethical approval LA			█	█														
Literature review				█	█	█												
Consent from school					█	█	█											
Recruit participants						█	█		█									
Methodology								█	█									
Data collection										█	█							
Data analysis											█	█						
Discussion													█	█	█			
Hand in Thesis																█		
Preparation for Viva																	█	
Viva																		█

## **Interview schedule**

### **Introduction**

Thank you for coming today and agreeing to take part in my study. I am hoping that you can tell me about your experiences of leaving your primary school and coming to this school.

I am going to record what you say, so that I can listen to it again and write down what you have said, so that I can use it in my study. Remember, I won't be using your name in the study, so that the information you give will be anonymous. (Nobody will know what you have said to me)

Are there any things that you would like to ask me about before we start?

### **Questions/prompts**

1. Tell me about how school is for you now?
2. What is good now? What is good at school?
3. What is not so good for you now? What is not so good at school?
4. Are there any difficulties/ problems? Could you tell me a bit more about them?

5. What was helpful to how you are now? What things have helped you?
6. What was not helpful to how you are now? What things have been tricky/difficult?
7. Who helped you to be as you are now? (e.g. parents siblings, peers, teachers, support staff)
8. Over the summer holidays was there anything that helped/didn't help you?
9. How did you get information about the school?
10. Was there anything that you did for yourself or asked anybody to do for you?
11. When you started here how was it for you?
12. Thinking back to Year 6 What do you think helped or didn't help you to be how you are in school now?

Is there anything that I missed about what helped you move you're your primary school to here, or anything that you think is important?

XXXXXXXXXXXXXXXXXXXX.  
XXXXXXXXXXXXXXXXXXXXXXXXXXXX  
XXXXXXXXXXXXXXXXXXXXXXXXXX,  
XXXXXXXXXXXXXXXXXXXXXXXXXX,  
XXXXXXXXXXXXXXXXXXXXXXXXXX  
XXXXXXXXXXXX.



Dear Headteacher

I am a Trainee Educational Psychologist currently on placement in xxxxxxxx.

I am completing a one year research study which will form part of my professional doctorate. I am writing to ask if you would consider giving permission for any Y7 pupil who has a diagnosis of an ASD and has transitioning to your secondary school to participate in the research.

**Title of research:** The views of young people with an autism spectrum disorder on their experience of transition to secondary school.

**What is the purpose of the study?**

The purpose of the study is to give the opportunity for students with an ASD to tell me about their experiences of transition from primary to secondary school.

The information gained from the research will serve to get more information about how children, with an ASD experience the transition to secondary school. It is hoped that this will also serve to inform practice when working with other pupils who are in the same position.

**What does this research involve?**

This will involve me meeting with the students individually to get their views about transition. Such meetings are likely to last no more than one hour and will be arranged at a date and time that is least disruptive for the student's education, ideally this will be before the Christmas break and take place at school.

**How will confidentiality be protected?**

All data that I gather following the interviews will be anonymised. No names of the school, participants, people or places will be used and numbers/code names will be allocated to make sure students cannot be identified.

I will talk about my research findings with my research supervisor, but each student will be referred by code and not name.

All the information collected will be stored securely in a password protected file.

The consent forms will be stored in a locked filing cabinet in a secure location.

In accordance with the Data Protection Act all data will be kept on appropriate storage facility for ten years to allow for any potential publication of findings to take place.

**Limitations of confidentiality:**

The discussion we have with the participants will be kept confidential except if there was a disclosure that meant they or someone they know is at risk of harm or in danger. If this was to happen then I would follow the schools safeguarding policy.

**CRB check:**

We have all had recent Enhanced Criminal Record Certificate from the Disclosure and Barring Service dated 30<sup>th</sup> July 2014

**Further information:**

Participation is voluntary and fully informed consent will be gained prior to commencing the research.

**It would be of great help if you would agree for the parents of potential student participants to be contacted for this research. If so please could you let me know by the 31<sup>st</sup> October 2016**

If you have questions or comments on any aspects of this study please do not hesitate to contact me at [susan.ackerley@xxxxxxxxxx](mailto:susan.ackerley@xxxxxxxxxx)

Or my research supervisor:

[H.Bunn@uel.ac.uk](mailto:H.Bunn@uel.ac.uk)

Kind Regards

Sue Ackerley

Trainee Educational Psychologist



XXXXXXXXXXXXXXXXXXXX.  
XXXXXXXXXXXXXXXXXXXXXXXXXXXX  
XXXXXXXXXXXXXXXXXXXXXXXXXX,  
XXXXXXXXXXXXXXXXXXXXXXXXXX,  
XXXXXXXXXXXXXXXXXXXXXXXXXX  
XXXXXXXXXXXX.

Dear Parent / Carer,

I am a trainee Educational Psychologist studying at the University of East London and I work for XXXXXXXXXXXXXXXX. I would like to invite you and your child to take part in a study which will take place at your child's school.

**Title of Research:** The views of young people with an autism spectrum disorder on their experience of transition to secondary school.

**What is the study about?**

The purpose of the study is to give the opportunity for students to tell me about their experiences of transition from primary to secondary school.

The information gained from the study will serve to get more information about how children, with an ASD experience the transition to secondary school. It is hoped that this will serve to inform practice when working with pupils who are in the same position as your child.

**Why has my child been asked to participate?**

You and your child have been invited to partake in the research because your child is a Year 7 student, has a diagnosis of an Autism Spectrum Disorder (ASD) and has transitioned to a secondary school.

**What does the study involve?**

Your child will be invited to a one off meeting with me in which I will explore his/her experience of transition to their secondary school.

The meeting will take place at your child's school and will be arranged at a time so that your child will not miss any significant learning. The meeting should take no longer than 1 hour.

I will make sure that your child is happy to talk with me about his/her experiences. I would like to audio record any discussions we have with your child to enable me to accurately capture their views. The only people who will hear the tapes or see the written discussions will be my university supervisor and the viva panel. These will be transcribed for research purposes.

### **What are the benefits?**

Your child's responses will inform the researcher how they have experienced the transition process and how they felt they contributed to the process. Your child will also be given the opportunity to comment about any changes that they feel would be beneficial to other students who will also go through the experience in the future. In this way it is hoped that having the child's view will develop a better understanding about how the transition process impacts on children who have an ASD diagnosis.

### **How will my child's confidentiality be protected?**

Your child will be anonymised within the study. Pseudonyms will be used for children's name, school names or places used during the data collection and in the final report. If the study is published, I may quote some of the words that the children have used, but I will make sure that no one can be identified.

### **Limitations of Confidentiality:**

The discussion we have will be kept confidential between the participants and the researchers. However, I would have to break confidentiality if there was any information shared that meant they or someone they know is at risk of harm or in danger.

### **Data Protection:**

In accordance with the Data Protection Act all data will be kept in a secure storage facility for ten years.

### **What if I decide I no longer want my child to take part?**

Taking part in the study is voluntary. You are free to withdraw your child from the study. However, it will not be possible for me to remove your child's responses from the written report after March 15<sup>th</sup> 2017

### **What will happen to the results of the study?**

- A detailed account of the research will be written up in the form of a doctoral thesis for the University of East London.
- A short summary of the findings will be sent to your child and the school

### **CRB check:**

We have all had recent Enhanced Criminal Record Certificate from the Disclosure and Barring Service dated 30<sup>th</sup> July 2014

### **Further information:**

If you have questions or comments on any aspects of this study please do not hesitate to contact me at a Susan.ackerley@xxxxxxxxxxx

Or my research supervisor:

H.Bunn@uel.ac.uk

If you would feel that your child may wish to participate in the research, please complete the attached consent form attached by 11<sup>th</sup> November 2016 and return it to your school's SENDCO.

*Thank you for taking time to read this information sheet.*

Kind Regards

**Sue Ackerley**

Trainee Educational Psychologist

**Parental Consent Form**

**Title of Research:** The views of young people with an autism spectrum disorder on their experience of transition to secondary school.

**Name of Researcher:** Sue Ackerley

**Please read the following statements carefully and indicate Yes or No:**

I confirm I have read and understood the information sheet for the above study.	<b>Yes</b>	<b>No</b>
I consent to participating in this research	<b>Yes</b>	<b>No</b>
I give permission for my child (name)..... to take part in the above study.	<b>Yes</b>	<b>No</b>
I understand that the participation is voluntary and that they are free to withdraw before February 28th without giving a reason.  I understand it will not be possible for the researcher to remove responses from the written report after March 15th.	<b>Yes</b>	<b>No</b>
I give permission for a digital voice recorder to be used during the interviews with my child.	<b>Yes</b>	<b>No</b>
I understand I can ask the researcher questions about the research by contacting her on the email provided.	<b>Yes</b>	<b>No</b>
I understand the limitations of confidentiality. If my child tells the researchers that they or someone they know is at risk of harm or in danger they will have to report this information.	<b>Yes</b>	<b>No</b>
I agree that any data collected may be published in anonymised form in a doctoral thesis.	<b>Yes</b>	<b>No</b>

**Data Protection Act:** I understand that the data collected about my child during the participation in this study will be stored securely in a password protected file. Each participant will be given a code name from the start of the research and any files containing information about my child will be anonymous. The consent forms to be stored in a locked filing cabinet in a secure location.

In accordance with the Data Protection Act all data will be kept on appropriate storage facility for ten years.

Name of Parent:	Signature:	Date:
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## Pupil Information Sheet

Hello my name is Sue Ackerley



I am a student at the University of East London. I am training to be become an educational psychologist.

I am doing a project to understand more about what children with a diagnosis of an autism spectrum disorder (ASD) or Asperger Syndrome experience when they move to high school. I understand that you have a diagnosis and I would like to invite you to take part in the project.

Before you decide it is important that you read this carefully. If you want to be part of this project this is what will happen.

### **I will come and see you once for this project:**

- 1.) After half term I will arrange with your school to meet with you so that you can tell me about how the transition went for you.
- 2.) These discussion will be recorded and written up as an account of the session so that I can use your ideas and information. You will be able to check these to make sure that they are accurate accounts.



At any time you can ask me for the recorder to be turned off.



I will also write some things down and you will be able to see this too.

### **It is important to know...**

If you feel uncomfortable at any time you have the option to withdraw from the task or the research. I will also offer you support if you feel that the process is upsetting you.

What you tell me will be confidential. But if you tell me about anything that puts you or anybody else at risk or in danger then I will have to tell another adult.

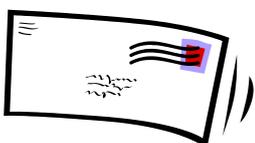


If you don't want to work with me that is fine. If we start working together but then you want to stop, that is fine to.

### **What will happen to the things you tell us?**

I will talk about some of the things you tell me in the research report.

I will not use your real name in the report, so nobody will know it was you who said the words. I will not use the name of the school.



After the project I will send you a letter explaining what I found out.

I hope that the information will be used to help the EPS to understand what young people feel that they would like from the service after key stage 2



You can ask me any questions when we are working together.

Or

You can email me at [susan.ackerley@xxxxxxxxxx](mailto:susan.ackerley@xxxxxxxxxx) to ask any questions!

**What should you do if you decide to take part in the research?**



If you do want to take part then fill in the consent form.

**Thank you!**

**Sue Ackerley**

Trainee Educational Psychologist

Participant Consent Form

**Title of the Research:** The views of young people with an autism spectrum disorder on their experience of transition to secondary school.

Please read the following statements carefully and tick **yes** or **no**:

	Yes	No
I confirm I have read and understand the information sheet for the research project.		
I would like to take part in this project.		
 I understand and agree that my interview can be digitally recorded		
I understand I do not have to answer any questions I do not want to.		
 I understand that I can ask the researcher questions about the project at any time.		
 I understand I can stop working with the researchers at any time without giving a reason and this is OK.		
I understand that no one will know who I am through the research because my name will not appear in the report or the name of the school.		
If I tell the researcher that I or someone I know is getting hurt or is danger they will have to let someone know.		
The digital recordings and writings from the research will be stored in a safe place for ten years, then destroyed		

Name:	Signature:	Date:
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**School of Psychology Research Ethics Committee**

**NOTICE OF ETHICS REVIEW DECISION**

**For research involving human participants**

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**REVIEWER:** Melanie Spragg

**SUPERVISOR:** Helena Bunn

**COURSE:** Professional Doctorate in Educational and Child Psychology

**STUDENT:** Susan Ackerley

**TITLE OF PROPOSED STUDY:** The stories of Year 7 students with an autism spectrum disorder who used self-advocacy strategies during their transition to secondary school

**DECISION OPTIONS:**

- 1. APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
- 2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
- 3. NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY**

*(Please indicate the decision according to one of the 3 options above)*

Approved
----------

**Minor amendments required** *(for reviewer):*

--

**Major amendments required** *(for reviewer):*

--

**ASSESSMENT OF RISK TO RESEACHER** *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

MEDIUM

LOW

*Reviewer comments in relation to researcher risk (if any):*

**Reviewer):** *Dr Melanie Spragg*

**Date:** 01/03/2016

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**Confirmation of making the above minor amendments (for students):**

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*):

Student number:

Date:

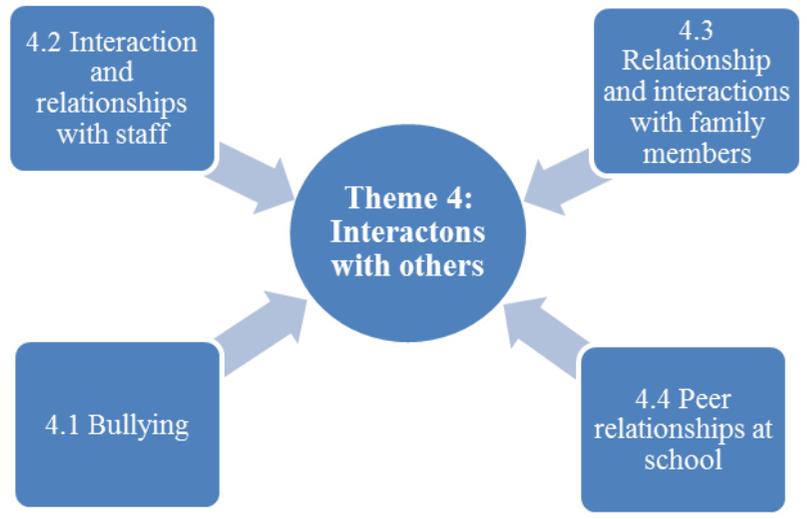
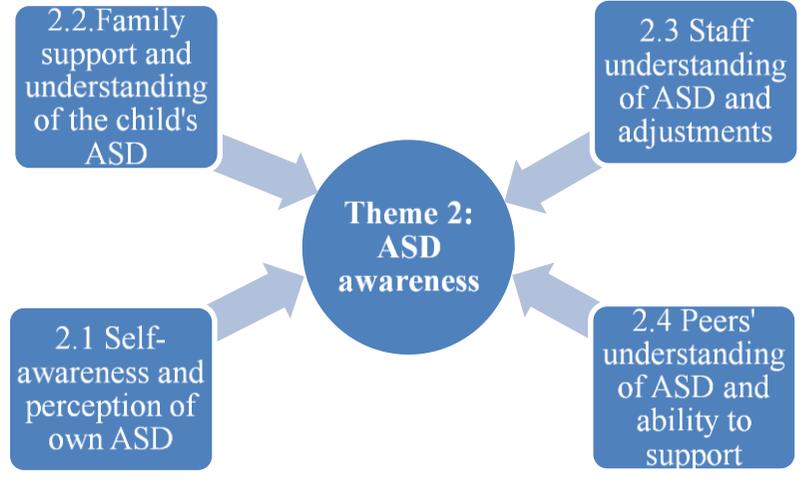
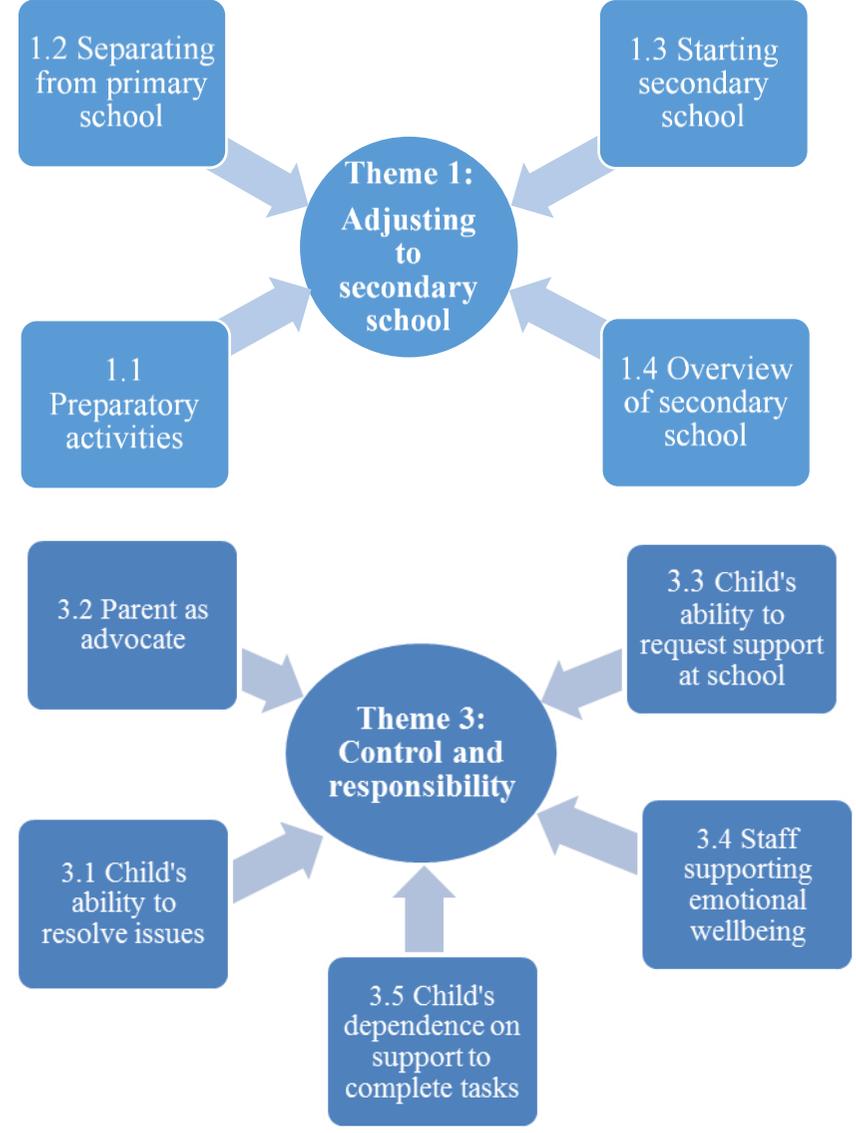
*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**PLEASE NOTE:**

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: <http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

**Appendix 12** Thematic Map



Example of visual support used during semi-structured interviews.



Q	Question
A	Answer
...	Pause/unfinished utterance
Xxxx	Anonymized name/place/school

## INTERVIEW 2- Ed

Q/A	Line No.		Code	Sub Theme	Theme
Q	1 2 3 4 5	Okay, thanks for coming today err to talk to me and today we are just going to discuss your experience of going from Junior school right the way over to Secondary School. Okay. So, would you like to tell me about how school is for you now			
A	6 7 8 9 10 11	Umm... <u>school is alright</u> umm <u>I sometimes get bullied</u> , I sometimes don't...it depends where I am and when umm when I am...like where I am when it happens...and umm <u>some lessons can be fun</u> but then umm <u>some lessons can be boring...but most of them are fun</u>	School is alright Sometimes I get bullied Some lessons are fun Some lessons are boring Most lessons are fun	Current overview of secondary school  Bullying issues	Adjusting to secondary school  Interactions with others
Q	12	Okay. So what is good now?			
A	13 14	Umm...what is good is umm... <u>well the lessons are a lot better</u> and <u>I don't get bullied as much</u>	At high school: The lessons are better I don't get bullied as much	Current overview of secondary school  Bullying issues	Adjusting to secondary school  Interactions with others

Q	15	Okay, so was the bullying at this school?			
A	16 17 18 19 20 21	Umm...there was <u>more bullying at middle school</u> . I was getting <u>bullied by younger children</u> ...that does <u>sound a lot...well, quite stupid</u> ...but I did get err bullied...they kept err like <u>punching me, pushing me and then they ran away</u> . It did get dealt with eventually but umm <u>it just really bugged me</u>	More bullying at the middle school Felt stupid when younger peers bullied Bullied by younger children- physical Getting bullied annoyed me	Bullying issues	Interactions with others
Q	22 23	Okay...okay. So the good bit about it now is...you are feeling <u>it's much better</u> ?			
A	24	<u>Yes</u>	Bullying situation has improved	Bullying issues	Interactions with others
Q	25	Okay. So what's <b>not</b> so good for you now?			
A	26	Umm... <u>still getting bullied really</u> and...	Still getting bullied at HS	Bullying issues	Interactions with others
Q	27	And how does that look?			
A	28 29 30	Well umm... <u>mostly Year 10s and 11s</u> they umm... <u>throw stuff at me</u> sometimes...try err get err <u>cover me in water</u> umm...that's really about it	Older pupils are bullies at high school, perceived physical bullying	Bullying issues	Interactions with others
Q	31	And what happens with that?			
A	32 33 34 35	Err...they did cover me in water at one time and umm <u>I got really frustrated</u> so err I had to... <u>I ran off crying</u> and umm I told one of the <u>teachers and they dealt with them</u>	Flight response to bullying Teachers dealt with the problem Being bullied frustrated me	Bullying issues	Interactions with others

Q	36 37	Okay. So is that your main difficulty or problem here or...?			
A	38 39 40	Probably one of my err difficulties because they are always like coming up to me... <u>calling me names</u> <u>umm...just bullying me really</u>	Bullying, name calling Being bullied is difficult Continuous bullying	Bullying issues	Interactions with others
Q	41	Are there any other difficulties or problems?			
A	42	Not really...no			
Q	43 44 45	Okay. So...thinking back to your journey again from junior school to here umm...what have you found that's helpful to get to where you are now?			
A	46 47 48 49	Well there's a <u>lot of teachers that understand autism</u> and umm... <u>well they like treat you like an autistic err child...not like a regular child...because autistic children are very different</u>	Teachers understanding of ASD. Treated differently to non-ASD peers, perceived as different but in a positive manner	Staff understanding of ASD and adjustments made at school	ASD Awareness
Q	50 51	So how...in what ways do they treat you differently?			
A	52 53 54	Umm...they be <u>nice to me</u> , they umm <u>wait for me to talk...and if they are talking and if I am about to talk they like stop and then they let me talk</u>	Preferential treatment given by teachers	Staff understanding of ASD and adjustments made at school	ASD Awareness
Q	55	Okay. Are they not nice to the other children?			
A	56 57	Mmm...I mean they do that but not umm... <u>they don't do as much as...well they do it more with me</u>	Preferential treatment given by teachers	Staff understanding of ASD and adjustments made at school	ASD Awareness

Q	58	Do it more for you...okay. Anything else?			
A	59	No			
Q	60 61	That's helpful...so are you saying that it's people's understanding?			
A	62	Yes, <u>people understanding my autism</u>	People's understanding of ASD is helpful	Staff understanding of ASD and adjustments made at school	ASD Awareness
Q	63	And that's really helpful for you?			
A	64	Yes			
Q	65 66	Okay. How do they learn to understand you...do you know?			
A	67 68 69 70 71 72 73 74 75	Umm well... <u>people always annoy me...I put my head on the table...and I used to go under the table and throw stuff. My autism is getting better but I am still autistic so...I do sometimes get angry, put my head on the table, I ignore everybody. I did get kicked out of the lesson one time...the teacher said I was going to get the detention but then I told her I am autistic...I can't help it. She fully understood and she got rid of my detention</u>	People always annoy me- interactions difficult Felt ASD was getting 'better' ASD associated with anger <i>I put my head on the table –a coping strategy.</i> Behaviour is excused through having an ASD diagnosis Preferential treatment given by teacher, accepted by child as appropriate	relationships with peers  Child's perception of their ASD  Staff understanding and support of ASD	Interactions with others  ASD awareness
Q	76	Okay...and then what happened?			

A	77	Umm			
Q	78	You don't know?			
A	79	No			
Q	80	Okay. So what's not helpful...to how you are now?			
A	81 82 83 84 85 86 87	It's mostly just the children...or the <u>bigger children</u> . Some of them are <u>my year umm are bullying</u> me...umm...they keep err pushing me around. I <u>mostly just get pushed and they just run away. I try</u> <u>chasing but they are always too quick...and one</u> time they <u>kicked a football at me on purpose and it</u> <u>hit my face</u>	Older students and peers bullying- physical (pushing around). Fight response initiated by child. Perceives actions as being targeted.	Bullying issues	Interactions with others
Q	88 89 90 91	Okay, so when...you said that teachers understanding of you has really helped you umm...have there been any other people that have helped you?			
A	92 93 94	Umm <u>my mum has helped me the most</u> umm...because <u>also my sister is autistic</u> and umm she...	Mum helped understands ASD	Parent supporting the understanding of ASD	ASD awareness
Q	95	Is that an older sister or a younger sister?			
A	96	No little sister			
Q	97	Okay			
A	98 99 100 101 102	And umm <u>she has helped me through everything</u> and if I am <u>getting bullied she always comes to</u> <u>school, tells the teachers and the teachers tell their</u> <u>parents to tell them to stop it and...yes, my mum's</u> always just been there for me	Mum has advocated throughout schooling. Teachers' respond to deal with situation Mum's always been there for me	Parent as advocate for the child	Control and responsibility
Q	103	Okay. Anybody else?			

A	104 105 106 107 108	Umm sometimes my <u>stepdad</u> ...because he used...I think he used to...I think he <u>sometimes teaches at this school</u> ...I don't really know...but he <u>teaches naughty children and autistic children</u> and umm he gets my autism as well	Stepdad understands because of experience with others and the context- gets his ASD Stepdad helps at times	Parental/family support and understanding of their child's ASD	ASD awareness
Q	109	Okay. Anybody else, like friends or...?			
A	110	<u>Not really friends</u>	Friends are not viewed as being supporters	Relationships with peers	Interactions with others
Q	111	Other people?			
A	112	No			
Q	113	No? Okay. <u>Your sister?</u>			
A	114	<u>She doesn't...no</u>	Siblings not regarded as being part of the support network	Interactions with sibling	Interactions with others
Q		<i>(laughter)</i>			
A	115	And <u>my brother I don't care really</u>	Doesn't care whether siblings have supported	Interactions with siblings	Interactions with others
Q	116	Is that an older brother or a younger brother?			
A	117	Older brother			
Q	118	Okay...and is he at this school?			
A	119	No, he is in College			
Q	120 121	Okay. Alright. So how did you get information about the school?			
A	122 123 124	Umm...well <u>my brother</u> err he always used to come to this school and his friends did umm and <u>him and his friends said, 'Be careful, don't talk to...or try not</u>	Advice given by older brother re: peers, appropriate behaviours	Interactions with siblings	Interactions with others

	125 126 127 128 129 130	<u>to talk to anybody bigger than you and don't say mean stuff to them'</u> and umm they just said, South block, West block, East block where the classes are there and...yes that was about it. <u>My brother and his friends told me basically where to go</u>	and locations within school site Support from older brother and brother's friends		
Q	131 132	And how did that make you feel when they told you that information?			
A	133 134 135 136	Umm it <u>was very helpful because</u> I have only got lost once...and if my brother wouldn't have told me, and his friends <u>wouldn't have told me where to go I would have got lost tons of times</u>	Information from brother perceived as helpful. Would have got lost more without the information	Interactions with siblings	Interactions with others
Q	137	Okay, anything else that it made you feel?			
A	138	No			
Q	139 140 141	No? So over the summer holidays, was there anything that you did that helped you or anything that didn't help you? So in that long holiday...			
A	142 143 144 145 146 147 148	In the summer holidays <u>I always play out because there is a lot of umm people or kids around my age umm that we always play out.</u> We sometimes <u>have err a water ball where we just get err buckets and chuck them over each other and umm yes, there are Year 8s that umm I play with...some Year 7s and Year 6 and they always just make me laugh</u>	Relationships with peers in the holiday helped.  Plays with mixed aged peers and they make him laugh	Relationship with peers at school	Interactions with others
Q	149 150	<i>(chuckles)</i> So what do they do that makes you laugh?			

A	152 153 154	Err <u>they just like push each other over but like umm just like funny push and then they just tell random, stupid jokes</u>	Pushing and random, stupid jokes are seen as fun	Relationship with peers at school	Interactions
Q	155	Anything else?			
A	156	No			
Q	157 158	So was there anything that helped you over the summer holidays?			
A	159 160 161 162 163 164 165 166	Umm <u>my mum and my nan</u> did err because I sometimes went round my nans and umm she just said, ' <u>Don't worry about school, if you don't do your homework don't worry about it</u> because you will go home eventually, you won't stay there forever' and err <u>my mum she just says what she usually says, 'If you get bullied come tell me and I will sort it out'</u>	Worried about secondary school during the holidays Mum / nan will sort out problems that he is worried about Mum provides assurance that she will sort any problems Worries about homework and bullies	Adults supporting emotional wellbeing  Parent as advocate  Sources of stress: bullies, homework	Control and responsibility
Q	167 168	Okay. Do you ever get the opportunity to sort things out?			
A	169	<u>Sometimes, not always...but sometimes</u> I...	Feels that he is given the opportunity to sort some things out for himself.	Child's ability to resolve issues	Control and responsibility
Q	170	And how does that look?			
A	171	Umm			
Q	172 173 174	Do you want to give me an example? <u>No?</u> <u>Shrugging your shoulders (laughs)</u> Okay...alright. So you said that nan helped you in the summer	Unable to give an example of when he has sorted things out for himself	Child's ability to resolve issues	Control and responsibility

A	175	Yes			
Q	176 177	And did she...so was that to stop you worrying or to...?			
A	178 179	Yes, <u>stop me worrying about homework and detentions</u>	Nan responsible for reducing some of the worry Detention was another source of worries	Adults supporting emotional wellbeing Sources of stress: detention	Control and responsibility
Q	180	Okay. So were you worried about some things?			
A	181 182 183 184 185	<u>I was worried about detentions and me getting detentions affecting umm how I feel and umm I haven't got a detention yet. My mum always looks on the website to see what homework I have and we always do it on the weekends</u>	<b>Worried that detentions would affect his feelings about school</b>  Mum takes responsibility for homework. Support/advocacy/dependency being developed	Starting at secondary school  Child's dependence on support to complete task	<b>Adjustment to secondary school</b>  Control and responsibility
Q	186	And do you ever look on the website?			
A	187 188 189 190	Err I sometimes do umm I log in with my umm computer and <u>I look... If it's easy and it's quick I do it straight away, but if it's hard and it takes long I wait until the weekend to do it</u>	Selection of tasks based on ease and speed.	Child's ability to resolve issues	Control and responsibility
Q	191	Okay, yes...when you have got more time?			
A	192	Mmm			
Q	193 194 195	Yes? So was there anything that you did in this journey for yourself, or you asked somebody else to do for you?			
A	196	Umm			

Q	197	During this time from primary to secondary school			
A	198	Well the <u>two transfer days were very big for me</u>	The transfer days were regarded as significant part of transition	Transition activities	Adjustment to secondary school
Q	199	When were the transfer days?			
A	200 201 202 203 204 205 206 207 208 209	The transfer days I think were before the summer holidays, when I was in Year 6...but <u>the two transfer days were very big for me.</u> <u>I met new people, I made some friends, I lost some friends</u> umm... I just saw what the school was like. <u>I didn't really know where I was going, I just had to follow my umm team leader and then I got lost from him a few times, he got lost a few times</u> umm but my <u>transfer days, they were good but they were just hard really</u>	Transfer day prior to start Repeated significance of the transfer days Relationships with peers changing during process. Didn't know where I was going  Relied on team leader to resolve getting lost issue. Transfer days seen as good but hard	Transition activities  Relationships with peers at school Transition activities  Child's dependence on others to complete task	Adjustment to secondary school  Interactions with others  Adjustment to secondary school Control and responsibility Adjustment to secondary school
Q	210 211	Did you come any other time, apart from the transfer days?			
A	212 213 214 215	It was only the transfer days <u>I have come up,</u> but my brother used to have umm parents' evening and I used to come up then, but <u>the school has completely changed now from then it was</u>	The school has changed from when he used to visit when his brother was there	Transition activities	Adjusting to secondary school
Q	216 217	And what was your first impression when you first came to the school on transfer day?			
A	218 219	My <u>first impression was, 'Oh, I am going to get bullied' umm 'I am going to get detentions a lot', 'I</u>	Initial fears of being bullied, detentions, not	Transition activities	Adjusting to secondary school

	220 221 222	<u>am not going to be able to do my work</u> , <u>'It's going to be too hard'</u> or <u>'I am not going to understand any questions'</u> and I was really worrying	being able to do the work, not understanding,		
Q	223	Mmm...are you still worrying now?			
A	224 225 226 227	<u>Not as much</u> as I were on the transfer days <u>but I am still worrying</u> if I get questions I don't understand and <u>some of the teachers in the school still don't get autism</u>	Worrying has reduced, still anxious around perceived difficulties in understanding questions. Some teachers do not 'get autism'	Transition activities  Others awareness of ASD	Adjusting to secondary school  Awareness of ASD
Q	228	Okay			
A	229 230 231 232 233 234 235 236	But most of them do. But like if I have one of the teachers that doesn't really understand autism and they tell me umm a question <u>I don't really get, I usually put up my hand and say, 'Miss (or sir) I don't get this'</u> and they say it again and <u>I say, 'I don't get this, can you please try change it'</u> and <u>they said, 'I have told you this too...too many times, just figure it out'</u>	If there is a problem in class he is able to ask for help from the teacher.  Some difficulty experienced in communicating lesson expectations between student and teacher	Child's ability to request help at school  Child's perception of their ASD	Control and responsibility  Awareness of ASD
Q	237	Okay...and then how does that make you feel?			
A	238 239	It just makes me <u>feel frustrated and worried</u> if I get <u>detention</u>	Increasing worry about the possibility of a detention	Staff understanding of ASD and adjustments made at school	Awareness of ASD
Q	240 241	Detentions seem like they are quite a big thing for you, aren't they?			

A	242	<u>Yes</u>	Detentions are a big thing	Anxiety about secondary school events	Adjusting to secondary school
Q	243	Tell me a little bit more about that			
A	244 245 246 247 248 249 250 251 252	Umm... <u>detention always worries me because you get the work that you didn't do. So if you don't do the work that you didn't get or didn't do, you have to do it.</u> But like if I got detention because of a question I didn't get umm I have to do it, but like umm none of the...some of the teachers help me with it but because you are in detention <u>you don't really get help apparently...that's what I have been told</u>	Perception of detention and not being able to complete the work without support if it is needed. You don't get help to do the work during detentions	Childs ability to resolve issues  Child's dependence on support from others to complete task	Control and responsibility
Q	253	So have you ever had a detention?			
A	254 255	<u>I have had a detention in middle school but I almost...I just lost a detention in this school</u>	Has had previous experience of detention	Anxiety about secondary school events	Adjusting to secondary school
Q	256 257	Okay and you said that...about that earlier didn't you?			
A	258	Yes			
Q	259 260 261	Alright. So from...go from primary school you came on your two transfer days umm so the first transfer day you had a team leader you said?			
A	262 263	Yes, we had umm <u>two Year 10s and they're now 11s</u>	Older students involved in transition activities	Relationship with peers at school	Interactions with others
Q	264	Okay...and do you still see them now?			

A	265 266 267 268	Umm...I sometimes see umm on the way to school and on the way home umm when I am walking through the corridor I sometimes see him... <u>I just say 'Hey' and then they say 'Hey' back</u>	Minimal interaction with older peer from transfer day.	Relationship with peers at school	Interactions with others
Q	269 270	Okay...and what about on your second transfer day? Tell me a bit about that			
A	271 272 273 274 275 276	My second transfer day was umm <u>weird because I burnt myself a few times...because we were doing Science with acids and I burnt myself a few times</u> and the teacher was like, 'Alright, you can watch for now, and if you want to do it again, or if you want to try it again you can'. So umm...	The science lesson seemed create a little confusion	Transition activities	Adjusting to secondary school
Q	277	So how did you feel about all that?			
A	278 279 280	Umm well umm well the acids umm <u>our Science teacher...I don't have him now but our Science teacher is really err nice</u>	The Science teachers are nice	Transition activities	Adjustment to secondary school
Q	281	Uh-hmm. Anything else that happened that day?			
A	282	Umm <u>I don't really remember much</u>	The experience of the science lesson was important aspect of the transition day	Transition activities	Adjustment to secondary school
Q	283 284	And what do you think those days did...did they help you or...?			
A	285 286 287 288	Umm <u>they helped me know where to go, like when my brother and his friends said, East block, West block, blah-di-blah-blah err German is in South block and umm stuff like that really</u>	Prior information was useful on the transfer day	Interaction with siblings	Interaction with others

Q	289 290	And how did you feel after you had done two transition days?			
A	291 292 293 294 295 296 297 298	The two err after <u>I did that I was umm I kind of forgot where to go umm in Middle School.</u> I kind of forgot where I was going because I have like really bad memory, so umm I just walked around. I asked <u>some people who were in my lessons like, 'Where do we go, I forgot'</u> and they were like, 'Oh go to blah-di-blah-blah class 15', something like that	Returning to middle school after transfer days caused some confusion	Transition activities	Adjustment to secondary school
Q	299 300 301 302	So are you saying that you had been up to the high school or secondary school and then when you went back to your old school it was all different again?			
A	303	Yes			
Q	304 305	Okay, so how did you feel about both schools at that time?			
A	306 307 308 309 310 311	Well...I like...I like high school and I still like it. There was a lot of seagulls when I came up umm because I went on the field. <u>There was tons of seagulls that were dive-bombing me. I had to go inside and wait until the end of break and lunch because I was just getting dive-bombed</u>	Likes high school  (fear of seagulls) Resolved seagull issue by going inside	Positive experience of high school  Child's ability to resolve issues	Control and responsibility
Q	312 313	Were you expecting to get dive-bombed by seagulls?			
A	314 315	<u>Yes, because we are right near the ocean...so...yes, I was...I can't say it...'suspecting' it</u>	Expectation based on experience/knowledge		

				Child's ability to resolve issues	Control and responsibility
Q	316	Yes...'expecting' it, yes?			
A	317	Expecting it, yes			
Q	318 319	Okay. Alright. So when you started here, how was it on your first day? When was that?			
A	320 321 322 323 324 325 326 327 328 329 330 331 332 333 334	My first day was very, very... <u>I was really worrying because I didn't know who was in my class...who I had...who I sat next to. All they gave me was a timetable and telling me where to go.</u> Some of the lessons were wrong but I...all I had to look...is where the lessons were...where the lesson was. So then umm I used to say like umm, <u>Science is in umm S3 but S3 is south umm...so I went to the Science class but I didn't have Science...so umm my Science teacher said, 'Just look at the...'</u> umm <u>'Look where to go not your lesson, because the lesson is always sometimes wrong,</u> and I said, 'Alright, I will go to where it was' and I was err <u>I went to it because German is at the south block,</u> so I went there...German	Worrying about unknowns Information given not enough to decrease worry  Attempted to make sense of the information after realizing that some items didn't make sense. Teacher clarified information giving a solution to the problem Confusion had arisen from misinformation, applied a rule	Starting secondary school  Child's ability to resolve issues  Interaction and relationships with staff Child's ability to resolve issues	Adjusting to secondary school  Control and responsibility  Interactions with others  Control and responsibility
Q	335	Okay, so did you...was that just once you got lost?			
A	336 337	Umm... <u>I got lost like once or twice but that was about it really,</u> just for the...	Getting lost was not seen an a pervasive issue	Starting secondary school	Adjusting to secondary school
Q	338	And how was that?			
A	339	Basically the same			
Q	340	Yes?			

A	341 342 343 344	Yes, <u>I forgot to look at the...well where to go and umm I went to...it said German and I went to German, but I didn't have German, I had to go to English</u>	Acknowledged that he could reference to timetable to help	Child's ability to resolve issues	Control and responsibility
Q	345	And you managed that?			
A	346	Yes			
Q	347	How did you manage that?			
A	348 349 350 351 352	Umm well you <u>have to go to the office to err write in why you are late and stuff like that and then you get a blue slip and then you have to take the blue slip to your teacher and then they're completely fine if you have a blue slip...err if you are late</u>	Knowledge of the procedures Is able to follow procedures at secondary school	Child's ability to resolve issues	Control and responsibility
Q	353 354	So it seems like there's lots of different things that you might have learnt?			
A	355	Yes			
Q	356 357	Yes? About different systems...how it works. So was that different to primary school?			
A	358 359 360 361 362 363 364 365 366 367 368	Err <u>it was very different to primary school. We didn't have really...we didn't have a timetable with us. We had umm I have forgot what it was called...something called a diary, but it's not like something you write in...like your secrets and stuff like that. It's like...umm because you had to read three times a week in middle school and then <u>your mum or dad would have to write down that you read three times a week and then they would have to sign it...and umm if you didn't do that you would get...I think you would get a detention at lunch</u></u>	Difference between primary and secondary school  Read three times a week, this was recorded in a diary	Differences between primary and secondary school	Adjusting to secondary school

	369 370	<u>time...because we didn't have detentions after school</u>	Detentions given if pupils didn't read		
Q	371	Mmm			
A	372 373 374 375	And umm the diary said umm where to go, but it doesn't say where to go <u>it just says err what lesson you have...</u> and basically, umm you knew where most of the lessons were	The diary indicated what lessons the pupils had	Separating from primary school	Adjusting to secondary school
Q	376 377 378 379 380 381	Okay...yes. Thinking back to Year 6, what do you think helped or didn't help you to be how you are in school now? You have mentioned your two transition days...was there anything else that you can think of that helped you where...to get to where you are now?			
A	382 383 384 385 386 387 388 389	Umm... <u>one of my teachers umm she was my Year 6 teacher and she umm she always understood err my autism,</u> and at the end of the year when we were leaving, apparently she well <u>they always did fire drills umm at least once a month...just to see what happened, and we were always ready.</u> was really ill and she wasn't in any of our lessons. She was really sick and she had to go to hospital, so no one ever really saw her. But our final day in Year 6 umm we got to see her and everybody just hugged her	The teacher had an understanding of ASD	Staff understanding of ASD and adjustments made	ASD awareness
Q	390 391	Oh right...and you say that that teacher you thought really helped?			

A	392	Yes, <u>she helped me a lot</u>	The teacher helped	Staff understanding of ASD and adjustments made	ASD awareness
Q	393 394	And what did they do that got you ready for going to high school?			
A	395 396 397 398 399 400 401 402 403 404 405 406	Umm...they umm always err We always know what we were doing, and then one time they were supposed to do it a lot more but they only did it once. They did umm a gas drill or a breaking in drill. Like, say, because we were outside and if you are in a lesson you have to go under the table, but if you are outside we have to run to the umm PE hall and we just had to sit on the sides quietly. But it was only a drill, so then they knew what we were doing	Safety routines were practiced		
Q	407 408	Okay...anything else that you can think of that helped?			
A	409	No, not really			
Q	410 411	And...so did everybody from your school come up on the transition days?			
A	412 413 414 415 416 417	Umm not everybody because some people left. <u>A few of my friends left and umm I was quite sad about that, but a lot of new people, like 20 new people came up and umm I made some new friends</u> and then of course I lost some and umm that's about it	I was quite sad when friends left  I made new friends	Relationships with peers at school	Interactions with others

Q	418 419 420	Okay. So and did...so everybody that was coming to this school from your school, did they all come up on those transition days?			
A	421 422 423 424 425 426	Umm yes umm the people who were in the school now... <u>some people have left umm because maybe they were moving or they didn't like the school.</u> Like three people have left but umm we haven't had any new people join since umm the first day of high school	Some people moved to different schools	Relationships with peers at school	Interactions with others
Q	427 428 429	And...so in September you joined and umm what happened then? What happened with how you went into your school day?			
A	430 431 432 433 434 435 436	Umm...I didn't really know where I was going to get to school because there's two entrances umm... <u>My brother had to take me to school because my mum was taking my sister to school. So my brother had to take me...he knew where he was going.</u> I had to take the main entrance but I now take the other entrance	I was taken to school by my brother  My brother knew where he was going	Child's dependence on support to complete task	Control and responsibility
Q	437 438	Okay, so you then came into school...and then what happened?			
A	439 440 441 442	Umm... <u>I walked up, there was umm a lot of people I didn't know...I just kept quiet, put my head down, hoped no-one talked to me, and I just looked for people who I knew who were in my year</u>	Didn't want to look conspicuous to unfamiliar peers. Looked for familiar peers	Relationships with peers at school	Interaction with others
Q	443	And who did you know?			
A	444 445	Umm...well there was a girl umm...I am not saying her name...but umm <u>she came up to me</u> and she	Other peer initiated interaction		

	446 447	said, 'What are we doing?', 'Where do we go?' and I was like, 'I have no clue, don't ask me'.		Relationships with peers at school	Interaction with others
Q	448 449	So do you think the two of you then worked it out or...?			
A	450 451 452 453 454	Err yes eventually because there was umm some people who umm eventually came to school and they knew what they were doing. They had basically the same lessons that I did umm and then <u>they told me where to go</u>	Information from peers to indicate where they should be	Relationships with peers at school	Interaction with others
Q	455 456	Do you think it was important to have people that you knew in school?			
A	457 458 459	It's quite important, <u>because then you know who to talk to and you know umm their personality</u> , but <u>it is good to have new friends</u>	Familiar peers are important to talk to	Relationships with peers at school	Interaction with others
Q	460	Okay...have you made new friends?			
A	461 462	I have made like <u>three or four new friends and they have helped me through school a bit</u>	New peers have helped at school	Relationships with peers at school	Interaction with others
Q	463 464 465	Mmm...and are there any things that you might have done differently to some of the other students here or...?			
A	466 467 468 469 470 471	Umm...well... <u>I am autistic and I do get in moods</u> , like I have already said, and I put my head down like I have said. My autism is a lot better than it was umm but <u>I don't act too much or not as bad as some other autistic people, because my autism isn't bad, bad</u>	Associates moods with ASD  Indicates that ASD is different for individuals Perceives ASD not to be severe	Child's perception of their ASD	ASD awareness

Q	472 473 474 475 476 477 478	Okay ( <i>laughter</i> ) alright. But do you...so sometimes, I mean we are all different, so sometimes we might do some things that are maybe differently or we are in different groups and things like that, and you have said that you are in err different groups to some of your friends, didn't you, before? Did you say that?			
A	479	Yes			
Q	480	I can't remember whether you did			
A	481	I think I did			
Q	482 483	Yes...umm and so how have you enjoyed being in those different groups?			
A	484 485 486 487 488 489 490	Umm it has been alright...I do sometimes <u>sit next to people who I don't like who are my enemies and I just ignore them.</u> If they say 'Hi' I say 'Hi'...I don't want to be rude to them...and <u>if they are rude to me I will go to a teacher and tell them that they are being rude to me, and I will ask to move to umm a different spot</u>	Peers viewed as friends or enemies Able to seek help and suggest a way to resolve a situation Often needs support of teacher.	Relationships with peers at school Child's ability to resolve issues	Interaction with others Control and responsibility
Q	491 492 493 494 495	So when you came from junior school to secondary school, what sort of things really got you ready for moving from junior school...because I think you went to infant school then to junior school...so you have had a move of school there			
A	496	Yes			
Q	497 498	And then you have had another move. So what got you ready so that you could do that?			

A	499	I <u>don't really know</u>	Don't really know what helped get ready for secondary school	Transition activities	Adjusting to secondary school
Q	500 501 502	What sort of things...did you...did you expect it to be...when you are at primary school did you think about how secondary school would be?			
A	503 504 505 506 507 508 509 510	Umm I didn't expect it to be...I <u>expected teachers to be a lot more strict than they were...than they are...and umm I expected a lot more homework than I usually get</u> , because some teachers only do like one piece of homework a term or one piece of homework a week and umm sometimes they are due in a week, sometimes they are due in a month...it depends how much it is and how big it is	Anticipated things to be harder at secondary school	Current overview of secondary school	Adjusting to secondary school
Q	511 512	That sounds quite complicated all this...the homework and things like that			
A	513 514 515 516 517	<u>It is kind of complicated...there are a lot of websites I have to go on...a lot of numbers and letters I have to remember for my log in and passwords. But once you have done it for at least a month you get used to it</u>	Some difficulty remembering procedures initially, became competent through practicing	Starting at secondary school	Adjusting to secondary school
Q	518	Okay...and what do you feel about school now?			
A	519 520 521 522 523	<u>School is better than it was umm middle school was my favourite school umm because you only got five lessons and this you get six. I liked the less lessons but umm some of the lessons are fun, some of the lessons boring...I have said this, umm and...</u>	Experience at secondary school is mixed  Preference for middle school and fewer lessons	Starting at secondary school	Adjusting to secondary school

	524				
Q	525	Which are the best...the fun ones?			
A	526 527 528 529	The <u>fun ones maybe Drama or Music...they are fun.</u> <u>Art can be fun,</u> Maths is alright err Science...I don't like Science...it's just too tech. It's like too tech err...and futuristic	Enjoys Drama, Art & Music. Science is too technical	Starting at secondary school	Adjusting to secondary school
Q	530	Alright...okay...anything else?			
A	531	No			
Q	532 533 534 535	No? Alright so it sounds from what you are saying is that...you came up to high school and...are things worse than you thought they would be or better than you thought they would be?			
A	536 537 538 539 540	Um <u>they are umm better than I thought they would be because the teachers umm...they are a lot nicer than I thought.</u> The homework is a lot less than I thought and umm... <u>I don't get as bullied as much as</u> I did in err...middle school	Secondary school is better than anticipated Teachers are nicer than anticipated Less homework Reduction in bullying	Current overview of secondary school	Adjusting to secondary school  Peer interaction
Q	541 542 543 544 545 546 547	Okay. Alright...now I think we have probably talked quite a lot about this journey. So is there anything that I have missed about things that might have helped you or people who might have helped you when you moved from your junior school up to the secondary school and how that experience was for you?			
A	548	No, no really			

Q	549 550 551	Would you like to sum it up as to how that experience felt for you...and how you felt at those times. So how did you feel at primary school?			
A	552 553 554 555 556 557	Umm... <u>I felt very depressed because I was getting bullied</u> umm... <u>I wasn't turning up to as many...I wasn't turning up lessons, I was turning up to lessons late...because I didn't know where to go</u> umm...I was just feeling very 'depressed' and I err ran away	Bullying was an issue at primary school Bullied made him feel depressed Lesson attendance was a problem at primary school Response to problems was to run away	Bullying issues	Interaction with others
Q	558	But is that the school that you said that...?			
A	559	That was my middle school			
Q	560	And so that was your favourite school?			
A	561	Yes... <u>it was my favourite school</u> but umm...	Middle school was the favourite		
Q	562	Apart from that bit			
A	563	Yes, in Year 6 it just got worse and worse for me			
Q	564 565 566	Okay. So...and then it...so you felt that it got worse and worse. Can you remember at what point it got worse?			
A	567 568 569 570 571	Umm...more or less the middle of <u>Year 6...because I was getting a lot more bullied and I was getting bullied at home</u> umm... <u>like when I was playing outside and umm I got so frustrated I ran away from home</u>	Bullying became an issue during Y6 in and out of school. Bullied made him run away	Bullying issues	Interaction with others
Q	572 573	Okay. Alright...and then you said that that was still your best school?			

A	574	Yes...umm			
Q	575	Yes...and you had a...			
A	576 577	Year 3, 4 and 5 were really fun but then when I started going up to <u>Year 6 it just wasn't nice</u>	Negative experience in Y6	Separating from primary school	Adjusting to secondary school
Q	578 579 580 581	So what changed then in Year 6 to make it...because from what you have said you then came and...did you say you got a little bit worried about coming up to high school?			
A	582	Yes			
Q	583 584 585	And then you came up and it wasn't as bad. So how was it towards the second half...and the end of Year 6 for you?			
A	586 587 588 589 590 591 592 593 594 595	The end of Year 6 umm like I have said already umm our teacher... <u>our Year 6 teacher</u> had to go to the hospital because she wasn't well. I don't know why she wasn't well...no one knew, but umm she was at the hospital most of the time and umm no one was really happy because <u>she always just made people laugh and helped people when they were upset</u> . But umm no one really... <u>no other teachers did that...so everyone was just getting all sad and miserable</u>	Reliant on positive relationship with Y6 teacher improved wellbeing.  Wellbeing suffered when key adult was not in school	Interaction and relationships with school staff  Adult supporting emotional wellbeing	Interactions with others
Q	596 597 598 599	Mmm...and then you came on your...so she had gone in that last term did you say...the last term...yes?...and so was there anything done in school to help get you ready for the high school?			

A	600 601	Umm well there were umm there was a <u>sheet that we wrote on that was...</u>	Wrote information on a sheet of paper to let adults know of thoughts about high school	Transition activities	Adjusting to secondary school
Q	602	So what did you put on the sheet?			
A	603 604 605 606 607 608 609 610	Umm it said like, ' <u>How do you think high school is?</u> ', ' <u>How do you think you are going to...</u> ' or ' <u>How do you think you are going to fit in with high school?</u> ', ' <u>How do you think...</u> ' or ' <u>How good grades do you think you are going to get?</u> ', ' <u>How much homework do you think you are going to get?</u> ' and I just put umm for my homework 'A lot' and umm good grades I just put, ' <u>Not very</u> '	Expressed that he thought high school was going to be difficult Expressed that he thought he was not going to achieve academically.	Transition activities	Adjusting to secondary school
Q	611 612	And what happened when you were filling that in? How did you feel?			
A	613 614 615	Umm because umm <u>because our teacher wasn't there I was just feeling depressed so I just wrote everything negative</u>	Relationship with teacher influencing responses given prior to transition	Interaction and relationships with staff Staff supporting emotional wellbeing	Interactions with others Control and responsibility
Q	616 617 618 619 620	Okay...and it's interesting that you wrote it negative. Would you have written it the same...and you said because your teacher wasn't there...if she had been there what would you have put? Would you have put the same things?			

A	621	<u>I would have put a lot more positive things</u>	Relationship with teacher influencing responses given prior to transition	Interaction and relationships with staff	Interactions with others
Q	622	What sort of things would you put?			
A	623 624 625 626	Umm <u>homework I would have kept the same but grades I would have put umm 'middle' and fit in umm I would put umm, 'I would fit in alright' because I put in fit in, 'I wouldn't fit in'</u>	Personal statements reflecting emotional wellbeing	Interaction and relationships with staff	Interactions with others
Q	627	Okay			
A	628 629 630	But umm because our teacher... <u>I wouldn't put it like, 'good, good' because I was still getting bullied, but I would have still put it at 'better'</u>	Bullying still an issue at primary school	Bullying issues	Interactions with others
Q	631 632	Okay. So at that point and then...what happened with that information that you wrote there?			
A	633 634 635 636 636	Umm <u>all the teachers looked at it umm but they didn't say to the class like how they felt, they just looked at it</u> and then they pulled the people out umm of the lessons and <u>just talked about it umm I never got pulled out though</u>	Teacher's decision on what to do with the information. Not sure what the information was used for	Adults support emotional wellbeing	Control and responsibility
Q	637 638	Okay. So did you have any more things that you did to come here or any...?			
A	639	No not really			
Q	640 641 642 643 644 645	Okay. So you came from the primary school up to the secondary school...okay. Is there anything else that you think that I should have asked you that you think is important or that you would like to share about that experience of coming and how you felt about that?			

A	646	No			
Q	647 648	No? So you are absolutely fine. Can I just say then thank you very much			

