Title: An exploration of the self-disclosure process for young people with Autism.

Submitted by Jessica Pares Landells to the University of Exeter as a thesis for the degree of Doctor of Educational Psychology in Educational, Child and Community Psychology in May 2016

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: ……………………………………………………………………………

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Contents

Abstract

The aim of the first phase of the research was to explore the self-disclosure process for children on the autistic spectrum. Self-disclosure refers to the process of an individual with autism telling others about their diagnosis. I wanted to find out what self-disclosure involved in schools and what support had been in place to create an environment where self-disclosure was considered appropriate. I thought it would be important to explore what sort of impact self-disclosure had on those involved. Case studies were carried out in order to explore the self-disclosure process in depth. Four participants (aged 13-16) from two mainstream secondary schools who had self-disclosed their autism to their peers participated in semi-structured interviews. These interviews were set up to gain an in-depth understanding of self-disclosure. I interviewed parents and staff from the schools in order to gain different perspectives of the impact of the self-disclosure process. The interviews were analysed thematically. Emerging themes from these interviews showed that self-disclosure had occurred as a result of young people feeling different and wanting to explain their differences. The self-disclosure in all cases was considered to increase understanding of autism through education both for the individual with autism and the peers they self-disclosed to. Increased understanding of autism led to an improved sense of self for the individual with autism and a positive change in behaviour and attitude of the individual's peers.

The interviews also provided some understanding of the factors that supported self-disclosure. The factors were incorporated into a model which was then used in the second phase of the research to support children with autism in the process of self-disclosure. Overall, this process supported children in gaining a more positive sense of self and educated those around them about their personal strengths.

Contents for table and figures

ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
EP	Educational Psychology
LA	Local Authority
TA	Teaching Assistant
ASW	Autism Support Worker
FT	Form Tutor
AIS	Autism Identity Scale
SEN	Special Educational Needs
TEP	Trainee Educational Psychologist
EHCP	Education Health and Care Plan

Thesis introduction:

Research context:

The following research was carried out whilst I trained to be an educational psychologist (EP) working in a Local Authority (LA) in the South of England. I had previous experience of working with children with autism as a SENCo assistant in a mainstream primary school. This experience made me acutely aware of the difficulties children with autism experience in their social environment. I supported lots of different social interventions mostly working with the young people, helping them in developing their social interaction skills. I then heard about one young person who had been supported in the process of self-disclosure. Self-disclosure refers to an individual telling others about their autism. The impact of this intervention was reported to be very positive. It was reported to be the turning point for the young person's social interactions and thereafter she began to develop friendships without adult support. This made me wonder whether it was the environment that needed to be the focus of social skills interventions rather than the individual with autism.

When I started placement as a trainee educational psychologist (TEP) I heard of another school that had supported children with autism in self-disclosing to their peers. I became curious about the evidence base behind this practice and decided to investigate it further. In researching the literature, I found there was very little information about whether or not self-disclosure could be successful or what should be in place as supportive factors. This motivated me to find out more about self-disclosure for children with autism and made me want to explore this process to find out about how it had been done and what impact it had in a mainstream school environment.

Chapter 1

Rationale:

The figures produced by the Department of Education in 2015 show that nearly 66,000 children on the autistic spectrum with Special Educational Needs (SEN) are currently educated in mainstream schools (2014). Research has shown that children with autism are the most bullied SEN (Humphrey and Symes, 2010). Research has suggested that children with autism can be lonely and isolated in this environment and are sometimes being teased and bullied as a result of their autism.

The role of the EP (devised from Cameron (2006)):
- to promote and support the use of pro-active approaches to reduce the likelihood of problems occurring
- to adopt a psychological perspective to gain a deeper understanding of problems
- to use evidence informed strategies to address these problems to generate change

I have heard anecdotally that self-disclosure can be successful as a method to improve social inclusion for pupils with autism. In reading the literature, I found that although there is further anecdotal evidence about the success of self-disclosure from individuals with autism and experienced individuals working in the field, there has been no research into the area. I carried out this research to explore self-disclosure and inform further self-disclosure processes, thus enriching the evidence base for this process.

My training as an educational psychologist has taught me that complex and delicate processes such as self-disclosure require thorough investigation in order to provide an evidence base for future practice. This research aims to outline the process of self-disclosure for some individuals, identify the similarities and differences between the experiences of these individuals and identify the sort of support that was considered effective for these young people. The purpose of the research is to help educators provide more effective support for young people wanting to self-disclose.

Introduction:

This paper presents an exploration of the literature associated with research into social identity and self-disclosure for children on the autistic spectrum in mainstream schools.

It also critically analyses the role of the school and educational psychologists in supporting identity development for children with autism. This review provides the framework for my doctoral thesis research and identifies how my research will extend theoretical and practice-based knowledge for children with autism in mainstream schools.

Research on autism is vast. I have narrowed down this literature research into the following areas:

- Social identity: This will include the background of social identity theory, how this is thought to affect minority groups and how this relates to children with autism.
- Self–disclosure: Outline of self-disclosure and the self-disclosure process for individuals with autism.
- Interventions: Identifying current practice and research on interventions for addressing social barriers of children with autism in mainstream classrooms.

In order to understand the topic of self-disclosure of autism it is necessary to clearly define autism and outline the current debates about the autistic label. In the first section I will discuss the relevance of the research I am carrying out in terms of inclusion and the difficulties children with autism face in mainstream provision. The second section will provide a critical review of the literature in the sections mentioned above. The final section will outline the gap in the literature and how my research will contribute to this field.

Search strategy:

Relevant literature was sourced using the search criteria in the box below. Primary source material was included if it was considered relevant to the research questions. Other papers were found from the reference lists of relevant papers.

Search engines	Using the key terms:
EBSCO PsychINFO ASSIA	autism and identity autism and peers' understanding autism and self-disclosure autism and friendship autism and disclosure

The Autistic Spectrum:

Autism Spectrum Disorder (ASD) is defined in the Diagnostic Statistical Manual V (DSM V) as a developmental disorder which affects social communication and interaction (DSM-V, 2013). Individuals can show little interest in other people, have difficulties reading others' emotions and can show a lack of reciprocity (Baron-Cohen, 2008). Individuals with autism also show repetitive behaviour or can have narrow interests. Key features of these difficulties can include highly repetitive behaviour, obsessions or need for sameness. The DSM V is widely used as the diagnostic tool for identifying autism as it is considered the standard classification manual for mental disorders. Autism is considered to be a spectrum disorder which means that severity is measured by the amount of support required by an individual in the areas impacted by the disorder mentioned above (DSM-V, 2013). Simon Baron-Cohen, the director of the Autism Research Centre in Cambridge argues that the terminology of 'disorder' should no longer be officially used because the medical meaning of the word refers to something being dysfunctional (Baron-Cohen, 2012). Baron-Cohen believes that 'condition' should replace 'disorder' as it is more neutral. This thinking is also reflected in recent developments into the psychological theory behind autism. The empathizing-systemizing theory acknowledges that many individuals with autism do experience a difficulty when it comes to empathizing. On the other hand, many have strengths in thinking in a systemic way (Baron-Cohen, 2009). Systemizing thinking refers to abilities in analysing and constructing systems. This provides some proof for the argument that the brains of autistic individuals' function differently and not necessarily in a dysfunctional way.

I concur with Simon Baron-Cohen's argument and think that using 'disorder' as a label for autism increases stigma and the perceived difficulties for these individuals. I will therefore be referring to autism either as autism or ASC (autistic spectrum condition).

This literature review will focus on individuals at the high functioning end of the spectrum. These individuals are the ones who "require support" (DSM-V, 2013, p.52) as opposed to individuals on the low functioning end of the spectrum who require "very substantial support" (DSM-V, 2013, p.52).

Relevance of the research topic for children, schools and the practice of Educational Psychology:

In order to address the relevance of this topic I will look at the numbers of children with autism in mainstream classrooms and outline the legislation about inclusion. I will go on to identify the issues children with autism experience in mainstream classrooms and define the role of the educational psychologist (EP).

Varying prevalence rates of autism have been identified. The National Autistic Society (2015) estimate that there may be 695,000 individuals on the autistic spectrum in the UK. The most recent census carried out by the Department of Education in January 2015 reported that in England, 90,775 children with autistic spectrum condition have a special educational need (SEN) in school (Department of Education, 2015). At this time a child with special educational needs was defined as any young person with a statement of SEN or an Education Health and Care plan (EHC plan) or receiving SEN support. This census also reported that 72.6% of children with autism with a SEN are currently educated in mainstream provision (Department of Education, 2015). These prevalence rates demonstrate that there are high numbers of children with autism receiving their education in mainstream provision in the UK. Neil Humphrey, a senior lecturer in education at Manchester University, summarises that research is emerging which suggests that there are many barriers to inclusion for these pupils (Humphrey, 2008). This research will be discussed in the following section.

Inclusion:

It is unlawful for any education provider to discriminate between pupils on grounds of disability under the Equality Act (2010). The principles of an inclusive education service are identified in the government's statutory guidance document where it states that education providers should "develop their culture, policies and practices to include

pupils" (DES, 2001a, p.2). In summary current legislation strongly advocates an inclusive mainstream education as long as this does not conflict with parental wishes or affect the education of other children (DES, 2001b).

Difficulties of inclusion for children with Autistic Spectrum Condition (ASC):

Inclusion is not just simply about placement. Inclusion is about ensuring children are socially included in the classroom environment. The National Autistic Society states that "inclusion is about the quality of the child's experience" (The National Autistic Society, 2011, para. 4) and these experiences include participating in the life of the school and playing with other children.

In my experience playing and forming relationships can sometimes prove one of the biggest barriers to inclusion for children with autism. This can be particularly difficult for children on the autistic spectrum because of the nature of their differences. The difficulties that children with autism have with social communication mean that they may display behaviours that are different and not understood by their peers. For example, they may not display reciprocity in communication with others and they may have difficulties understanding someone else's perspective (Baron-Cohen, 2008). There is a great deal of research that has focussed on the social inclusion of children with autism in the classroom. Bauminger and Kasari (2000) measured loneliness and friendship in 22 children with high functioning autism and compared this to typically developing children. Bauminger and Kasari (2000) state that the research was carried out solely on children with high functioning autism in order to "differentiate deficits unique to autism" (Bauminger and Kasari, 2000, p.448). High functioning autism is not explicitly defined in this research, although Intelligence Quotient (IQ) scores are recorded as falling between 84 and 138 on the Wechsler Intelligence Scale for Children. Bauminger and Kasari (2000) concluded that children with autism do feel lonely more often in the classroom and children on the high functioning end of the autistic spectrum do desire social inclusion. However, this is quite a small scale study which makes it difficult to generalise to all children with autism in mainstream classrooms. Kasari, Locke, Gulsrud, and Rotheram-Fuller (2011) supported this research by comparing the social integration of pupils with autism in the classroom to their typical peers. They used several different measures to explore friendships and social networks including a friendship qualities scale, a playground observation, a social network and friendship survey and a teacher perception measure. They found that children with autism rated a

best friend significantly poorer in five domains of friendship; closeness, helpfulness, security and companionship. It was therefore concluded that children on the autistic spectrum had a poorer quality of friendship than their neurotypical peers. Measures from the social network and friendships survey suggested that children with autism are less likely to have their friendship choices reciprocated and they were often on the outskirts of social interaction. This means that they are not considered an important part of the classrooms social network by their peers. This research was carried out on a larger scale with 60 children on the autistic spectrum and 815 typically developing children.

In conclusion there is evidence to suggest that some children with autism are aware of the concept of loneliness and many are not as socially included in the classroom as their neurotypical peers.

Social misunderstandings can be exacerbated by the fact that autism is an invisible disorder as there are no visual cues. This means peers have no way of knowing that someone is autistic unless they are told or work it out for themselves. There is concern that if peers do not understand the underlying difficulties causing the differences then they may resort to negative labels (Davidson & Henderson, 2010).

Critical review of the literature:

Within this section I will look at identity theories in a social context. First I will outline social identity theories. I will then outline literature in relation to social identity theory and minority groups. Finally, I will review the literature about the development of autism identities.

Social Identity Theories:

There have been many psychological approaches developed in order to gain understanding into identity development. I am going to focus on identity development in the social context. I have decided to focus on this area because identity is an area of great importance in mainstream secondary schools and in addition it is an area where individuals with autism often experience difficulties.

The idea of social identity was originally conceptualised by Henri Tajfel (Turner, 1996). This theory suggests that identity is developed as a direct result of interactions within social groups and is based on the assumption that "people derive their identity (their sense of self, their self-concept) in great part from the social categories to which they belong." (Hogg & Abrams, 1988, p.19). Individuals first categorise themselves as part of a group. Then they begin to identify with that group. Finally, they compare their group to other groups. Members will only stay involved with that group if they feel that being a member positively contributes to their self-identity (Hogg & Abrams, 1988). A group is defined as "a collection of individuals who perceive themselves to be members of the same social category" (Tajfel and Turner, 1986, p. 15) and "share some emotional involvement in this common definition of themselves." (Tajfel and Turner, 1986, p.15).

Adams and Marshall (1996) focus on identity in relation to the social context and argue that socialisation is essential to enable the individual to differentiate and integrate. Differentiating means to enhance an individual's uniqueness and integration means to enhance an individual's sense of belonging to others. They believe that socialising allows individuals to develop their identities by striving to feel unique and also by belonging. Both these aspects are thought to be linked to psychological wellbeing. Adams and Marshall (1996) also theorise that "an individual's personal or social identity is not only shaped, in part, by the living systems around the individual, but the individual's identity can shape and change the nature of these living systems" (p.432). In other words, identity development interacts in a reciprocal fashion with the social context in which an individual lives.

Both these theories demonstrate the importance of groups in the development of identity. Social identity theory emphasises belonging to a group whereas Adams and Marshall (1996) acknowledge that being an individual within that group is also important.

Social Identity in minority groups:
Bat-Chava (2000) explored identity development in Deaf individuals. A capital D is used by some people who are deaf to emphasise that they are part of the Deaf community which shares the language of British Sign Language and a culture (Frederickson & Cline, 2009). Bat-Chava (2000) argued that for members of stigmatised groups social identity theory dictates they may have one of two reactions;

either moving away from the stigmatised group which they are part of or trying to initialise social change and attempt to reduce the stigma of their group. Bat-Chava (2000) tested this hypothesis by carrying out questionnaires and interviews on a large sample of deaf individuals. They found three types of identity; Deaf, hearing and bicultural (associating with both deaf and hearing cultures). It was argued that these results found support for social identity theory. I.e. some people distance themselves from the stigmatised label and others associated with it. Bat-Chava (2000) also found that those with stronger Deaf identities (bicultural and deaf identities) had higher self-esteem. This suggests that identification with a group, even a stigmatised one, is beneficial for psychological wellbeing. Hintermair (2008) also explored these different types of identity. It was found that deaf individuals with bicultural identities were found to have more positive self-esteem and general satisfaction with life. Hintermair (2008) did find, however, that some individuals who were not aligned to either deaf or hearing groups had acquired a high satisfaction in life.

I think this demonstrates that having a "cultural anchor" (Hintermair, 2008, p.294) can be a very significant factor in supporting psychological wellbeing for individuals with a stigmatised identity. It also demonstrates that for some individuals having a strong cultural link is not important in order to achieve satisfaction in life. In conclusion the identity process for individuals from stigmatised groups could be described as a very individual process.

Young people with autism do not have a collective identity in the same way as Deaf children. However, I will go into more detail about how this research might link to children with autism in the following sections.

Research into identity formation of individuals with autism:
In order to explore research into the importance of social identity for individuals with autism I will first discuss the history of the autistic community. I will then outline research into how individuals with autism feel about the autistic label. Finally, a review of the literature about individuals with autism developing identities will be undertaken.

There is a paucity of research into identity formation for individuals with autism because there has been a focus on autism as a disorder rather than a difference. Ward and Meyer (1999) outline how the development of the internet in the 1990s allowed

individuals with autism to communicate effectively and independently of others, thus enabling them to share ideas and create advocacy groups such as the Autism Network International. A community has developed which is described by some as an Aspie world (Bagatell, 2007). This is a "network of people" (Bagatell, 2007, p. 420) who understand autism as a neurological difference rather than a disability.

Perspectives of diagnosis:

Many individuals with autism embrace their diagnosis. For example, one individual states that "it was the definitive that finally made sense of my life, the missing piece of me that, once found, made me whole." (Willey, 2006, p.19). This experience is echoed by other individuals who speak about finding out about their diagnostic label (Shore, 2004; Sainsbury, 2000). Research carried out by Huws and Jones (2008) provides further proof of the benefits of individuals learning about their diagnosis. One of the emerging themes from a qualitative research study looking into the perspectives of diagnosis in young people with autism showed their diagnosis "provided explanations" (Huws & Jones, 2008, p.102). It allowed them to have a better understanding of why they had experienced difficulties in certain situations. Davidson and Henderson (2010) analysed 45 autobiographies and personal accounts from individuals with autism and summarised that the worst thing you can do is hide the diagnosis of autism from an individual. Although this is usually done by people attempting to protect the individual with autism it actually has the opposite effect. It means that important choices about disclosure are withheld from that individual. David Andrews, a respected author in the field who is autistic himself, states that autism is linked to an individual's identity "we are complete people, with 'our autism' as an integral part of who we are." (Andrews, 2006, p.95). These views represent a positive response to the label of autism. Some people do not feel so positively about this label and examples of these perspectives are outlined below.

Some individuals with autism distance themselves from the label of autism because they feel that it negatively impacts on how they are perceived by others (Baines, 2012). Themes arising from the research carried out by Huws and Jones (2008) suggest that some children with autism are aware that having a label of autism can have a negative impact. For example, one participant, Mark, perceived that having the label can cause others to prejudge. An important theme appearing from the analysis of personal accounts found that as a result of the stigma relating to autism individuals who can pass

as neurotypical often do (Davidson & Henderson, 2010). "Individuals use deception to manage selves, identities, and situations in ways that can diffuse potentially threatening socio-spatial encounters" (Davidson & Henderson, 2010, p.161). This suggests that individuals with autism are aware of possible negative consequences of revealing their autism to others.

In conclusion it seems that individuals with autism are aware of positives and negatives of receiving the autism label. Some feel it is an important part of their identity whereas others would prefer not to acknowledge it.

It may be challenging to gain a balanced perspective of the autistic label from individuals with autism. It is thought that individuals with autism prefer to write accounts and this is why autobiographies are considered to be a good method of analysing their perspectives and perceptions (Davidson & Henderson, 2010). However, it is precisely for this reason that the literature may be biased. Individuals who feel negatively and try to distance themselves from their labels may be less (if at all) likely to publish their perspectives on autism in relation to themselves. It may only be the advocates for the autism community that choose to record their views. This is maybe why the research carried out by Huws and Jones (2008) and Bagatell (2007) seems to present a more balanced perspective of the negatives and the positives.

Taking this into account I believe the evidence suggests that learning about autism does help individuals to develop a more positive understanding of themselves and can be considered a very important part of their identity. It also recognises the pressures many face in social situations attempting to fit in and hide a label they may perceive to be stigmatised. In conclusion, I think the research suggests that children should be told about their autism but then supported in making their own choices once they have received the diagnosis. Within this process it is essential to listen to the child's perspectives of how they feel and develop support around each individual accordingly. The current advice from The National Autistic Society supports this perspective about informing a child about autism as it suggests that children have a right to know their diagnosis (Pike, 2008).

Identity development for autistic individuals:

I will now outline how the social identity theory could be linked to the identity formation of individuals with autism. Some believe that hiding a stigmatised label has an impact on identity development. For example Huws and Jones (2008) believe that attempting to be normal compromises an individual's identity.

Humphrey and Lewis (2008) researched children aged 11 to 17 with autism in schools. A theme of "constructing an understanding" (Humphrey & Lewis, 2008, p.30) emerged from semi-structured interviews. This theme demonstrated that some children accepted their differences and others thought of these differences in a negative manner. Humphrey and Lewis (2008) argued the "extent to which this understanding is part of their developing identity, is likely to influence the way in which they make sense of their educational (and other) experiences" (Humphrey and Lewis, 2008, p.30)., that is their understanding of their autism is likely to have an impact on their identity development and how they experience their environment. Humphrey and Lewis (2008) also believed that children can sometimes construct perceptions of themselves through feedback from others. This explains how they may begin to think of themselves as a "retard" or "disabled" (Humphrey and Lewis, 2008, p.31) if they feel they are being treated differently in a negative way.

Children with autism may also have difficulties developing an identity because of the nature of their social difficulties. According to social identity theory, experience of groups is essential in identity formation. Individuals with autism may lack experience in groups because of the nature of the condition i.e. their difficulties in social interaction and communication may either mean they avoid groups purposefully or they may never feel they belong to any particular group. Bauminger, Shulman, & Agam (2004) found a link between the development of the self in a social context and the development of social relationships for children with autism. They concluded that for children with high functioning autism, social competence is considered by them to be very important in how they think of themselves. This research provides some evidence to suggest that difficulties in social situations can have a negative impact on sense of self for individuals with autism.

Bagatell (2007) discusses this issue in her research. Ethnographic methodology is used to explore the identity of a young man with autism, named Ben. Ben recalls feeling like

there was something wrong with him when he was at school. Ben felt that he needed to fit in by attempting to "act normal". He is described as being isolated and depressed. Bagatell (2007) concludes in the discussion that it may be harder for individuals with autism to develop an identity because they have "limited experiences of social worlds" (Bagatell, 2007, p.424). I think this experience demonstrates how Ben did not fit in and did not feel as if he belonged to any group at school. It is hypothesised that this is why he had difficulties developing a positive identity. However, another important aspect of identity development in children with autism is not mentioned in this research. Ben's struggle to form a positive identity may be due to receiving a late diagnosis of autism. Teenage years are considered to be a particularly difficult time to accept the autistic spectrum label (Pike, 2008). I think although Bagatell's (2007) research cannot be generalised to others with autism due to the case study methodology used, it does give a good insight into possible difficulties that children with autism face in developing their identity. It demonstrates how social differences for children with autism may influence their development of a social identity.

Bagatell's (2007) research further supports the idea that individuals with autism have difficulties with identity formation as a consequence of their social difficulties. Ben's involvement with the Aspie community in later life allows him to reframe his experiences as part of the normal experience of autism. He begins to develop what is described as a "positive identity as a person with autism" (Bagatell, 2007, p.420) acknowledging autism as a difference and not a disability. It seems when Ben feels he belongs to a group he begins to develop a positive autistic identity.

Children with autism may have less social experience and therefore less experience of being a member of a social group. When they are integrated in groups they may be treated differently or receive negative feedback. According to social identity theory these experiences may lead to individuals having less opportunity to form a positive sense of self. Furthermore there is research to suggest that hiding a stigmatised identity can have a negative impact on their sense of self and an individual's behaviour towards others (Newheiser & Barreto, 2014). This research concluded that although individuals thought that hiding their stigmatised identity would have positive consequences it actually decreased their sense of belonging. They also found that individuals hiding their stigmatised identity did not show behaviours that were thought to elicit closeness in social situations. This research was carried out on individuals with four stigmatised

identities including a lesbian, gay, bisexual or transgender, mental illness, physical illness or poverty. Even though it was not carried out on individuals with autism it does show that others' perceptions have an impact on self-worth and a feeling of belonging. I think this implies that hiding an autistic identity may not only have a negative impact on the individual's sense of self but may also affect how that individual interacts with others.

Myers, Ladner, and Koger (2011) argue that comparisons can be made between deaf identity formation and autistic identity formation. They argue that children with autism are part of a minority group. Myers et al. (2011) go on to suggest that developing identity may have similar links in autism as it does in Deaf individuals. For Deaf individuals it has been found that children who develop a better sense of self are predicted to have a higher self-esteem. Jarrett (2014) explored the identity of students with autism and found the identity groups were not as definite for these individuals as had been found in different minority groups. Although no statistical significance was found for biculturalism (alignment to both autistic and non-autistic groups) and self-esteem the descriptive statistics showed that children with autism who had a bicultural identity had a higher average mean. No significance may have been found because autistic culture is a more recent development when compared to the Deaf community and not all individuals may be aware of its existence. Ben, for example, in Bagatell's (2007) research only discovered the Aspie world later on in his life.

Myers et al (2011) argued that children with autism should be allowed to "explore and embrace their autistic identities" (p.515) and Jarrett (2014) found evidence to support the suggestion that enabling adolescents to explore their autistic identity could support their psychological wellbeing.

In summary, children with autism may have more difficulties than other children with identity formation as they feel they need to 'fit in'. These difficulties may be exacerbated by the nature of the social difficulties that define autism and how they are treated by others. The practical implication being that when children are misunderstood by their peers in the classroom, this negatively impacts on the view they have of themselves. Moreover, there is tentative support for the argument that children with autism may benefit from being given the opportunity to explore their autism identities.

Self-disclosure:

Self-disclosure for individuals with autism:

There has been no specific research about self-disclosure of autism in schools. Humphrey and Lewis (2008) briefly discuss disclosure as part of their research into the perspectives of young people aged 11 to 17. They state that they have observed situations where "sensitively handled" (Humphrey and Lewis, 2008, p.40) disclosure assisted the development of positive relationships of individuals with autism with their peers by reducing intolerance to difference. Unfortunately, this information provides no further insight how self-disclosure can be "sensitively handled" (Humphrey and Lewis, 2008, p.40). However, many individuals with autism writing about good practice and their experiences, discuss developing disclosure skills.

Ask and Tell: Self-Advocacy and Disclosure for People on the Autistic Spectrum is a book written by adults with autism (Shore, 2004). The editor of the book, Stephen Shore, is a professor at Adelphi University where his research focuses on matching best practise in autism to need (Shore, 2012). The book discusses the issues of self-disclosure with the overarching message that self-disclosure is necessary in order for individuals to self-advocate. The reasoning behind this is that in order to make sure that an individual receives the provision and adaptations they need, it is essential to be prepared to give a reason why. Shore (2012) states that:

without embracing the twin issues of self-advocacy and disclosure, we face an even greater risk: living unfulfilled lives and depriving communities and societies as a whole of the potential for people on the autistic spectrum to make significant contributions. (p.iii)

Sibley (2004) also states that autistic individuals need to be taught this skill because it is not something that they pick up naturally by watching or learning from others. Sibley (2004) believes that there are a few reasons individuals with autism do not learn the skills of self-disclosure independently; Individuals with autism need specific instruction to learn social patterns, adults advocate for individuals with autism in order to support them, preventing them from needing to self-disclose themselves. Finally, individuals with autism can have difficulties understanding that another individual is not already aware of their difficulties. This difficulty is related to their difference in ability to empathize with others (Sibley, 2004, p.34).

Three main reasons are given in the book as to why it is important to tell others about autism. These are (Willey, 2006):

- Makes you feel safer

- Enables you to be your true self (no longer having to hide autistic traits)

- Educates others about the spectrum of autism

I think this suggests that self-disclosure could affect an individual's sense of self. In terms of social identity theory, it may increase their sense of belonging to a group. It may do this in two main ways. The first is by changing the behaviour of the group towards the individual. The second is by changing the individual's behaviour towards the group. The group may be more accepting of that individual because they have more understanding of their differences. The individual will no longer have to hide their identity so they may act in a more positive way toward the group (Newheiser & Barreto, 2014). This conclusion is based on personal reports of self-disclosure and from theoretical assumptions. No specific research has been found into the impact of self-disclosure for individuals with autism.

Willey (2006) also acknowledges the difficulties that individuals may experience when self-disclosing. She recognises that when some people are told about autism they sometimes fail to see the positives and only understand it as a disability. This suggests that self-disclosing may lead to others increasing their doubts in an individual's ability and personality. Tony Attwood (2006), a professional in the field, recognises the many advantages and disadvantages to telling others about a diagnosis of autism. Among the disadvantages he says that the diagnosis may be "misused" (Attwood, 2006, p.50) by uncompassionate individuals. He also believes that informing others of a diagnosis can sometimes limit others' expectations of the individual.

It must be noted that many of the individuals writing in the book "Ask and Tell" (Shore, 2004) are involved with the advocacy movement and say that they are proud to be autistic. They may feel more positive about self-disclosure. Other individuals with autism do not feel proud to be autistic (as discussed in 'perspectives of diagnosis'). It may be that these individuals would strongly disagree with the perspectives of individuals in this book and the idea that self-disclosure is necessary.

I agree with Pukki (2006) who believes that there is no single answer to self-disclosure. It is an individual process and should be judged on the individual and the context. However, if self-disclosure has been felt to have a positive impact on some individuals with autism maybe it is something that should be explored in schools as an initiative to support children with autism.

Interventions that support children with ASC in the classroom with social inclusion and social identity development:

Now I am going to discuss research into interventions that focus on enabling children with autism to be socially integrated in mainstream classrooms. If the difficulty in developing a positive social identity is negatively impacted by their difficulties with social interaction, improving social interaction in school may be an essential step for enabling children to develop a positive identity.

Some research has found that children between the ages of 11 and 16 do not have much understanding of autism. Campbell (2008) asked 450 children in Northeast Georgia and found that 71.3 % understood that autism is a disability but did not know any more about it. This shows that some children are aware that having autism can lead to individuals experiencing difficulties. I think this demonstrates that individuals' perspectives of autism can be negatively skewed as individuals do not understand the nature of these difficulties or the strengths associated with autism. I think this demonstrates that children in schools may have a paucity of knowledge of autism.

Swaim and Morgan (2001) found that educating peers had no effect on children's attitudes to children with autism. However, I think this research may not have been successful in changing attitudes because the information they provided about autism was presented very negatively. The researchers showed a video of a child displaying typical behaviours often associated with autism, in the first condition no information about autism was given and in the second, children heard a short description about autism. In the second condition, some behaviours typical of autism are described in such a way which may incite fear in the children listening. For example, phrases are used such as "he may even hit or bite himself or other people or things" (Swaim and Morgan, 2001 p.199) and 'He's not trying to make trouble' (Swaim and Morgan, 2001 p.199). I think the way in which the description of autism was presented makes individuals with autism sound unpredictable, frightening and troublesome. Perhaps, if it had been written

in a more sensitive manner they may have found that it did change people's attitudes. Silton and Fogel (2012), on the other hand, provided evidence to show that educating peers about autism can have a positive impact on intentions towards individuals with autism. They compared the results from children in different conditions who received different sorts of information about autism. All of the children received descriptive and explanatory information, those in the second received additional information about helpful strategies and those in the third received information about specific strengths that individuals with autism might have. It was concluded that giving children information about strategies is the most beneficial in changing children's behavioural intentions. The strategies information was presented in a video and gave examples of some difficulties experienced by individuals with autism and then suggesting methods the children could use to help individuals with autism cope with specific difficulties they experience. Some of these strategies were then modelled by actors. Silton and Fogel (2012) also concluded that information about the strengths of individuals was useful but only if it is given alongside the strategies.

I think this research demonstrates that peers of individuals with autism may have very little knowledge about autism. It also suggests that if information about autism is presented in a sensitive manner then this may have a positive impact on the behaviour of those individuals to their classmate with autism.

Further research has been carried out to identify the impact of educating peers about autism in school. The Circle of Friends intervention was researched by Whitaker, Barratt, Joy, Potter, & Thomas, (1998) The Circle of Friends harnesses the understanding of the peers. It helps adapt the environment around the child by increasing the supportive social contact that the child receives. A class discussion is held without the child being present in order to discuss the child's strengths and difficulties. This intervention had a positive impact on the social inclusion of the child with autism in the classroom with "increased levels of empathy and improved understanding" (Whitaker et al., 1998 p.62) from the peers.

Gus (2000) carried out a case study of a child with autism in the classroom. Adam, a boy with autism in mainstream school was unhappy because children were not including him at break times. The peers in Adam's class did not know about autism and did not know Adam was autistic. When asked what they found difficult about Adam, his

peers stated characteristics that were linked to aspects that are thought to result from the core autistic difficulties. The peers were then educated about autism and many responded positively. They stated it enabled them to be "more sensitive, understanding and patient" (Gus, 2000, p.46).

Both these pieces of research demonstrate how educating peers about autism and the difficulties and strengths associated with it can improve behaviour towards the individual with autism in mainstream classrooms. However, it is not clear whether these pieces of research are carried out with the informed consent of the individual with autism. In-depth discussions occur about the strengths and difficulties of that individual. They're usually absent from the classroom when it happens. This could be considered unethical as it seems that the child is not informed or involved with the process. One of the three main principles for the current Special Educational Needs Code of Practice (the statutory guidance for those working with children and young people) insists that all young people participate as "fully as possible in decisions." (Department of Education & Department of Health, 2014, p.19). I think disclosure maybe more beneficial if the young person were given more support in participating fully in the process of educating those around them.

In conclusion, I think the research demonstrates that teaching peers can improve social inclusion in the classroom for individuals with autism. When educating peers, the research suggests that the teaching should include the strengths and difficulties peers with autism experience as well as providing strategies to help them adapt and support the individual with autism. If social inclusion in the classroom improves for individuals with autism I think there is also evidence to suggest this will impact on their sense of belonging in the class and their self-worth.

Conclusion:

The social isolation of children with autism in mainstream schools may impact on their sense of self and social identity. Hiding what they may see as a stigmatised identity in these situations may intensify these feelings of not belonging.

This literature suggests that self-disclosure may improve the social inclusion of children with autism by generating change in two ways: First, it may educate peers about autism thus enhancing their understanding and secondly, it may enable the individual with

autism to develop a more positive autistic identity by ensuring that they no longer have to hide what they may think of as a stigmatised identity.

Gaps in the research addressed by this thesis:

Some schools involve children with autism in the process of educating their peers about autism. In cases of disclosure and peer education all of the research focuses on adults taking the lead. As the advocates for the autistic community and the new special educational needs code of practice suggest, individuals should have more involvement in decisions and processes which impact on their education. I intend to explore how children understand their own diagnosis of autism and how they feel about revealing this to others at school. Exploration of supportive factors could enable schools to develop a more inclusive environment where individuals could feel more comfortable exploring their strengths and difficulties in relation to their labels.

Chapter 2

Methodology

The methodological assumptions for this research are derived from an interpretivist paradigm, which assumes that the nature of reality is socially constructed. The goal of this research is to gain further understanding of the phenomena under investigation, but it is important to remember that the knowledge that is generated is context bound and cannot be generalised. The purpose of the research is to explore examples of practice and reflect on this practice, thus generating methods by which good practice can be followed. I also acknowledge the influence of my own perspectives, as this paradigm recognises the researcher as an essential component within the research process.

As a social constructivist, my beliefs and values should be clarified, as I recognise these as an essential part of the research. My work with young people with autism in the past has motivated me to generate positive change for these individuals in mainstream schools. In a previous role as a SENCo assistant I have been involved with supporting individuals at a social level, both in increasing individuals' social interaction skills and in helping them to develop friendships in school. As a result of this experience I believe that children with autism can be very successful in mainstream education as long as they are supported appropriately with the social challenges they face. I also believe that intervention is sometimes necessary in order to encourage peers to gain a better understanding of individuals with autism, as behaviour can sometimes be misunderstood.

I became interested in exploring self-disclosure because I had heard through anecdotal evidence that it could empower individuals with autism to begin to change the environment for themselves. If individuals could be encouraged to self-disclose, for example, would this also support them to self-advocate? I believe that this is an avenue that should be explored further, as it currently has only a small evidence base.

Research aim and questions

Aim

The aim in the first phase of the research was to explore how some young people with autism self-disclosed in mainstream schools. I intended to gain an understanding of the impact of the self-disclosure process on some young people who had self-disclosed and

explore the perceived impact on each young person's environment. Finally, I planned to identify the factors that were considered to be supportive on the journey of self-disclosure.

This investigation has three main aims. The first is to gain an understanding of the process of self-disclosure for a few individuals with autism and gain understanding of how and why self-disclosure happens in schools. The second aim is to explore the impact of the process of self-disclosure on the individual with autism and what impact their disclosure then had on their environment. The final aim is to identify any factors in their environment that helped them in this process.

Research questions (RQs)

RQ1: Why did self-disclosure happen?

RQ2: How did self-disclosure happen?

RQ3: What impact did the process of self-disclosure have on the individual and their environment?

Explore these themes that have been identified from the literature:

- In what ways did self-disclosure educate others about autism?

- How did self-disclosure impact upon perceived social inclusion?

- What impact did self-disclosure have on the individual's sense of self?

- In what ways did self-disclosure impact on self-advocacy?

- How did self-disclosure impact the identity formation of the young people?

RQ4: What factors are perceived to have been effective in supporting young people with the process of self-disclosure?

Research design

In order to explore the process of self-disclosure, I chose to apply elements of the action research design. The elements I chose to apply from the action research design were the cycles of reflection and action, as these can be used to observe practice, reflect on practice, and then make changes as a result of reviewing current practice (see Figure 1 for details of the action research cycles).
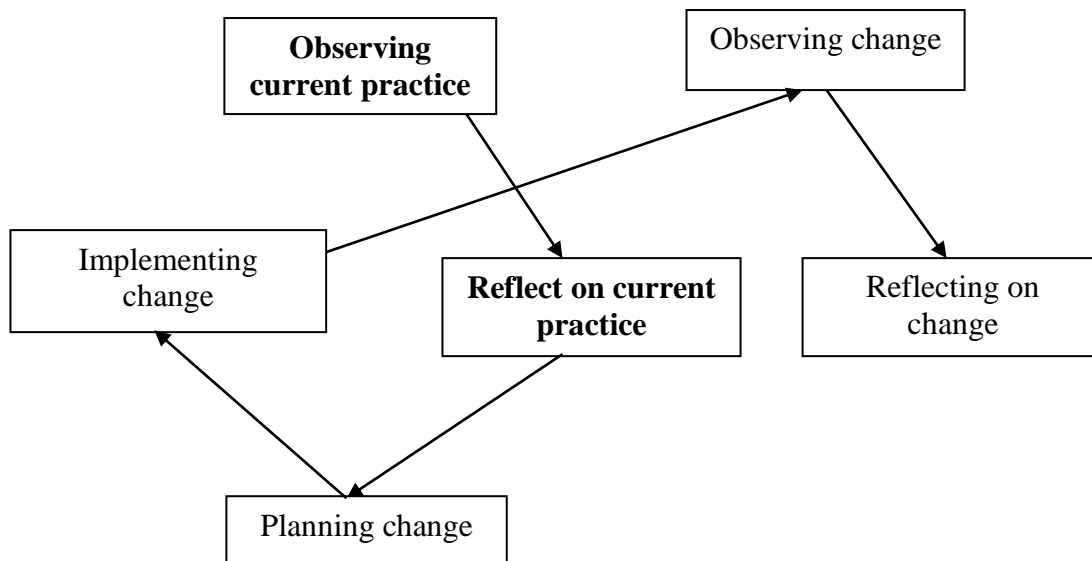
Figure 1: Action research cycle (Lawson, 2009, p.ix)

I felt that using the cyclical process of the action research design was an appropriate way of exploring the process of self-disclosure because it enabled me to investigate self-disclosure events that had already happened in the context of a secondary school and use the analysis to support others with the self-disclosure process in future. Action research is a powerful tool for empowerment and change (Cohen, Manion, & Morrison, 2007). Action research allowed me to develop a clear picture of how and why self-disclosure occurred for some individuals and to develop a model that presented the important factors in supporting the process for those individuals. The action research design then created an opportunity for me to apply and evaluate this model in a different context.

In order to empower the young people with autism, I ensured that the young people in the first part of the research were involved in the process of developing the emerging themes. I did this by feeding back the emerging themes and discussing them with them. In this way I could ensure that the participants' voices were truly reflected in the model that I developed.

There are two main phases of action research. The first one is the diagnostic stage, in which practice is analysed and a hypothesis is developed. The therapeutic stage follows, in which the hypotheses are applied in context using a directed intervention.

The diagnostic phase in this research involved conducting interviews with individuals who had self-disclosed, as well as interviewing parents and school staff who had supported them with self-disclosure. These interviews were analysed and used to develop a model comprised of potential supportive factors. Within the therapeutic stage of the action research, the supportive model was applied to other individuals with autism to support their self-disclosure process. Action research was considered to be an appropriate design because it allowed change to develop from analysis of the current practice. I also considered that this method of research could be empowering for the participants, because it enabled them to support others who may wish to self-disclose.

I chose to complete the diagnostic phase of the action research design using individual case studies. I selected this method because it allows an in depth inquiry about a phenomenon within its real life context (Yin, 2014). I considered case studies to be a beneficial way of exploring self-disclosure for many reasons. For this piece of research, I wanted to gain further insight into individuals' perceptions surrounding an event. Case studies gave me the ability to produce a chronological narrative for specific self-disclosure processes. This provided vivid and rich descriptions of the experiences surrounding specific self-disclosures. Carrying out in depth case studies allowed me to explore the complexity of the process thoroughly. I felt that the information gathering process allowed me to describe and analyse the intricacy of all the interacting factors within the process of individuals' self-disclosures. This was incredibly important for self-disclosure because it is such a personal and individual process (Cohen, Manion & Morrison, 2007).

Case studies were also used in order to establish cause and effect within the specific environments I was examining. This method allowed me to gain understanding as to how and why self-disclosure occurred in some instances. These interpretations and hypotheses were used to contribute to the theoretical understanding of self-disclosure. As psychological theory develops in this field, it could be generalised to support individual self-disclosure in different environments. Case studies are very valuable when they are used within the action research cycle, as the insights can be directly interpreted and used to help others in a practical manner (Cohen, Manion & Morrison, 2007).

I also felt that it was important to interview children with autism because there has been a developing awareness in the literature that the views of autism from the perspective of those who have autism need to be highlighted (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). I felt that using case studies allowed me to ensure the voice of the participants could be clearly heard.

Criticisms of case studies as a research method suggest that results can be biased because they rely heavily on self-reporting by the participant and the researcher. This criticism of case studies increased my awareness of my previous experience of self-disclosure. The experience was a positive one and I realised this may impact on my understanding and interpretation of the interviews. I reflected on this throughout the research and as a result made explicit attempts to record information in a balanced way.

The first phase of this research makes up the first stage of the action research design. The case studies then provide the first cycle, covering "observing current practice" and "reflecting on current practice" (see Figure 1).

Participants

For each case study, I interviewed a young person with autism who had been supported through the self-disclosure process in mainstream school, a member of staff who had been involved in the process of self-disclosure, and a parent of the child who had self-disclosed.

I chose to interview children with autism who were identified as falling within level 1 on the "severity level" (DSM V, 2013, p. 52) in the DSM criteria, which is the level of

autism considered to need the lowest level of support. In order for me to gain an insight into the self-disclosure process, I felt that it was necessary for the young people to be able to discuss their experiences with me and express their perspectives clearly. Many people in the field of autism refer to these individuals as having "high-functioning" autism (Baron-Cohen, 2008) The participants in this study were identified as having high-functioning autism by their schools and parents.

Some of the participants had received a diagnosis of Asperger syndrome. Asperger syndrome was a separate criterion of autism in the fourth version of the DSM, but was removed from the fifth and most recent version of it in favour of 'autism spectrum disorder' (ASD). Asperger syndrome was defined as an individual who meets the criteria for autism but has no significant delay in their language or cognitive skills (DSM-IV Diagnostic Classifications, n.d.). Before I talked about autism with the young people, I checked which terminology the young people preferred to use. Some understood the labels of 'autism' and 'Asperger syndrome' to mean the same thing and used them interchangeably, whereas others saw Asperger syndrome and autism as different and only associated their condition with one of the labels. I use the term 'Asperger's' rather than 'Asperger syndrome' throughout the thesis, because this is how the young people referred to it themselves.

Sampling strategy

I used a purposeful sampling technique. Participants were asked whether they would like to be a part of the research based on whether or not they were perceived to be appropriate to the research aims and questions (Marshall, 1996). This technique has been highlighted as a valuable one when investigating complex psychological issues (Marshall, 1996).

Inclusion criteria

I found participants willing to be involved in my research through contact with a SENCo in one secondary school. Participants were also found through an autism support service in a different LA. The participant recruitment criteria were as follows:

- The young person needed to have been given a diagnosis of autism.

- The young person needed to be aware of this diagnosis.

- Their current educational placement would need to be in a mainstream secondary school.

- Participants were considered if they had been supported with the process of self-disclosure of their autism to their peers.

- Participants were identified as having high-functioning autism by their school and parent/s.

Participant details

I received details of five young people from the SENCo and autism support worker. During the interviews I became aware that one young person had not been involved in a formal self-disclosure process. I therefore discounted this young person from the research. I have changed the names of the participants in order to protect and maintain their anonymity. Please see Table 1 for the participant details.

Participant	Age of participant	Gender	Age at self-disclosure	Measures completed I = Interview AIS = Autism identity measure ISM = Ideal Self Measure
Finley	16	M	11/12	I AIS ISM
Finley's mother				I
Finley's form tutor				I
Alfie	16	M	11/12	I AIS ISM
Alfie's mother				I
Alfie's TA				I
Matt	12	M	12	I AIS ISM
Matt's mother				I
Matt's Autism support worker				I
Simon	16	M	11/12	I AIS ISM
Simon's mother				I
Simon's				I

form tutor				

Table 1: Participant details

Data collection

Qualitative interviews

I chose to carry out semi-structured interviews. This is a technique of open questioning which allows new ideas to be introduced by the interviewee. The constructivist uses interviews as a method of accessing others' experiences of the world by interpreting the participants' perceptions of their experiences. I used the semi-structured interview as a tool to gain understanding of the young people's experience of the self-disclosure process.

Tomlinson (1989) argued that for researchers approaching interviews from a constructivist perspective it is necessary to have a clear idea of the topic (Tomlinson, 1989). I made my own perception of the topic explicit before I started developing the interview schedule (see Appendix 2). I found this a useful way of ensuring that I had a good grasp of the different areas I wanted to cover before I started. Initially, I developed a very rigid interview structure through this process, which I attempted to use for the first few interviews. During the interviews, however, the detail on the schedule became confusing due to the amount of information present. I also felt that the hierarchical structure with all the detail did not suit the natural fluid process of information gathering. I decided to reduce the interview schedule to just the main topic areas guided by the research questions with a few prompting questions, following advice from King and Horrocks (2010). This provided me with a guide that outlined the essential topic areas but allowed flexibility in the wording and the order in which the topics were addressed within the interview. The guide for the interviews with the young people was as follows:

- **What is your understanding of autism?**

- **Self-disclosure process:**

- What did the process of self-disclosure of autism involve?

- Would you do anything differently if you did it again?

- **Factors influencing self-disclosure process:**

- During this process of self-disclosure, what helped you?

    o Would it have been better if you had more help?

- **Impact of self-disclosure process**

- What sort of impact did the process of self-disclosure have?

    o Did you learn more about autism through self-disclosure?

    o Did self-disclosure have any impact on how you feel about yourself?

    o Did self-disclosure have any impact on people around you?

    o Do you feel it affected other people's understanding of autism?

I found this schedule much more practical and helpful. The flexible structure of the interview was essential to allow me to explore the individuals' experiences, the advantage being that I could cover the topic areas as well as having the ability to explore events and perspectives in a natural manner. The interview process allowed me to acknowledge each experience of self-disclosure as individual and unique. This guide was adapted appropriately for the parents and school staff.

Before starting the interviews, I was concerned that I might not get enough information from the participants, especially as the self-disclosure had happened a few years previously for some individuals. I was quickly reassured because the first few interviews were incredibly rich in their content. Alfie, his mother and Teaching Assistant (TA) spoke at length about the process and demonstrated a good memory of the events. I found their accounts moving and enlightening, with a strong sense of positivity about the process of self-disclosure.

During the first few interviews I found it very difficult to follow what the participants were saying, remember what they had covered, and ask them appropriate follow-up questions. As I carried out more interviews, however, I became more confident in my ability to cover the main topic areas and I referred to the schedule less. This growing

confidence allowed me to pay more attention to the content of the answers and prompt participants to go into more detail in certain relevant areas.

The challenge for many of the interviews was keeping the participants focused on the topic of self-disclosure. Sometimes, the participants diverted from the topic so much that I felt the question had not been sufficiently answered. When I listened back to the interviews, however, I realised the questions often had been answered. On reflection, I felt these unexpected answers were sometimes the hardest for me to process and follow, which was why I was sometimes left unsure about whether the participant had answered the question.

I felt that the parents relished the opportunity to discuss their children at length and were the hardest to keep on the topic of self-disclosure. After the first interview I specified at the beginning that I was interested specifically in the event of self-disclosure to try and focus their thoughts and answers on this event. The staff, on the other hand, were slightly more concise with their answers and sometimes needed to be prompted to say more.

The interviews with the young people were inspiring. They recounted events with amazing insight, reflecting on their own behaviour and the behaviour of others with incredible clarity. I was taken aback by the maturity with which they did this. Their own understanding of autism was beyond what I was expecting, as it was clear through the language they used that they had each developed a unique way of describing their autism.

Autism Identity Scale (AIS)

The AIS was created by Jarrett (2014) who based the questionnaire on the Deaf Acculturation Scale (see Appendix 2). It measures whether individuals with autism feel more aligned to autistic culture, neurotypical culture, both, or neither across five areas: culture preference, cultural knowledge, cultural involvement and cultural identification. Rather than carry out the AIS as a questionnaire, I used it as a tool to gather information about the young people's identities.

I chose not to use the AIS as a measure because I had reservations about the usefulness of identifying the participants' cultural alignment. I did not believe that knowing the

participants' cultural alignment would give me further insight into the young people's perspectives. Instead, I encouraged participants to discuss their answers with me by reading the questions with them. In order to increase the expectation that participants would comment on their answers, I added a space for notes under each question. I did not anticipate that the participants would justify their choice for each question, as this would have taken up too much time.

Using the questions as a qualitative tool provided me with useful prompts to initiate discussions around challenging topics, such as how they saw autism in relation to themselves. Some of the questions prompted some unexpected answers from the participants, which gave me a deeper insight into the young people's perspectives on their autism and their identities. I got the impression as the participants talked through some of their justifications that the questions were prompting reflection. I felt that the AIS encouraged participants to reflect on their own identity by giving them an opportunity to verbalise how they felt about themselves.

Heather Moran's 'ideal self'

The Personal Construct Psychology method developed by Heather Moran, "drawing the ideal self" (Moran, 2012) was used to gather information about how the individual feels about themselves. This technique is based on Kelly's Personal Construct Theory (Kelly, 1955). Kelly proposed that a person develops constructs to help them make sense of the world and these constructs impact on an individual's behaviour and approach to life. The constructs we use most often become our core constructs, which then come to define our identity. The emphasis when 'drawing the ideal self' is on trying to understand a child through understanding the way the child construes him or herself. The procedure provides a very personal measure of self-esteem by giving an insight into how the young person feels they compare to their ideal selves. I used the 'ideal self' activity to support the young people with autism to express how the process of self-disclosure as an event changed their feelings about themselves. Moran (2012) suggests that this can be done by asking the young person to rate themselves on a scale before and after the event.

All the young participants greatly enjoyed carrying out the self-esteem activity, especially when it came to imaging the person they would 'least' like to be like. Descriptions of the 'ideal' and 'not ideal' self were rich and colourful. The findings

allowed me to gain some awareness into how the participants viewed themselves according to the constructs that were important to them. I think this method of drawing out information in regards to self-esteem worked particularly well for the participants because it provided a systematic and depersonalised method of assessing their feelings towards themselves. This perspective was supported by Moran, who argues that this method appeals to individuals on the autistic spectrum because it is systematic (Moran, n.d.).

Procedures

I arranged introductory meetings with the parents. The purpose of this was to introduce myself as the researcher and to ascertain whether the young person would be an appropriate participant. I also wanted to build a positive relationship with the parents in order to gain their trust as I was intending to explore the topic of diagnosis, a subject which can be very sensitive. To ensure the parents were fully informed of how the interviews would work, I discussed the content of the interviews with them in detail. I also wanted to check that the questions would not generate any anxiety for the young people. In order to reduce the possibility of the participants experiencing anxiety, I also used this opportunity to ascertain the most conducive environment, in the parents' view, for the young person's interview and whether any resources would be necessary to aid understanding. This procedure was successful in reducing parents' anxiety about their children discussing a topic which could be challenging for them.

Following this initial meeting with the parent, I then arranged all three interviews with the young person, parent and school staff. I followed the good practice guidance from the Autism Education Trust (AET) (The autism education trust, n.d.). The guidance suggests that visual cues should be used in order to support understanding. I used timelines in order to support the participants in remembering the process of self-disclosure. I also provided a clear visual timetable of the interview to ensure that the participants had an understanding of the structure.

Feedback was offered to each participant once the data had been analysed. This was given in the form of a summary of the findings and a mind map of the emerging themes from the interviews (Appendix 3). I discussed the emerging themes with the young people and described what each theme meant. I wanted to check that my interpretation

of the interviews reflected how the participants understood their self-disclosure. In some cases, this prompted some reflection about the process of self-disclosure. Simon, for example, was interested to hear his form tutor's very positive perspectives on the impact of self-disclosure. He wondered out loud whether the impact had been more positive than he had remembered.

I presented the young people with the model of supportive factors to show them what I had developed from the interviews. On reflection, the model could have been presented in a much simpler format. The model's meaning was clear to me because I was so involved in its creation; however, I do not think that it was an easy model for the participants to understand, especially if they do not already have understanding of the Bronfenbrenner model. The young people looked briefly at the model but did not take much interest in it, perhaps because it was presented in too complex a manner.

Data Collection

Research question 1, 2 and 4:

- Interview with the young person who self-disclosed

- Interview parents and a member of school staff who was involved in the process

Research question 3: What impact does the process of self-disclosure have on the individual and their environment?

- Interview the young person who self-disclosed

- Use Heather Moran's "ideal self" to look at the perceived impact of the self-disclosure event on the concepts identified

- Interview the parents and a member of school staff who was involved in the process

- The AIS was used in a qualitative way to prompt discussion about how the young person feels about autism and their identity (Jarrett, 2014)

Data analysis

I began fully transcribing the interviews, as I did not want to miss any of the detail. I soon realised that this was a much more complex process than I first realised. There were many points throughout when the participants discussed topics that I did not consider relevant, for example. As a result, the first transcription took hours and was incredibly lengthy. For the next transcriptions, I decided to transcribe only the content of the interview that seemed relevant to the research questions (see Appendix 4 for examples of transcribed interviews).

Throughout the interviews I was struck by the depth and breadth of insights that each participant provided. At this point I found it difficult to envisage how the thematic analysis could capture the essence of each interview. I was concerned that the depth of the interviews and their individuality would be lost through the process of attempting to find shared themes.

In order to analyse the qualitative data, I used King and Horrocks (2010) as a guide for the thematic analysis process. This is a three-stage procedure that involves developing interpretive codes from descriptive codes, then grouping these codes to find the overarching themes (for a more detailed description of how I executed this see Appendix 4). The analysis process proved challenging because each of the case studies were so rich in themselves. It was essential to remain flexible throughout this analysis, as I re-labelled and regrouped quotes from the case studies several times throughout the process as the themes emerged. The interpretive codes, for example, became either more general or more specific to incorporate the themes emerging from each case study. At various points I became absorbed in the details of what the participants had told me, thus I found it difficult to group and label certain significant sections. I was very aware of the risk of misinterpreting or undermining the importance of the content of each interview.

I found it incredibly challenging to hold themes from 12 interviews in my head, so I produced mind maps of each case study detailing the themes and the overarching themes. These mind maps were continually evolving and helped me to visualise each case clearly (see Appendix 4 for examples of the final mind maps of themes). Towards the end, I realised that the interpretive codes did not fully represent the content of some

of the interviews. I overcame this by analysing the impact of the self-disclosure process as separate case studies in order to incorporate the differences between each one.

The main advantage of this process was that I was able to gain a deep understanding of the similarities and differences between each case study. I also gained information about the differences and similarities between the participants in each case study. Within case study analysis, it is essential to interpret the significance of the data rather than the frequency of its occurrence. This offers "the researcher an insight into the real dynamics of situations and people" (Cohen et al., 2007, p.258).

The AIS was analysed qualitatively. The statements made by the young people were collated and those that were considered important in relation to the research questions were summarised.

The 'ideal self' measure was analysed individually for each of the case studies. This analysis was carried out with the young people themselves. I identified a selection of some of the concepts that were identified in the drawing of the 'ideal self'. For each case study I selected the concepts that seemed the most relevant to the research question. The young person was then asked to identify the opposite of that concept. The concepts were rated zero to 10. The young person was then asked to rate where they felt they were on that scale at that moment and where they would like to be. This enabled me to understand which concepts the young person saw as being positive. The young person was then asked to plot on the scale what they felt their score had been before self-disclosure. I recorded the difference between the young people's scores before and after self-disclosure and judged whether or not this was a positive change from where they had plotted their 'ideal self'.

For research questions 1, 2, and 4, I reported the emerging common themes from all of the case studies.

For research question 3, I reported the emerging common themes. For this question, however, I believe that the differences between the case studies and the participants provides crucial information about the perceived impact of self-disclosure. In order to analyse these differences effectively, I have given a separate analysis of each of the case studies.

Ethical considerations

I have previously been made aware of the delicate nature of the topic of self-disclosure by parents, who were very anxious about what their children were told about autism. I realised that in order to increase the likelihood of the parents feeling relaxed about their child's participation in the research, I needed to be clear about what the research would involve and the purpose of the research. I emphasised that the research would be applied in the future to support other young people with autism wanting to self-disclose.

My concerns were alleviated when the parents all expressed interest in being involved in the research when approached by the school. When I first contacted them, however, I sensed some anxiety around the topics I would be covering in the interviews. One parent was unsure about participating and another expressed concern about the content of the questions in the 'ideal self'. She believed that her son might find it challenging to discuss the difference between his 'ideal' and 'actual' self, because it may prompt him to think of himself in a negative way.

I realised it would be essential to personalise each of the interviews in order to address the topics in the most appropriate way for each participant. I took time to meet with the parents and discuss the research in as much depth as they wanted. I gave them detailed information about the interviews and asked them advice about their child, such as the best location and resources to use within the interviews. Once these discussions and introductory meetings had taken place, all of the parents gave their consent and in the end suggested very few further changes. Building rapport and a positive relationship with the parents from the beginning in all of the case studies was essential in order to reduce their anxiety and reassure them about their children's participation in the research.

In preparing for the interviews with the young people I was aware that some of the questions might be challenging and difficult for them to answer because of the personal topics I was covering. I was expecting to have to approach some of the topics very sensitively. In order to engage the young people fully, I carried out the interviews in an informal style and always begun by introducing neutral topics of discussion. I also ensured that the participants were aware they could stop the interview at any time and offered a debrief session to discuss any issues that arose.

To my surprise, the young people were enthusiastic about the topics and they spoke openly about themselves, their self-disclosure and their autism. It was interesting for me to note the parents' concerns were not reflected in the interviews with the young people. This observation could suggest two different things; either the young people were very good at hiding their emotions, or the topic of self-disclosure proved a more emotive topic for the parents than it did for the young people. I believe that the latter is more likely because the young people were eager to discuss the subject and the content of their interviews did not suggest they were anxious. It is possible that the parents' anxiety originated from their increased awareness of the social challenges and difficulties that could have arisen from the self-disclosure process.

Chapter 3

Findings

In the thematic analysis, participants tended to echo the same ideas about the process and consequences of self-disclosure. Some themes emerged consistently across the interviews and were clearly salient (for a diagram of all the common themes please see Appendix 4). Unique themes also arose in each of the case studies. I felt that the emergent themes matched well with the research questions that I had set out to explore. Eight overarching themes arose from the data that I considered significant. All of these themes were made up of a few interpretative themes. For four of these overarching themes, I felt that the smaller interpretative themes were too significant not to report. I have therefore labelled these themes under the overarching themes in the results section.

Within a few of the case studies, unique themes arose. In order to understand these unique themes, I decided that it would be essential to analyse them in the context of the case study as a whole. Within the "impact" section of the findings, each case study was therefore analysed in order to examine the importance of these distinct themes on the impact of self-disclosure for that young person.

Themes emerging for the process of self-disclosure

Six main overarching themes emerged in the descriptions of the process of self-disclosure. These themes provide insight into how and why self-disclosure had happened. These themes were*: 'transition to secondary provision', 'awareness of differences increasing difficulties' 'desire to change peers' attitudes and behaviours', 'celebrating autism', 'knowledge of individual and autism' and 'supportive environment'. These themes encompassed a holistic picture of the experience of the young people with autism in their educational environment, including the behaviour of classmates, desire for change, and aspects of the environment that were considered important.

'Transition to secondary provision' describes how the secondary school environment was considered to be a particularly difficult educational provision for the young people with autism:

"secondary school was where it all kicked in, because it's new people, you know, new experiences" (Alfie's mother).

Simon showed awareness that starting secondary school had been difficult for him, stating:

"Generally, I hadn't got off to a good start".

There was a sense that the young people's differences were magnified in this environment because it was a new situation and their peers were less accepting of differences. Finley showed awareness that his classmates in primary school had been more accepting of the differences he displayed, saying:

"In primary school nobody really cared that I acted the way I do".

Matt's mother described how growing up with the other children in primary school was a protective factor for understanding differences:

"Primary school was an easy ride for him. The kids are non-judgemental. They started together when they were four".

Consequently, the young people described finding themselves in a less sensitive environment that increased the difficulties they were experiencing as a result of the transition.

'Awareness of differences increasing difficulties' describes how the young people experienced difficulties at school as a result of their differences. These difficulties were described as the reason the young people felt different. Behavioural differences between them and their peers had become noticeable and difficulty in the social environment sometimes led to the young person with autism displaying challenging behaviour. Simon spoke of becoming very angry with others:

"I would walk out of lessons, I would shout at someone, I would hide under my blazer. That was my favourite, underneath the tables".

The young people had difficulties making friends and understanding their classmates. Alfie's TA describes how Alfie "found certain aspects of the environment and social interaction very, very difficult". In many cases the social integration difficulties resulted in the young people being isolated, picked on, mocked and teased by their classmates:

"I think school identified that he was quite isolated in his class" (Matt's ASW).

Finley identified how his classmates behaved as:

"Kids can be harsh, bullies sometimes".

I don't think that the difficulties these young people experienced in their social environment were enough to prompt the self-disclosure in themselves. It was the young people's awareness of these social difficulties that led to confusion and frustration for them:

"Whenever I spoke to him, that was always the first thing he would ever mention. Because of his Asperger's he struggles to make friends. "I can't make friends. I can't talk to people. Nobody wants to talk to me" (Finley's FT).

The participants also described how the young person's awareness of these differences caused them frustration and upset.

In summary, the theme '*awareness of differences increasing difficulties*' describes how the young people felt "different" to their peers. They also felt they were perceived as 'different' by their peers:

"It was blatantly obvious; I was the different one" (Alfie).

Finley also reported that:

"I started to feel different from everybody else".

Due to the heightened awareness of the difficulties experienced by the young people with autism, a '*desire to change peers' attitudes and behaviour*' evolved. Matt said he self-disclosed in order to improve his social life, for example. He was hoping that the self-disclosure process might make it easier for his classmates to interact with him. This

theme was proactive and encompassed a desire by the young people, parents, and school staff to attempt to educate others about autism. Self-disclosure was seen as a way of increasing peers' understanding of autism by providing explanations for the observable differences. Finley and Matt echoed this in their interviews:

> "I just wanted to make people understand me. I would have done whatever it takes to get there" (Finley).

> "I believe that my form didn't know much about autism and I wanted them to understand a little bit more about me" (Matt).

There was an underlying assumption that classmates were sometimes aggravating the difficulties due to ignorance of the young person's needs rather than with malicious intent. Self-disclosure evolved as a method of improving the social environment for children with autism by increasing their peers' sensitivity to their needs. This theme was reflected in the content of the self-disclosure. Providing practical strategies within the self-disclosure was a method of increasing sensitivity to the needs of the young people who were self-disclosing, thus changing peers' behaviours. The young people first described some of their difficulties to their peers. Alfie's mother gave an example of how Alfie had talked about his difficulties:

> "I struggle when it is too noisy or things go at a certain pace".

Matt's ASW outlined the information Matt had wanted to include in the self-disclosure:

> "He was really good at going through the things that he didn't like. He didn't like it when they were speaking or singing behind him or whispering in class or being rude to the teachers".

After describing these difficulties, changes in behaviour were suggested by the young person in the form of strategies:

> "It was just about how I see the world and how other people should react around me" (Finley).

Alfie's mother described how the self-disclosure was carried out in order to teach others how best to react to Alfie when he became upset. Previously, Alfie's classmates had attempted to comfort him, whereas Alfie would have preferred to be left alone at these times.

Driven by the desire to increase understanding, it was considered important to focus on the individual self-disclosing by making the content personal and specific to them. Alfie's mother encouraged Alfie to make the self-disclosure personal:

> "I said, 'Alfie, speak from your heart. Don't speak from a book. A book is not all of you, it's Asperger's in general. So if you are going to talk about yourself, talk from the heart'".

Alfie's TA spoke about the importance of making the self-disclosure unique:

> "The whole process of disclosure was not about autism awareness; it was about the child. That particular pupil at that time".

The theme '*celebrating autism*' describes the general approach to autism displayed by many of the participants and young people. There was evidence of this celebratory approach towards autism throughout the whole process of self-disclosure, from the moment the young people were first informed about their diagnosis to their self-disclosure presentations.

Parents described encouraging their child to see autism as a difference rather than a disability. Alfie's TA reflected this when she spoke about Alfie's parents' attitudes towards autism:

> "They also have a positive attitude, 'there is nothing you can't do'".

Matt's mother described how she had helped Matt to understand autism:

> "You are different, this is your strength and this is your weakness. We are all different".

It is clear that parents encouraged the young people not to see autism as a disadvantage:

> "There are no limitations regardless of who you are in life. It doesn't stop you. If you have a will in life, go for it" (Alfie's mother).

The young people themselves spoke about their understanding of autism in a very positive way. Matt, for example, corrected his own use of the word "disorder" when describing autism, saying:

"Well it's not really that much of a disorder".

Other children also described their own perspective of their autism in a positive manner:

"I try to, you know, having fun and sort of looking at things with an open mind, try to look at things in a different way" (Alfie).

The content of the self-disclosure process reflected this positive approach. Alfie's TA said:

"What you have to do is focus on the child and their individual strengths and build upon them".

Many of the young people took the opportunity of self-disclosure to speak about their interests and their strengths, outlining what they were good at and what they enjoyed. '*Celebrating autism*' was also reflected in the approach held by the individuals supporting the self-disclosure process. The interesting and amazing aspects of autism were outlined to peers during the self-disclosure:

"So we would talk about hyper senses and hyper abilities because it is cool" (Alfie's TA).

Simon described how his TA gave the following metaphor to describe Asperger's to his class:

"Normal people without Asperger's syndrome run Windows and people with Asperger's run Macs and Macs are better".

Finally, '*celebrating autism*' included looking in a more general way at the strengths associated with autism. Famous individuals such as Bill Gates (co-founder of Microsoft, believed to have autism) and Derek Paravicini (famous musician with autism) were introduced as 'Aspie heroes'. Finley's mother described how the school supported the children in understanding difference as a positive:

"It was always done in a positive light. Then, when he moved to secondary school at 12 they had pictures of all sorts of people on the walls, for instance, and he would come home and say, 'did you know that Keanu Reeves has this'" (referring to Keanu Reeves having dyslexia).

Celebrating successful individuals with autism was an important part of the self-disclosure process. Alfie's TA stated:

> "Basically he just came out in front of the class and told them that he had Asperger's syndrome and described and talked about his Aspie heroes".

Matt's statement demonstrates how finding out about individuals with autism who had done well made him feel good about his future:

> "It encouraged me to do better in life because I know a lot of people can do great things. But I know now many people who did great things, had autism. So I think I might do great things…".

In summary, a positive and celebratory attitude was projected by the participants. The theme '*celebrating autism'* describes an overall sense that the young people with autism could do anything they put their minds to and autism was not a barrier. Alfie showed awareness that his positivity could rub off on others:

> "For me to be happy about it, cause, if I was happy then that would reflect on them and they would be happy about it as well".

'*Knowledge of the individual and autism*' referred to the young person's self-awareness and the level of knowledge of supportive individuals at school and at home. Many of the participants outlined the importance of the young person's awareness of their own autism:

> "In terms of how it affected him, I think he was very aware." (Finley's form tutor).

The young people had gained this understanding through many means including support from parents, support staff at school, and their own research into autism. Alfie read lots of books about autism:

> "I read books on the subject – Martian in The Playground by Claire Sainsbury, that's another good one".

The young people had read books, researched on the internet and watched YouTube videos of autism advocates. Matt's mother described why self-awareness was important

"You need to understand your condition before you can describe it to other people".

It was also considered important for the adults to have a good experience and understanding of autism. Autism impacted on the young people in very different ways, so general autism information was not considered to be that useful. It was more important to have a good understanding of the individual. Alfie hinted that his TA at the time had been very knowledgeable about autism:

"She's done two publications on Asperger's and autism and her experience in the area is very…"

Finley's mother outlined how all individuals with autism are different, therefore general autism education is not enough:

"I think one of the hardest thing is, as a disability it's so particular to each individual child. They're all just completely different. So I think that that knowledge is power really, yeah.".

Education was also considered important for parents as well as the school:

"Educating ourselves so you understand when they had a bad day and helping them out, instead of making it worse. I think it is a case of educating everyone. Education for everyone!" (Alfie's mother).

'_Supportive environment_' refers to the importance of creating an inclusive and accommodating environment for self-disclosure. Many sub-themes were identified under the main theme of 'supportive environment'. I have described each of these sub-themes because I felt each were very important in outlining how supportive environments in schools were created and maintained. An overall '_ethos of inclusion and equality_' was considered important:

"If they want these children in mainstream school you have to support them. You have to follow it through within the foundations I think, in the school" (Finley's mother).

Developing '_trusting relationships_' between home and school was also considered critical especially by the parents of the young people. This involved constant communication:

"I personally think that if you are supporting a child with autism, you have to keep going back to the parents and saying, 'we are going to do this'" (Alfie's TA).

On a more individual basis, a supportive environment was considered to be one that encourages the young person to develop *'trusting relationships'* with an adult. This was described as someone to turn to for support and someone who provides '*teaching and advice*'. In order to maximise the positive impact of the self-disclosure a *'supportive peer group'* was considered important.

Finally, the process of self-disclosure was acknowledged to be the beginning of a lifelong journey rather than a short intervention. This was encompassed in the theme '*continued support*'. Supporting the young people in telling their peers was considered to be the start of this journey. Self-disclosure would then evolve and develop for the young person in different ways depending on themselves and their environment. Continuing support for this journey was considered necessary after the self-disclosure process.

Impact of self-disclosure

Common themes
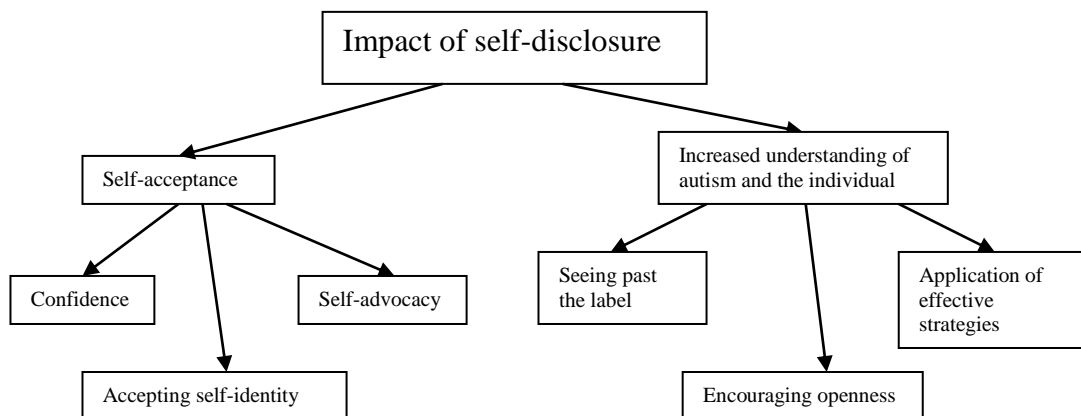
Figure 2: Emerging themes for the impact of self-disclosure

In all of the case studies, two overarching themes emerged: *'Increased understanding'* and *'self-acceptance'*.

'*Increased understanding*' refers to how self-disclosure was considered to improve others' understanding of the young person with autism:

> "I think there was more understanding there" (Simon's teacher).

It enabled peers to understand the reason behind the differences by educating them about autism. Themes emerged that demonstrated how peers' understanding had been improved, which were '*Encouraging openness*', '*Application of effective strategies*' and '*Seeing past the label*'.

'*Encouraging openness*' demonstrates how self-disclosure opened up discourse about difference and autism, as Finley's mother described:

> "I think there was a bit of a chat about it between the kids. It became like normal to chat about it".

Alfie's TA describes how "he could go to his peers to say 'you know what sorry, is that an Aspie thing to say?'". Alfie became so comfortable talking about autism with others:

> "I joke about my Asperger's and there has been a bit of banter. I like making jokes".

'*Application of effective strategies*' refers to the young people listening to the strategies suggested in the self-disclosure process and applying them to support the individual when necessary. For Alfie, for example, when he became overwhelmed he often needed space. Before the self-disclosure, some of his classmates would approach him to comfort him, not realising that actually this overwhelmed him more. Alfie's mother described how the self-disclosure helped his classmates to understand:

> "So I think it helped him for people to understand he just needs a little time on his own and then he is fine".

Another example was when Matt left the class because of difficulties he was having coping with the noise a few weeks after the self-disclosure. Some of his classmates came out to check he was OK:

> "They had bought another chair because they didn't want him to be sitting on his own. They were talking to him and stayed with him" (Matt's ASW).

Matt's ASW felt that the self-disclosure had made them more aware of the some of the difficulties Matt faced and this event demonstrated that they were more likely to help him.

'Seeing past the label' suggests that self-disclosure supported classmates in gaining more information about the individual and meant that peers began to get to know them on a personal basis. Simon's FT stated:

> "The way that they treat him has completely changed. They treat him as like a member of a group rather than the, 'Simon who's a bit different'".

This theme was also expressed very clearly by the TA who had worked with Alfie, who said:

> "Greater knowledge brings greater understanding and respect. And that's something that children do not give automatically".

It was also expressed by Alfie's mother, who believed that the self-disclosure had helped classmates to see Alfie as a friend:

> "I think people started to listen to him and see what his interests are and then realise actually we have loads in common and they build those relationships".

The overarching theme of *'self-acceptance'* emerged. The self-disclosure process was seen as an event that supported the young people in discovering and feeling happy about themselves. Self-disclosure improved some of the young people's confidence:

> "So after the disclosure he was very proud about what had happened. He talked about it all the time" (Alfie's TA).

Parents also perceived a change in confidence after the self-disclosure process:

> "His confidence has really come on.. He walks standing up straight" (Alfie's mother).

> "I think it is more for him than for the class. The class is aware anyway. For him to be able to stand in front of everyone and talk about it. It's confidence there" (Matt's mother).

Some participants believed the self-disclosure supported the young people in accepting autism as an important aspect of their identity. Alfie's mother and TA spoke about how the process of self-disclosure allowed Alfie to feel good about who he was:

"It was part of him and it was not something which he hid or denied" (Alfie's TA).

His mother echoed this, saying:

"I think that's when he, actually, 'this is who I am. I can do this and you can either take it or leave it'".

After the self-disclosure Finley wrote a poem about Asperger's. Finley's mother recited an excerpt from the poem:

"I've just got Asperger's and it's just part of me".

This quote was given to demonstrate how self-disclosure helped Finley to accept autism as a part of his identity. For these children it seemed that there is something about the process of the self-disclosure that enabled them to accept autism as a part of who they are.

The practical implication for some young people of this self-acceptance was the ability to self-advocate. For example, Finley's mother talked about how Finley was able to verbalise his needs:

"So now if he's really, really angry he'll say 'I just really need some time, I need to go for a walk'".

Alfie in particular was very open about his autism after the self-disclosure. Alfie's TA said:

"If he wanted some help he could go to his peers to say 'you know what sorry, is that an Aspie thing to say?'" "He would say 'I don't understand you, I am autistic.'"

Matt's ASW described how the self-disclosure supported the self-advocacy:

> "I think it gives him a bit more of a language about it. Sort of almost practice being able to say that in a much more everyday way, without it being planned."

In two of the case studies, participants had different perceptions of the impact of the self-disclosure process. These individual differences will be further discussed in the individual case study analysis below.

Finley's self-disclosure

Summary of Finley's self-disclosure

Finley was diagnosed with Asperger's at 10 years old. His parents told him that he had Asperger's as soon as the diagnosis came through. He describes feeling shocked when he was first told about the diagnosis. Finley says he did not tell others about his Asperger's at this time because he didn't really care to. When Finley was 11, he started to feel different and began to want to explain Asperger's to others. He said that he had begun to feel inferior to others and he wanted to make himself "feel equal". In secondary school, he described how some people began to tease him and he took the teasing literally and began to get into trouble. Finley self-disclosed to his tutor group when he went to secondary school.

Understanding of the impact of autism

Finley described his Asperger's thus:

> "In some ways that is a good thing. I have a very musical brain. I have perfect pitch. I can play musical instruments fluently. It is very handy in the non-social world; in the social world you are very distinguishable. People start to notice you as different. Some people use that in a good way, others don't. That's my perception of it".

AIS results

Finley saw autism as a very important part of his identity, saying:

> "If autism isn't a part of my identity, I don't know what is".

He also stated he felt that if members of his family had Asperger's, it would help him relate to them. This suggests that Finley feels he can communicate better with other individuals with autism.

Summary of impact of self-disclosure from interview

Overall, parents and teachers considered that self-disclosure had a positive impact. Other emerging themes were *'expectations not met'*, however Finley felt that self-disclosure had been successful in some ways. He expressed awareness that the positive impact of the self-disclosure had only continued for a few weeks after the event, however, there may have been several reasons for this. Finley believed that the '*timing*' of the self-disclosure had not been right. He felt he was unable to verbalise what Asperger's meant to him clearly during the self-disclosure process. Finley believed that if he had been able to give a more personal description of his Asperger's then his peers would have responded more positively. As it was, Finley did not feel the general information provided by his TA accurately described how he felt about himself.

Finley's mother provided another reason that might explain why Finley felt the impact of the self-disclosure process was short lived. She described how self-disclosure was bound to lead to disappointment for Finley because the expectations of the impact were too high. Finley thought that telling others about his Asperger's would solve all of the difficulties he was having socially and when his peers didn't react in quite the way Finley was expecting, he felt that the self-disclosure had not changed anything. Finley's mother spoke about the importance of "managing expectations" of the impact of self-disclosure as a supportive factor.

ISM

Concept (0) and opposite (10)	Rating post self-disclosure	Rating during interview	Difference between 'actual' and 'ideal' self	Difference between post self-disclosure and now
Relaxed – A worrier	8	8	8	0
Good communicator – Socially awkward	5	5	4	0
Caring – selfish	2	2	1	0
Popular – Lonely	6	6	4	0

Finley rated himself as quite far from his 'ideal self' on many of these concepts, which suggested that Finley would like to worry less, be less socially awkward, and be more popular. There are large discrepancies on some of these scales, which suggest that Finley may have felt quite negatively about himself in social situations. Finley felt that self-disclosure had not changed any of the concepts identified in Heather Moran's 'ideal self' activity. This demonstrates that Finley felt the self-disclosure process did not impact on how he felt about himself in terms of the concepts above (for more details of Finley's 'ideal self' activity please see Appendix 5).

Alfie's self-disclosure

Summary of Alfie's self-disclosure

Alfie was eight years old when he found out that he had Asperger's. In primary school, he felt that everyone knew that he was different. He would mention that he had Asperger's in conversation if he felt it was appropriate. Alfie's interest in finding out about Asperger syndrome grew between the ages of 9 and 11 and the transition to secondary school in year 8 spurred him on to find out more about his condition. At this point, Alfie did not want people to know that he had Asperger's and he was very selective about who he told. However, the new environment in secondary school proved to be a challenging one. Alfie describes finding himself in "awkward social situations". Alfie chose Asperger's as a topic in his Year 8 public speaking assignment.

Alfie describes his Asperger's in the following way:

> "What's identified with Asperger's? Sometimes an extended memory, advanced vocabulary, limited social skills and response to, sort of, stimuli, whether that be social interaction with other people. I don't know, for me, it's made me more observant if anything."

AIS

Alfie felt that autism is an important part of who he is. He stated that "it has shaped him".

Alfie feels comfortable sharing his autism label, but is also happy not to share it "if the situation needs it". He appreciates knowing people who are both autistic and non-

autistic because he appreciates seeing "different perspectives". Alfie's best friend also has autism.

Summary of impact of self-disclosure from interviews

Overall, self-disclosure was considered incredibly positive by all the participants interviewed. A further theme that emerged about the impact of self-disclosure was *'understanding positives and strengths'*. Peers, in this case, were felt to have a greater understanding of Alfie's strengths and the things he was good at. It was felt that without self-disclosure they would not have become aware of these strengths.

In this case study, both the parents and the TA had a very positive attitude about autism themselves, expressing that autism should not hold an individual back. The TA spoke about positivity spreading like a ripple in a pond. I felt that this positive, 'can-do' attitude was very obvious from the interviews and perhaps this is what had made the self-disclosure for this individual so positive.

ISM

Concept (0) and opposite (10)	Rating pre self-disclosure	Rating during interview	Difference between "actual" and "ideal" self	Difference between before self-disclosure and now
Selfless – Self absorbed	4	4	2	**0**
Easy-going – Unpredictable	7	6	3	**1**
Reserved – outspoken	5	3	1	**2**
Intelligent – ignorant	3	3	1	**0**
Engaging – boring	5	5	5	**0**

Most of Alfie's "actual self" scores were close to his "ideal self" scores apart from within the concepts; "engaging- boring" and "easy-going –unpredictable". This demonstrated that Alfie felt that he could be more easy-going and more engaging. Alfie felt that self-disclosure had a positive impact on these two concepts. He felt self-disclosure had made him more easy-going and less unpredictable. Alfie also felt that

self-disclosure had made him more reserved, which he felt was a positive thing. All the concepts that Alfie felt had changed after self-disclosure seemed to be about how Alfie perceived himself in social contexts. This suggests that Alfie believed self-disclosure supported his interactions within social groups (see Appendix 5).

Matt's self-disclosure

Summary of Matt's self-disclosure

Matt was diagnosed with Asperger's when he was six years old. He was told about the diagnosis when he had finished primary school. Matt remembers looking through a book with lots of examples of people who have autism. He said that learning about people like Einstein and Bill Gates helped him:

> "I knew I was different but that actually helped me and actually encouraged me because I know I could do good things".

School staff reported that Matt was struggling to make friends and was isolated in his form group. Matt disclosed his Asperger's to his form group in Year 8.

Matt described his Asperger's in the following way:

> "Well, I'd say your brain is like a bunch of gears moving all together and all those gears make your brain function. Asperger's basically just changes the direction of all those gears, to make you think differently. Just changes the way…how your brain works, how you process information. That's how I see Asperger's, it just changes the way you think".

AIS

Matt makes it clear that although Asperger's is "a part of who I am". He does not believe that it is an 'important part' of who he is. Matt also expressed that he feels that friends having a label is not important:

> "It doesn't matter if they have Asperger's or not".

When asked if he wished he did not have Asperger's, he commented that although he is happy with who he is, there are some instances where he wished he could understand others better:

"I sometimes wish that I could understand how people feel".

Summary of impact of self-disclosure from interview

There were no unique themes emerging from this case study. Overall, self-disclosure was considered to be very positive from all the participants, although Matt's mother felt she did not know much about it because Matt liked to keep school separate from home. Matt especially believed it had been positive, stating:

"I thought it might help and it actually did help" (Matt).

ISM

Concept (0) and opposite (10)	Rating pre self-disclosure	Rating during the interview	Difference between "actual" and "ideal" self	Difference between before self-disclosure and now
Kind – Selfish	0.7	0.7	0.4	**0**
Thinks about other people – thinks about themselves	3.7	3.5	1.5	**0.2**
Helpful – someone who makes things harder for others	2.5	2	0.5	**0.5**
Good to be around – Disruptive	2	1.6	0.6	**0.4**

Overall, Matt identified himself as being very close to his 'ideal self' on many of the concepts above. Matt felt that he would like to think about other people more and be more helpful to others. These scores suggest that Matt has relatively high self-esteem within these concepts, because there is little discrepancy between his 'actual' and 'ideal' self. Matt felt that the self-disclosure process had a positive impact on his ability to 'think about other people' and it had made him more 'helpful'. He also felt that self-disclosure had meant that he was less disruptive and someone who was 'good to be around'. This shows how Matt believed that self-disclosure had supported his

interactions with others (for more details from Matt's 'ideal self' activity see Appendix 5).

Simon's self-disclosure

Summary of Simon's self-disclosure

Simon was diagnosed with Asperger's when he was attending primary school. He remembers finding out about this diagnosis around the age of 11. Simon had already begun to feel different from his peers by this age. His parents told him about the diagnosis when he asked them why he felt different. He did not talk tell about this diagnosis at all at school until he was in year 8. When he started at secondary school there had been some difficulties with Simon and his tutor group. School staff felt that carrying out a presentation about his autism, would improve his situation, so they encouraged him to do this. At the end of Year 8, he carried out a presentation about his diagnosis with his class. He was supported in the presentation by another young person who had already self-disclosed to his peer group.

Simon described his Asperger's in the following way:

> "Before I was told I had Asperger's I thought I was naughty. Then I found out and it gave me a reason about why I was different. I am more intelligent at the cost of my social abilities. It doesn't have a massive effect on my life. It does impact on eye contact, speech and I used to have an urge to do silly things. I lost my temper easily".

AIS

Simon does identify with the 'Asperger's' label:

> "I say I have Asperger syndrome".

Simon is aware of this label but he stated that:

> "I don't let it affect me".

In response to the statement: "Having Asperger syndrome is an important part of my life" he stated:

"It is a label. It doesn't describe who I am it is just something I have got".

Simon does feel that autism is a part of his identity, but he clarified how he felt about autism saying:

"It is a part of me but it is not me".

In response to many of the questions relating to whether he would prefer to relate to others with autism or Asperger's syndrome, Simon made it very clear that the label was not important to him, stating:

"It depends on the person, autism or no autism".

Summary of impact of self-disclosure from interview

The staff member at the school felt that self-disclosure had a positive impact for the young person and his peers and it marked a turning point for Simon's inclusion within his tutor group at school.

An emerging theme for both Simon and his mother was *'doubt'*. Self-disclosure was originally suggested by school staff who had experienced the positive impact of other self-disclosures. This unique emerging theme went some way to explaining the reasons behind individuals wanting to self-disclose. Simon and his mother, for example, experienced some pressure, because the school felt that self-disclosure would have a positive impact following successful self-disclosures by other children. Simon described being persuaded that it was a good idea:

"It was marketed as this grand thing that would make everything better".

His mother echoed her son's sentiments. Both Simon and his mother felt the positive impact was short-lived and did not live up to Simon's high expectations. Simon reported that:

"Overall it was positive but it was not the golden package it was set out to be".

ISM

Concept (0) and opposite (10)	Rating pre self-disclosure	Rating during the interview	Difference between 'ideal' and 'actual' self	Difference between self-disclosure and now
Clever – stupid	3	2	0	**1**
Caring/outgoing – self-centred	8	5	2	**3**
Loud – quiet	8	7	2	**1**
Good at relating to people – antisocial	7	3	2	**4**

These scores demonstrate that Simon would like to be more caring, louder and better at relating to people. The differences between his scores on his 'ideal' and 'actual' self were not huge, which may indicate that Simon was relatively happy with himself within all of these concepts. Simon rated all of the post self-disclosure scores more positively. He rated himself as; cleverer, more caring, louder, and better at relating to people after the self-disclosure. This shows that he believes self-disclosure did impact on how he saw himself, especially in relation to the concepts Simon identified that involved interacting with others (i.e. relating to and caring for other people). This suggests that he believed his self-disclosure helped him to interact better in his social environment.

Chapter 4

Discussion

I have developed the following model from reflecting on the emerging themes from the interviews carried out in Phase One of the research. The following model gives an overview of the process of self-disclosure for the participants in this research:

```
┌─────────────────────────┐
│ Difficulties in secondary│
│ provision               │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│ Young person is aware of │
│ differences             │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────────┐
│ Desire to improve environment by│
│ changing attitudes and behaviours│
└─────────────────────────────┘
            │
            ▼
┌──────────────────────────────────┐
│ Increase understanding through    │
│ education                         │
│                                   │
│  • Increasing understanding of the│
│    impact of autism on the young  │
│    person.                        │
│  • Increasing positive attitude through│
│    celebrating autism.            │
└──────────────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│ Improved understanding of│
│ autism and the individual│
└─────────────────────────┘
        ╱           ╲
       ▼             ▼
┌──────────────┐  ┌──────────────┐
│ Self-acceptance│  │ Change in peers'│
│               │  │ attitude and   │
│               │  │ behaviour      │
└──────────────┘  └──────────────┘
```

Figure 3: *Process of self-disclosure.*

The above model provides some understanding about how an individual might decide to self-disclose and how self-disclosure might support young people who are having social difficulties in mainstream secondary school. The process of self-disclosure might not

always follow this model, however. In different contexts such as work environments, for example, difficulties in secondary provision would not always act as a cause.

I will now address the main themes that arose from the data and discuss these in relation to the research.

Impact of self-disclosure

This is one of the first pieces of research that has explored the reasons behind the self-disclosure process and the impact of self-disclosure on the individual and the environment. It provides in-depth insight into the complex events and experiences that may lead to a young person with autism opening up with their peers about what their autism means to them. Some aspects of the findings resonate with anecdotal evidence from professionals in the field and accounts from individuals with autism. The experiences described by the participants also reflect wider research carried out in the field of autism.

Overall, the participants reported that self-disclosure had a positive impact for both the social environment around the young people and for the young people themselves. In every case, the participants discussed how peers' attitudes and behaviour changed as a result of their self-disclosures. In a couple of the cases, however, participants perceived the impact differently, but this will be discussed in more detail below (see the 'individual analysis discussion' section).

These case studies demonstrate that self-disclosure can be used as a tool to change others' behaviours towards individuals with autism. This research supports the beliefs held by self-advocates in the field, such as Willey (2006) who argues that self-disclosure serves to educate others about the autism spectrum. The self-disclosure process was believed to adapt the environment to the young person's needs by educating others about autism. The experiences of these young people with autism reflects previous research in the area, which has found that educating peers about autism can improve inclusion for those individuals (Silton & Fogel, 2012; Barrett, 2004; Gus, 2000).

This research provides a richer understanding of how social inclusion can be improved through peer education. The themes portray how self-disclosure helped to reduce the stigma around the label of autism. Prior to self-disclosure, the differences and difficulties experienced by the young people had been perceived to be a barrier to their social inclusion. Self-disclosure reduced this barrier by initiating open discourse about these difficulties. It seems that initiating conversations about their perceived differences provided opportunities for the stigma to be made explicit. Making it explicit and explaining the difficulties reduced stigma and increased social interaction with peers.

The main theme that gives insight into the reason for the increase in social interaction suggests that as peers' understanding of autism increases, the atmosphere becomes more supportive. Self-disclosure provided peers with explanations for behaviour they had previously considered 'weird'. Peers reacted with curiosity, wanting to know more about autism and the individual. Peers were given strategies to support the young person, such as using clear language and knowing when to give them space. It is not entirely clear what motivated this change in behaviour for the participants' peers, but the strategies and explanations given in the self-disclosure were considered to initiate this change. In some of the case studies, peers considered to be more empathetic were more likely to listen and change as a result of the self-disclosure. It is therefore possible that the personalities of the peers to whom the young person self-discloses is an important factor in the perceived impact.

Furthermore, self-disclosure had important implications for the individuals who self-disclosed. For some it was perceived to have little impact; however, for others, it was seen as a turning point. For those individuals, it seems that the process of speaking out about their autism supported their own acceptance of the label. Their confidence grew and their social identity was perceived to have developed after the self-disclosure to their peers. From Heather Moran's 'ideal self' measurement activity, I found that three of the individuals felt they had become closer to their perspectives of their 'ideal self' on measures that related to social interaction and communication. This suggests that self-disclosure can raise children's self-esteem concerning their abilities to interact socially.

The theory of social identity indicates that as the stigma around a label is reduced, the individual's sense of belonging to that group will increase. A better sense of belonging

to the group will also impact on the individual's feelings towards themselves. This theory explains how the participating young people's improved sense of self-confidence may have developed. Classmates may be more accepting of that individual because they have more understanding of their differences, while the individual no longer has to hide their identity, so they may act in a more positive way towards their classmates (Newheiser & Barreto, 2014). This is a perspective supported by Bauminger, Shulman, and Agam, (2004), who concluded that social competence for children with high functioning autism is considered to be important in terms of how they perceive themselves, because as their social environment improves, so does their sense of self.

Shore (2004) argued that self-disclosure was an essential step in the process of self-advocacy. There were one or two examples of the young people self-advocating after the self-disclosure, but it is unclear whether the self-disclosure in itself supported self-advocacy. It may be that the process of maturing also helped the young people with autism to self-advocate. Shore (2004) argues that self-advocacy programmes are necessary to support young people in this process. This research supports this argument, because there are very few mentions of self-advocacy, suggesting that the relationship between self-disclosure and self-advocacy is not straightforward. More targeted support may thus be required in order to encourage individuals with autism to self-advocate.

Individual analysis discussion

Analysing the case studies separately allowed me further insight into the personal experience of the self-disclosure process for each individual. These varying perspectives on the perceived impact of self-disclosure helped me to gain further understanding of the importance of some supportive factors as well as identify changes in the provision that could have enhanced the impact.

Finley and Simon both felt their "expectations" of the self-disclosure had not been met. Although both felt that their self-disclosures had been positive to some extent, they felt that the positive impact had been short-lived. These findings suggest that the individuals self-disclosing can sometimes feel disheartened by the lack of change they experience after the event, which may be a limitation of self-disclosure. Several reasons for this were suggested by the participants, such as feeling pressured into carrying out the self-

disclosure, feeling that the content of the self-disclosure did not accurately reflect them as individuals, and expectations of the process being too high.

The issue of both Finley and Simon's disappointment raises an important question: is the impact of self-disclosure limited for some individuals? Perhaps the impact experienced by these young people in the weeks following self-disclosure was not driven by peers' attitudes changing, but by temporarily silencing the peers who were causing difficulties. For example, perhaps self-disclosure shocked those students who had been engaging in bullying and teasing into stopping for a brief time, only to return to the same behaviour a few weeks later. It may be that in some situations, breaking the cycle of misunderstanding and hostile behaviour requires an ongoing programme rather than a one-off presentation.

Several factors might have enhanced the impact of the self-disclosure for these young people. In both these cases, the teachers noticed a more lasting positive impact, which suggests that the young people concerned may not have been aware of some of the changes that occurred as a result of the self-disclosure. Perhaps if the teachers' observations had been explicitly shared, the young people may have gained further awareness of the positive impact of the self-disclosure. When discussing my findings with Simon, for example he expressed surprise at his form tutor's perspectives of the impact of self-disclosure. This prompted him to further reflect on the impact himself and he wondered whether his perception of the self-disclosure had been negatively biased. This suggests that increasing the individual's awareness of the changes may be beneficial in supporting them to recognise the impact of behaviour change by peers.

Another method of enhancing the positive impact might be to carry out further work with the individual's peers after the self-disclosure event. Throughout all of these self-disclosures, the work was solely focussed on the individual with autism. It is possible that finding ways of increasing peer engagement would successfully increase the impact of the self-disclosure. Peers might, for example, be supported to reflect and discuss how they might change their behaviour in order to implement the strategies suggested in the self-disclosure.

This information from the case studies emphasises the importance of some of the supportive factors identified in the analysis. It may be essential to ensure that lengthy

preparatory work is undertaken prior to the self-disclosure to support the young people in developing further awareness of their own autism and helping them to express their autism in a manner that feels comfortable for them. Simon's case study also emphasises the importance of ensuring that the young person does not feel pressured into sharing this information. Finally, sufficient work may need to be done with the young person to manage their expectations of the impact of the process of self-disclosure.

Within Alfie's self-disclosure process, the positives of self-disclosure were a huge focus. This self-disclosure was considered extremely successful for all involved and Alfie was very positive about self-disclosing. While positivity towards autism was mentioned in other case studies, the emphasis was not as great as in Alfie's case. I think this shows the salience of positive attitudes towards autism as a supportive factor in self-disclosure.

The individual factors highlighted in these case studies demonstrate the importance of providing the young person with the tools to self-disclose without any pressure to do so. The evidence also emphasises that self-disclosure is a process. Alfie's TA spoke about facilitating the self-disclosure process using the metaphor:

> "Disclosure is planting the seed. You have to water it and move it into the sunshine".

Bronfenbrenner model

I felt that a visual model could be created to specify the different levels of support considered essential for enhancing the success of self-disclosure. Nuttall and Woods (2013) used the Bronfenbrenner model to create a supportive model for 'school refusers' who had been successfully reintegrated back into school. This model incorporates aspects of the supportive factors into the different systems outlined in the Bronfenbrenner system's ecological theory (Bronfenbrenner, 1979). I propose that this model would be an appropriate method for incorporating the supportive factors for self-disclosure because it includes the environmental and individual aspects in terms of the support necessary to successfully self-disclose. It also clearly articulates how the supportive factors interact within the context. In addition, I think the Chronosystem can accurately represent how self-disclosure is a process that occurs over a lifetime, as it demonstrates how self-disclosure can change over time due to developing awareness, transitions, and in different environments (Bronfenbrenner, 1994).

The model depicted in Figure 3 shows the young person at the centre, surrounded by the themes that specifically impact the young person self-disclosing. In order to create the model, I used the emerging themes from the case studies and Bronfenbrenner's ecological systems theory. I have chosen to use the later version of Bronfenbrenner's theory, which not only focuses on the importance of the context, but encompasses the interactions between the following four concepts: Process (reciprocal interaction between individuals), Person (individuals' characteristics based on experiences and context), Context (the different levels of the systems) and Time (chronosystem) (Tudge, Mokrova, Hatfield and Karnik, 2009).

'Context' is clearly visible in the different layers of the systems supporting the individual. The self-disclosure investigated for this research occurred in the school environment, which can be found in the microsystem. The home environment also impacts on the self-disclosure process at school; these supportive factors are displayed at the mesosystem level. The final level (exosystem) shows how overall ethos and culture is considered to be a supportive factor.
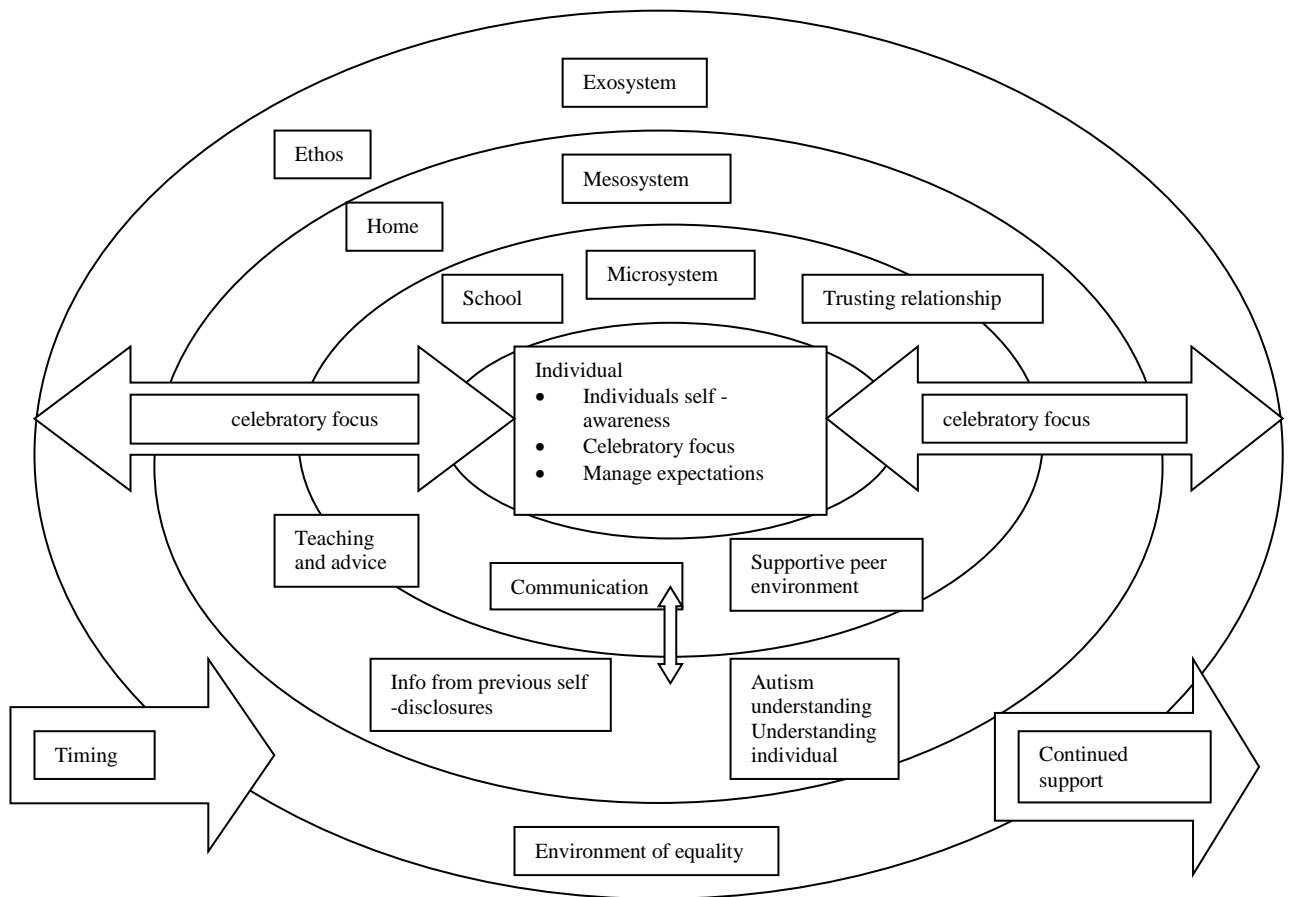
Figure 4: *The supportive model of self-disclosure (developed from the Bronfenbrenner model using the emerging themes from the case studies).*

I will now describe each of these aspects of the Bronfenbrenner model to demonstrate how the findings from this research can be explained within the context of the model. Within each section, I will discuss how these interacting factors may have contributed to self-disclosure occurring, as well as how these factors interact to provide support for the self-disclosure process. Themes emerging from this research will be discussed in relation to the literature and relevant psychological theory.

Context

One interpretation of the emerging themes is that the secondary school environment itself exacerbates the challenges faced by individuals with autism. Barratt (2006) argues that self-disclosure usually happens in secondary schools because the environment is particularly challenging for individuals with autism. Barratt's perspective on self-disclosure was developed through years of experience working with individuals with autism.

The personal accounts in this research suggest that the young people with autism experienced a significant decrease in their peers' sensitivity to their differences after their transfer to secondary provision. Bullying, isolation and confusion became issues for these young people. This is a common experience for children with autism in mainstream secondary school. Research carried out by Humphrey and Symes (2010) found that pupils with autism experienced the highest rate of bullying compared to pupils either with dyslexia or no SEN. Humphrey and Symes (2010) concluded that the characteristics associated with the autistic spectrum condition increased the risk of bullying.

This research provides further insights into how situations develop in which children with autism find themselves socially isolated and bullied. It seems that there are many interacting factors that make the secondary school environment more challenging for individuals with autism. In terms of the sensory environment, the secondary school is a much busier and noisier place, with bustling corridors to negotiate and different classroom environments. Alfie's mum spoke about how a fan in one of the classrooms had been a huge distraction for Alfie. It is much easier to adapt the primary school environment to make it more appropriate for individuals with autism because the children spend most of the day in one classroom and the teaching staff are consistent. Moving around different classrooms and having many different teachers could increase the possibility of sensory difficulties becoming a barrier to learning.

In terms of the social environment, the participants are described as understanding 'teasing' very literally. The way children communicate at this age may change, becoming 'jokey' and involving poking fun at others. Young people with autism can find this hard to understand, as their comprehension of language can be literal (Baron-Cohen, 2008). Literal understanding of language increases the likelihood, for example, that threats meant as a joke might be taken seriously by a young person with autism.

All of the challenges that autistic young people face may lead to higher levels of anxiety in the secondary school environment. It has generally been accepted that due to the characteristics of the disorder, individuals with autism are more susceptible to experiencing high levels of anxiety (Groden, Cantela, Prince & Berryman, 1994). This increased anxiety may be a trigger for some of the extreme reactions described by some of the participants. If the children are displaying what may seem to others as unexpected

responses, this may increase the likelihood of them being teased. This sequence of events may become a negative cycle, in which the needs of the young person with autism are misunderstood by their peers, thus they become more and more isolated.

The environment was not only seen as a reason why self-disclosure occurred. Elements of the environment were identified by the participants as essential supportive factors for self-disclosure. These supportive themes provided further insight into those aspects the participants considered important in enhancing their experience of self-disclosure. Interestingly, some of these themes seem contradictory to those that were suggested as the cause of self-disclosure. The environment was not only seen as an element that could cause someone to self-disclose, but it was also identified as a protective factor for the success of self-disclosure. The model encompasses these supportive factors within the micro, meso and exosystems and provides a clear visual explanation of all of the themes emerging from the research (see Figure 4).

Person

The 'person' is conceptualised by the individual and the themes in the centre of the model (see Figure 4). The relevant themes at this level are: the individual's self-awareness, their self-esteem, their ability to manage their expectations of the process, and finally, how they perceived their own autism. Bronfenbrenner believed that these are a consequence of individual characteristics and are developed through their experiences, along with the support received from family and friends.

The analysis suggested that the social isolation described in the previous section is not enough in itself to prompt self-disclosure. Many children with autism have negative social experiences in mainstream school and many do not self-disclose. Accounts in the literature suggest that young people with autism can react in two very different ways to becoming aware of their differences. Differences can either be hidden in an attempt to be 'normal' or the opposite reaction could occur (Humphrey & Lewis, 2008, p. 40). The young people could attempt to reduce the stigma associated with the label. This reaction can be interpreted using Bat-Chava's (2000) theoretical stance of social identity theory for individuals in stigmatised groups. The individuals in these case studies hoped to educate their peers about autism in order to increase understanding and decrease the stigma around their behaviour and their difficulties. It suggests that self-disclosure may be an attempt to educate others about their label in order to reduce the stigma attached

to it. This is not necessarily the usual reaction to social isolation or bullying, however. So what was it about these individuals that made them want to self-disclose?

In interviewing the young people, I was taken aback by their understanding of themselves and their autism. Each clearly articulated their autism and the impact it had in a very practical way. These findings suggest that the participants considered self-awareness to be an important supportive factor within the self-disclosure process; in other words, the young people needed to be aware of themselves and their autism if they wanted to tell others about it. The participants also suggested that self-awareness did not necessarily come naturally for the young people with autism. It may be important that individuals are supported to develop self-awareness to help them understand what their autism means to them. Of course, it is possible the process of self-disclosure itself further supported these individuals' understanding of their own autism by encouraging them to articulate it to others.

Not only were the young people in this study aware of their autism, there was also evidence to suggest they acknowledged and accepted autism as a part of their identity. This suggests these young people were all comfortable being associated with their label of autism. It is impossible to prove cause and effect, but it seems that self-disclosure and this acceptance of autistic identity are related. Perhaps the young people felt drawn to self-disclose because of how they felt about their autistic identity, or perhaps the process of self-disclosure itself had supported them in accepting autism as a part of their identity. Alfie's mother said:

> "When Alfie joined year 8 he tried to fit in sometimes by trying to be someone else and I said 'That's not you Alfie. You are not going to be happy doing that. You might think you are being happy because you are fitting in, you're not. You should be yourself. You know who you are. Be yourself and people will accept who you are.' I think that's when he, actually, this is who I am. I can do this and you can either take it or leave it." (Appendix 4).

I believe that this demonstrates how self-disclosure and identity formation are intertwined; each reciprocally impacts on the other.

Simon was the only young person who did not say that autism was an important part of his identity. He was also the only young person who felt that he had been pressured into self-disclosing. It is possible that Simon did not really want to announce his autism to

his class because he did not feel that the label was important to him. This suggests that self-disclosure should not be proposed for individuals who do not consider autism to be an important part of their identity.

The emerging theme of '*celebrating autism*' describes a few other reasons why these children may have felt driven to self-disclose to their peers. At the individual level, self-esteem may impact on the likelihood of a young person with autism self-disclosing to their peers. Some of the participants spoke about how it was essential for them to feel good about themselves in order to self-disclose. It is possible that self-esteem is a supportive factor in the process of self-disclosure because it enabled the young people to feel confident in presenting information about their autism to others. Participants also outlined how it was necessary to build self-esteem in young people with autism by giving them positive messages and providing them with opportunities for success.

Finally, all of the young people expressed awareness that autism made them different but not inferior to their peers. The positive attitude described in the theme '*celebrating autism*' resounded throughout the interviews. It is possible the desire to educate others and change their perspectives evolved from a core belief that autism was a difference and not a disorder. Perhaps the reason these young people chose to self-disclose is explained by their positive approach to autism. Alfie stated:

> "I wanted people to accept me as an equal, not to pity me or to feel sorry for me".

The desire to de-stigmatise the label in these case studies may have originated from a core belief about the nature of autism.

The celebratory approach and positive attitude that emerged as a significant theme in this research may reflect a general change in approach towards autism. Simon Baron-Cohen is at the forefront of this change and he has concluded that individuals with autism can experience what he has labelled as a "triad of strengths" (Baron-Cohen, 2004, p.946). This involves good understanding of systems, specific areas of strength, and repetitive behaviour. Acknowledging the positive aspects of autism gives individuals a different perspective on their condition and means that society can begin to see it as a difference rather than a disability (Baron-Cohen, 2008). Having an

understanding of the positive aspects and strengths of autism may have been an important catalyst in the self-disclosure process. Alfie's TA clearly expressed this:

> "The self-disclosure process comes from the acceptance that you are different, not any less, not any better, but you are different".

The catalyst for self-disclosure may have been one or a combination of the emerging themes discussed in this section. The young people's self-awareness, self-esteem, and awareness of their own equality developed through the belief that autism is a difference, not a disability. I believe that self-disclosure may have evolved due to the frustration of experiencing situations where they were made to feel unequal as a result of their differences. In these instances, self-disclosure may have been seen as a tool to address this imbalance of equality.

Time

The *'timing'* arrow and the '*continued support'* arrow demonstrate the chronosystem in this piece of research, thus recognising the importance of time in the self-disclosure process. Self-disclosure is one event in a lifelong process of developing an understanding of the self.

Process

The 'process' concept is demonstrated in this model by the acknowledgement of the interaction between individuals in all the different layers. These interactions can impact on each other in a reciprocal way. The '*celebratory focus'*, for example, encompasses what I believe to be an essential aspect of the supportive factors of self-disclosure. It describes the 'ripple effect' explained by one of the participants. The arrows point in and outwards because the positivity is described as impacting in a bi-directional manner. The positive attitude towards autism in the environment can impact on the individual's positivity towards themselves and their autism. The general attitude towards autism and the young person in their environment can be impacted by self-disclosure, as well as the individual demonstrating a positive regard for themselves and their autism.

Conclusion

In summary, I believe the accounts from the research participants show how a well-supported self-disclosure can enable individuals with autism to educate others about autism. I think the emerging themes show that the inclusivity of the environment can be enhanced through the self-disclosure process. Self-disclosure can also provide an important step in supporting individuals with autism to have a greater understanding of themselves and their autism.

The impact of self-disclosure for children with autism can be positive for both the young person and their peers. Tajfel argued that social categorisation is necessary for the development of identity (cited in Hogg & Abrams, 1988). This theoretical perspective provides an explanation for the success of self-disclosure. The label of autism could be seen as a barrier to becoming part of a group by some individuals with autism, because they are aware that others see them as 'different'. Individuals with autism attempt to reduce their barriers to inclusion by educating others about the observable differences. Education can reduce the stigma and increase their sense of belonging and social inclusion.

Limitations

For three out of the four case studies the self-disclosure had happened around three years prior to the interviews. The interviews relied on the participants accurately recalling these events. Some of the participants remembered the events very clearly, whilst others had difficulty remembering some aspects of the self-disclosure process. Perhaps if I had been able to interview all of the participants a few months after the self-disclosure, this would have limited the difficulty some of them had in remembering the impact of it.

The time delay between self-disclosure and the interviews may also have changed the perceived impact of the self-disclosure. Over time, the young people may have matured and developed in themselves. The impact of the self-disclosure may thus have been exaggerated or played down as a result of this time difference. The school may have reported that changes had taken place over time because the young people had matured, for example, rather than the actual impact of the self-disclosure.

During the interviews I had got the impression that the events were remembered accurately, as detailed examples were given. I also felt the participants were honest when their memories were not clear. In my opinion, the self-disclosure process had been an important event for the participants, therefore this increased their ability to remember it clearly.

It must also be considered that the participants were all diagnosed with 'high-functioning' autism or Asperger syndrome. Self-disclosure for individuals with autism who do not lie at the high-functioning end of the autistic spectrum, may be a very different process. There may also be huge variations in the support that individuals with autism who are not 'high-functioning' would need. The supportive framework may therefore only be applicable for individuals with high-functioning autism.

Participants in this research were all boys. It is generally accepted that autism is more common in boys. A recent review of 329 articles reported the most common ratio of males to females was around 4-5:1 (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). The participant recruitment hence reflects this difference in gender. As I did not interview any girls who had self-disclosed about their autism, however, it is possible that the self-disclosure process for girls may be different. The framework of supportive factors should be cautiously used for girls with high functioning autism, if at all.

Implications for practice

This research presents further opportunities for research into the growing literature of inclusion from the perspectives of the young people themselves (Humphrey & Lewis, 2008). It offers an insight into how some young people negotiate their differences in a 'challenging' environment. In providing a comprehensive description of the way that specific children have attempted and succeeded to increase the inclusivity of their school environment, understanding could be increased and constructive change could be driven in mainstream schools.

The research impacts practice for educational psychologists by providing in-depth information about the process of self-disclosure, thus giving information about how future practice for individuals with autism in this area could be supported. It focuses on

the idea of "practice based evidence" which is a paradigm that describes "a way of shaping and harnessing the activities of everyday practitioners in building an evidence base" (Barkham, Hardy & Mellor-Clark, 2010, p. xxi). I have analysed current practice in supporting self-disclosure and provided a model that could guide future practice for school settings, families, and educational psychologists.

The supportive model provides information that can be used to support future self-disclosures. The model has not been created in order to produce a systematic intervention that can be applied to all children with autism, however. It has been provided to create awareness of all the possible interacting factors that could impact upon the success of the self-disclosure process. The model acknowledges that the self-disclosure process is unique to each individual and to every context. It also acknowledges that the self-disclosure process is one that will change and adapt over time as the individual also changes. The supportive model recognises that self-disclosure should only be carried out when the individual is ready and that self-disclosure will perhaps never be right for some individuals with autism. Finally, the supportive model developed in Phase One of this research (figure 4) takes account of the weaknesses and limitations identified within the self-disclosure process, such as the disappointment experienced by Simon and Finley, and makes accommodations for such issues in the model so that future practice can adapt support appropriately.

Self-disclosure is a delicate and personal event. There is evidence from the research to suggest that young people with autism have to be ready to self-disclose. I feel that my model creates the opportunity to put into place an early, proactive intervention that would indirectly support the process of self-disclosure. At the individual level, there were several themes that were considered important by the participants, including having a good awareness of themselves and how autism impacts on them. There were also aspects that related to the '*celebratory attitude*' such as building self-esteem and focusing on strengths. All of these supportive factors could be put into place at an individual level without the need to even propose self-disclosure. Shore (2004) states that:

> Being productive and fulfilled requires the ability to effectively make our preferences and needs known to others. To do so, in turn, requires a heightened sense of self-awareness – we must come to grips with who we are and what our needs are before we can communicate them to others.

Future research could further explore the self-disclosure process and support young people with autism using the supportive model as a basis in order to evaluate its practical value in schools. Research could also focus on how to increase the impact of self-disclosure for the young people and exploration could be done in how to maximise the engagement of peers after the self-disclosure event. Further investigation could also be done into the self-disclosure process for individuals who are not considered to be on the high-functioning end of the autistic spectrum. Future studies could also explore the process of supporting self-advocacy after self-disclosure.

Phase Two

Chapter 5

Introduction

Barratt (2006) stated that there is an underlying assumption in the general literature on autism that it is beneficial for young people on the autistic spectrum to discuss their needs with their peer group. She goes on to state, however, that there is no evidence or discussion about how or when this should be done. The aim of the second section of this research is to demonstrate how the model created in the first phase could be used to develop and evaluate an effective intervention for supporting children in developing the skills they need in order to self-disclose (see Figure 5).
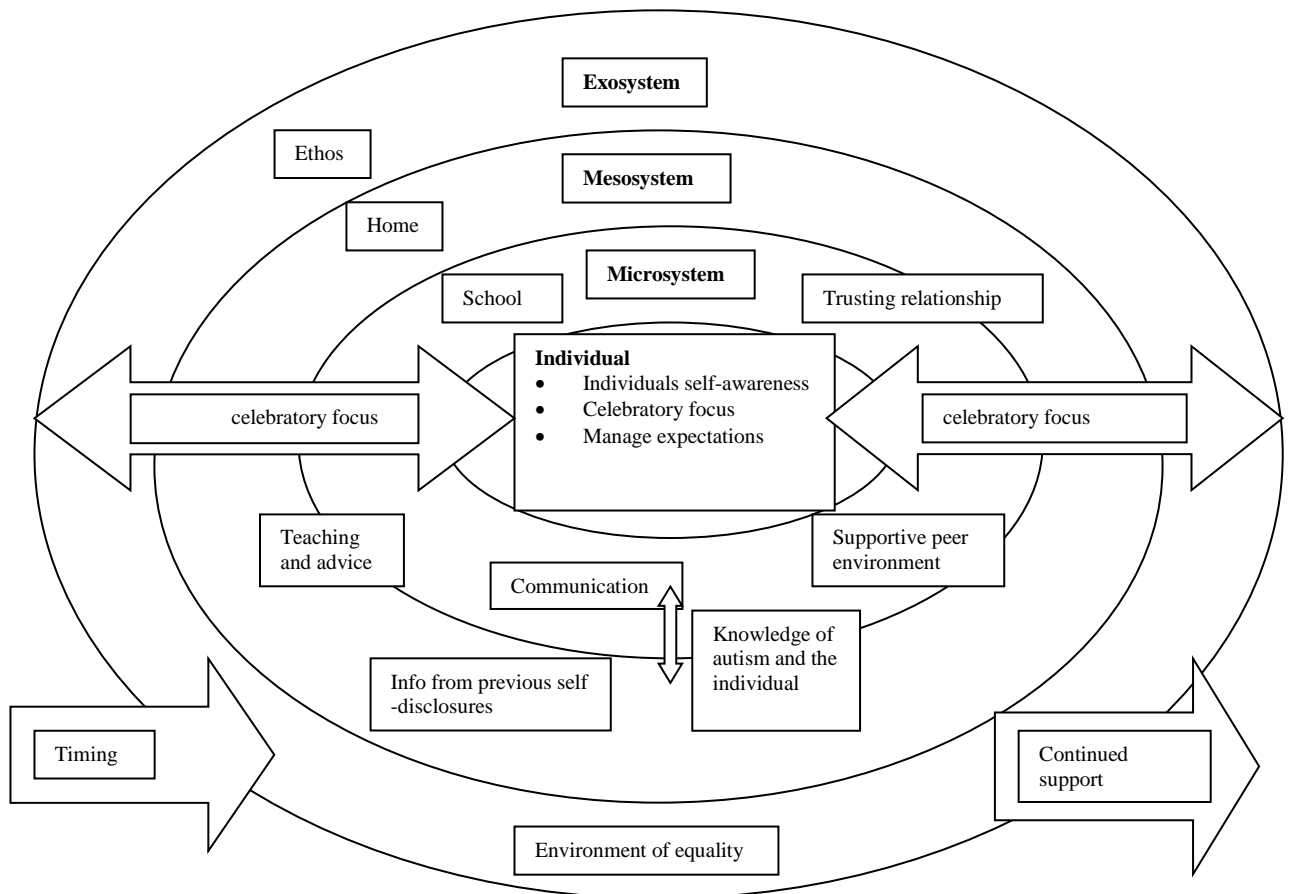
Figure 5: *The supportive model of self-disclosure (developed from Phase One)*

The first section of the research found that it was crucial for the young person with autism to have a clear understanding of themselves and be able to express this understanding to others. The intervention will therefore focus on the individual's

understanding of themselves and aim to facilitate them to develop a better understanding. The intervention will focus on the centre of the circle at the level of the individual (see Figure 5). This focuses on the concepts of 'person' and 'process' from the Bronfenbrenner model; i.e. the understanding of the individual and the individuals' reciprocal interaction in their environment.

Another essential aspect to the self-disclosure process was the focus on assisting the young person to understand the positives and strengths of their autism. This suggests that an intervention supporting young people to develop this understanding of themselves should focus not only on the aspects they find challenging, but also on their strengths. Within the intervention developed in this phase of the research, I will focus on assisting young people to understand the positive aspects of autism.

The '*timing*' aspect of the model describes how in order for the self-disclosure to be successful, the young person with autism needs to feel ready to self-disclose. The intervention created in this research will not pressure or encourage the young person to self-disclose. It will, however, provide them with the appropriate skills and tools to self-disclose whenever they wish.

Baron Cohen's most recent theory focuses on autism as a different way of thinking rather than a disability (Baron-Cohen, 2008). The Systemising theory describes how individuals with autism have strengths in systemising. 'Systemising' is an ability to understand and create systems. A system is something that relies on rules, which enables predictions to be drawn about the way it behaves or works. There are many different types of systems, including collectible, mechanical, numerical, and abstract systems. A 'systemising quotient' has been developed to measure individuals' systemising abilities and it has been found that individuals with autism score higher than matched controls on this measure (Baron-Cohen et al, 2003). This research concluded that individuals with autism have a stronger drive to systemise than individuals who do not have autism.

Baron-Cohen has concluded that individuals with autism can experience what he has labelled a 'triad of strengths'. This 'triad of strengths' involves good understanding of systems, specific areas of strength, and repetitive behaviour (Baron-Cohen, 2004).

These theoretical ideas can be used as a basis for supporting individuals with autism to understand the strengths and difficulties that relate to their autism.

Aim

My aim is to use the supportive model of self-disclosure to develop an intervention that supports schools in assisting children with autism understand their strengths and the challenges they face. I will identify how the intervention supports young people in the process of self-disclosure.

The intervention was developed using the themes from Phase One of the research:

- Individual's self-awareness (individual level): Intervention focuses on increasing the young person's awareness of the impact of their autism.

- Focus on the strengths (individual level): Focus the intervention on the strengths the young person displays.

- Knowledge of autism and the individual (micro and mesosystem level): Create a medium with the young person that they could use if they wish to educate others around them about autism and themselves.

- Timing (chronosystem): If the timing is right for the young person, support them in sharing the information they have learnt with whomever they choose.

Research Questions (RQs)

The research question for this phase of the research was as follows:

What is the impact of a six-session intervention designed to support young people with autism in gaining a better understanding of their autism?

Chapter 6

Methodology

Case studies were carried out to explore the process of supporting children in gaining awareness of their autism. I chose case studies because they enable the intervention to be explored in detail. As self-disclosure is such an individual process, I thought it would be essential to focus on how the intervention was applied and this methodology provided vivid descriptions. The analysis was rich and descriptive and provided a clear example of how the intervention was applied. The benefit of this type of analysis is that it makes the research easier for others to replicate and adapt in the future.

The case study methodology also enabled myself as the researcher to become directly involved with trialling the intervention. I thought it would be important to carry out the intervention myself in order to provide full descriptions for others to follow.

Research design:
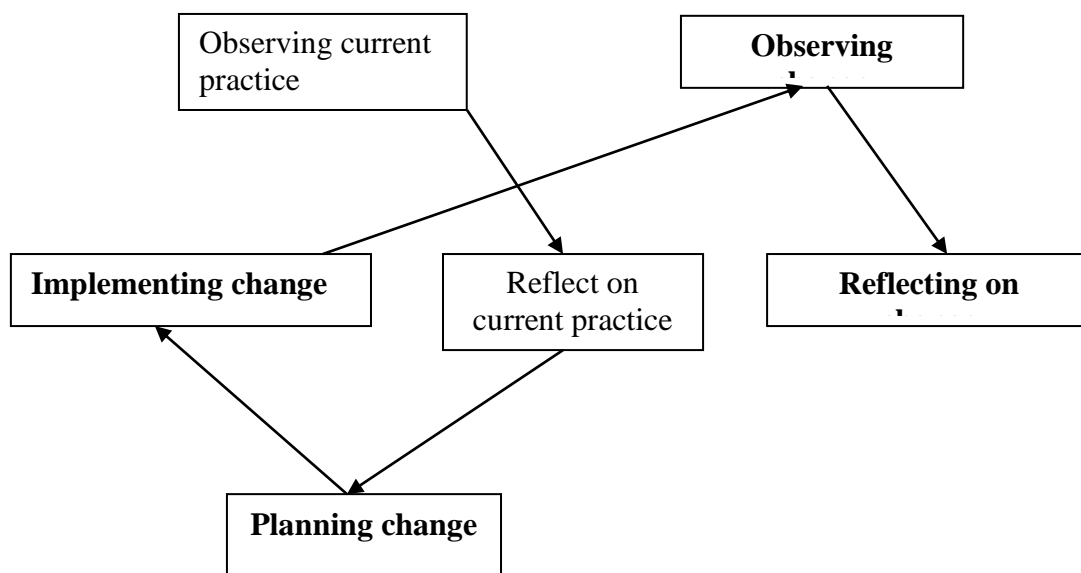
Figure 6: *Action research cycle (Lawson, 2009, p.ix)*

The research will form the therapeutic stage of the action research design. This is where the hypotheses developed in the first phase are applied in context using a directed

intervention. The intervention was planned using the supportive model for self-disclosure that was formed as a result of observing and reflecting on current practice. The 'implementing change' stage was put into practice through carrying out the intervention using case studies (see Figure 6). Finally, the change was observed and reflected upon within the findings and discussion section of this research (for more information about action research please see the methodology section in Phase One).

Participants

The participants were young people with high functioning autism in middle school and primary school. I chose to work with this age group because the transition to the secondary school environment was considered to be particularly challenging for individuals with autism. Evidence from the first phase of the research suggested that one of the many factors that prompted self-disclosure were the challenges faced in secondary school. I therefore felt that the intervention could be effectively developed as a strategy to support this transition. In assisting the young people to have a clearer understanding of their differences and strengths, they may be able to enter a new environment with more confidence. The first phase of the research suggested that the intervention might help the transition in two ways: firstly, the young person's self-awareness could support school staff in understanding the young person's needs if the information is shared. It might also support the individual in their confidence to ask for the support they need, i.e. to self-advocate.

Recruitment and inclusion criteria

Participants were recruited through communication with the SENCos in two schools. Requirement for participation in the research was as follows:

- The young people were aware of their diagnosis of autism.
- The young people's schools and parents believed that the young people would benefit from a more in-depth understanding of autism.

- The young people's willingness to work with me.

Participant details

Three participants were recruited. One other young person was identified in one of the schools. Following discussion with the parent, however, it became clear that the young

person had not yet received an official diagnosis, so this young person was discounted from the research. The participants were as follows:

Jo: A boy in Year 6 at a middle school

David: A boy in Year 8 at middle school transitioning to secondary provision

Laurence: A boy in Year 6 in primary provision

Data collection

Semi-structured interviews were carried out with the young person with autism, a member of school staff, and a parent, in order to explore the young person's understanding and awareness of autism. The purpose of these interviews was to provide baseline information for the intervention. The information gathered in these interviews informed me about the understanding the young person had of themselves and their autism and whether or not they were happy to explore the topic of autism further (see Appendix 7).

In the preliminary interviews I was shocked to hear such negative descriptions of autism. Not only did the young people have very negative connotations with the label, but the parents also described autism very negatively. Participants focused on the difficulties and challenges that are associated with it. I thought at first the participants gave me negative descriptions because that is what they thought I wanted to hear; however, when I asked for them to describe positives and strengths they often found this hard. This was a stark contrast to the positivity of the participants in the first phase of the research.

Stephen Shore's (n.d.) list of strengths and challenges was used as a guide to support participants in thinking about their child/student strengths and challenges. In my experience, some parents can find it difficult to spontaneously produce a list of things that their child is good at, especially in an interview situation. The parents spontaneously came up with one or two strengths, but when they were presented with the list they gave examples of many more. The list prompted the parents to reflect on their child's strengths and gave them the prompts needed to support them in this process. I therefore think encouraging the parents to consider all the possible strengths an individual with autism might display prompted them to consider their child in a more positive light.

I removed "difficulty processing in non-favourite modalities such as aural, kinaesthetic" from this list as I felt this would be difficult for the school and parents to understand (Appendix 7). A 10-point marking scale was used to measure the perspectives of all the participants before and after the intervention (Appendix 7). These scores were used to provide an idea of the impact of the intervention for the young person in the following areas:

- Understanding of autism in general

- Awareness of how autism impacts on them

- Awareness of their difficulties

- Awareness of their strengths

- Self esteem

- Feelings towards their diagnosis

- Young person's ability to self-advocate

The scaling I used is an example of a semantic differential rating where the participants are asked to rate the concepts identified out of 10. At one there was an adjective and at 10, the opposing adjective (Cohen, Manion & Morrison, 2007). I was aware this method would not enable me to compare the scores between the participants, because a score of five for one participant could mean something very different to a score of five for another. I used the scores to compare each participant's score before and after the intervention. There is a possibility that the participants did not mark the post-intervention scores reliably due to a participant bias affect. I decided not to rely completely on these scores, but to use them in a descriptive way to support the qualitative data from the interviews.

Ethical considerations

It is difficult to arrive at a completely rigorous approach to ethics around self-disclosure that allows for the variability of feelings. A participant can easily say at one point that they wish to self-disclose, and then change their mind. In the context of this study, my

position on this matter is that all the researcher can do is to explain in as much detail as possible what self-disclosure entails, and what the potential consequences might be, as suggested by those who have previously self-disclosed. Subsequently, participant feelings should be monitored, and opportunities given to shift position where appropriate. Of course, once self-disclosure has occurred, all that can be done is that the participant can be supported through the process afterwards. In other words the researcher has ongoing responsibility to the participant.

I was aware that by producing and applying a model labelled 'the supportive model of self-disclosure' this might increase expectation on the young people to self-disclose. I wanted to avoid putting any pressure on the young people, because this had led to Simon in the first phase finding the whole process difficult and led to him feeling that it had not been effective. I therefore came to realise that in applying the model, the focus should not be on the young person self-disclosing; rather it should be on supporting them to feel confident and understanding themselves. Self-disclosure should only be considered if the young person expressed a desire to tell others about their autism once the support outlined in the model was all in place. I also ensured the parents were aware that although my overall aim was to support the self-disclosure process, I would not be expecting the young people to self-disclose as part of the intervention. I informed the parents that I would develop a medium that would be owned by the young person. The information could then be used by the young person in whichever way they wished. Following the intervention, I offered further consultation and support to the family and the school.

I was aware that parents might be very nervous about the idea of their child discussing their diagnosis with a researcher. I therefore arranged an introductory meeting where I introduced my research in depth. I gave parents information about the research to take away with them (see Appendix 6). I spent time building my relationship with the parents by asking them about their children. I reassured them that nothing would be carried out without first communicating with them. Throughout the research I kept in regular contact with the parents to feed back about the sessions.

Overall, the parents seemed very happy to have the involvement of a trainee educational psychologist. I noted they were very open with me about some of the difficulties they were having and used the interview as a time to reflect and ask for advice about some of

the challenges their children were facing. I felt that it was important to listen to them about these issues, because it built up a trusting relationship.

In terms of the methodology I used I chose to use the cyclical design of action research and apply it to separate case studies in this way because I felt it was important to gather the perspectives of individuals who had experienced self-disclosure and use this to support others in schools. I am aware of the limited opportunity for participant input in the action research. I listened to participants and tried to act on their feelings. In an ideal world, it would feel ethical to incorporate more participatory interaction, and this might occur rom the research design stage through interpretation.

Content of the intervention

I developed the intervention using the information from the first phase of the research. The content of the intervention therefore involved increasing the young person's awareness of the following:

- Autism heroes (celebratory focus)

- Personal strengths (personalised celebratory focus)

- Personal challenges (personalised information)

- Supportive strategies (in order to generate change in the environment)

I used a few different resources such as the book *Different Like Me: My book of autism heroes* (Elder, 2006) and Stephen Shores' list of "strengths and challenges" (Shore, n.d.) to gather information and prompt conversation. Although I wanted the intervention to be flexible and adaptable, before the interventions started I created a general intervention structure and plan, as shown below (see Appendix 11 for further examples of intervention plans).

Session	Plan
Autism heroes	Support the young person in celebrating autism by gaining an understanding of individuals with autism who have been very successful (Elder, 2006).
Focus on strengths	Identify all the things the young person feels they are good at. Discuss the strengths that lots of individuals with autism have as a way of helping the young person to acknowledge more strengths (Shore, n.d.).
Focus on supportive strategies	Summarise some of the challenges the young person experienced and clarify and outline some of the things that they or others could do to reduce these challenges (Shore, n.d.).
Share the information with parents and school staff	Provide information about the systemising theory of autism in the form of a PowerPoint Presentation. Link the triad of strengths to the young person. Provide an opportunity for the young person to share the information gathered in the previous three sessions.
Generalising the information to school and home	Encourage the school to continue adding to the PowerPoint Presentation with the young person. Continuing with the focus on the strengths.

As I went through the sessions, I encouraged the young person to record the information they found useful or interesting. I gave the young people a choice about the method they used to record this information.

Procedure

I first met up with the parents of the participants to discuss the purpose of the research. I shared some information from the previous phase of the research and presented the purpose of the intervention (Appendix 6). In the first meeting with the parents, I shared the model developed in the previous section. Laurence's mother looked confused and a bit taken aback by the complexity of the model, so I decided after that it was better not to share it with the parents.

The purpose of the first meeting with the young people was to introduce myself and check whether they were happy to work with me. I talked to the participants about their

interests and things they enjoyed in order to get to know them a bit better. I informed the young people what the purpose of our meetings would be and asked them if they would feel comfortable working with me.

I planned to adapt the sessions for the intervention as I went along as I wanted the sessions for the intervention to remain flexible. Some of the phases took a lot longer than I expected to complete and some were a lot shorter. All of the participants chose to record the information using Microsoft PowerPoint presentations on the computer.

Throughout the whole process I allowed the participants to maintain control over the sessions. They all really enjoyed making the PowerPoint presentations themselves, for example, which was not something I had expected. This meant that the process of choosing pictures, writing about them, and creating the animations took longer than I had planned. When asked about what they enjoyed about the process all of the young people mentioned creating the PowerPoint Presentation itself. David said:

"Yeah, it has been a good thing because I like doing stuff on the computer".

This demonstrated that in order to capture and maintain the young people's full attention it was essential to use a medium that motivated and excited them. I also found that it was important to give them time to write about their interests, as this was an aspect they all found enjoyable. I felt that the young people were proud of the presentations they produced and perhaps they would hence feel more comfortable to share it with others.

Once the information had been recorded by the young person, I gave them the option to share the information with parents and school staff. I then arranged an informal meeting with all the participants if the young person agreed. I began the meeting with a talk about autism and then supported the young person to share the information they had recorded during the intervention (for details of the talk about autism see Appendix 11).

The school and parents were then asked to continue the work at home and adapt and add to the information. The purpose of this was to personalise the content of the PowerPoint presentations and to engage the staff and parents in the process. I encouraged both the staff and the school to continue to focus on the positives and strengths.

Interviews were arranged with the participants after the school staff had revisited and had the opportunity to add to the presentation. During this interview, I carried out the scaling to see if any of the ratings had changed. At this point I gave the young person the option to share the information with others, including peers and other teachers, if they wished.

Data analysis

I analysed the interviews using a thematic analysis process following the three-phase structure by King and Horrocks (2010). The thematic process was much more simple than in the previous phase of the research, as the interviews were shorter and more precise. When creating the interpretative themes I only had three interviews to consider, so I did not have to edit and adapt the themes in the same way as I had in the previous phase of the research. The pre and post-intervention scales carried out by the participants were used to see if any change had been observed after the intervention in the areas identified.

In the following chapter, I present the preliminary information gathered from the interviews before I carried out the intervention, followed by a detailed description of the interventions, including information about how the young person responded to each of these sessions. The impact of the interventions is then discussed through analysis of the interviews and the scaling.

Chapter 7

Jo (Case study 1)

Background information

Jo was in year 6 at middle school. He enjoyed reading, collecting plants, playing chess and video games. He said that he quite enjoyed school but preferred to be at home because he felt home was more comfortable than school. In school he said preferred history and maths. Jo said that he did not have any friends and he said he didn't really want any.

During the interview Jo told me he saw autism as a very negative thing:

> "It is a bad disability".

I explored his perspectives more, and Jo stated that autism meant:

> "Not being very good at things".

When prompted to talk about his strengths, Jo didn't label any. Jo's mother described how she had explained autism to Jo:

> "I have explained to him. That's why he finds even day-to-day things difficult and that's why when we go out he is very sensitive to loud noises and things".

Jo's mother also said that she encouraged him to watch programmes such as Channel 4's *The Autistic Gardener* (Seywald, 2015). She described that although there were so many things Jo was good at, at he found it difficult to acknowledge these strengths.

Jo's TA described how Jo is very aware of his differences and sees his autism as a disability. She described how Jo thinks that he is "stupid" and "dumb" (see Appendix 8 for further information about Jo's strengths and challenges).

Intervention description

Autism heroes

Jo was really interested by some of the autism heroes. He was particularly drawn to Benjamin Banneker, Albert Einstein, and Stephen Wiltshire. When Jo saw the print of Stephen Wiltshire's work he was amazed by the level of detail in the drawing. He told me he would never be able to draw like that. I let Jo choose a print from a calendar produced by Stephen Wiltshire. Jo was really pleased about this and said he would like to take it home to show his parents.

Focus on strengths

Jo recalled information about the autism heroes and remembered the names of the individuals we had spoken about. I then discussed how individuals with autism often had strengths in particular areas. Jo seemed to find it hard to talk about his strengths. I felt like he began to lose interest in the conversation. I noticed that his body language changed, his shoulders slumped and he began to respond to my questions with monosyllabic answers. We discussed each area and I encouraged Jo to think of practical examples of the strengths that Jo displayed. If Jo was finding it challenging to come up with examples I suggested some of the examples provided by staff or parents. When I pointed out what others had said about his strengths in certain areas he did not contradict me and seemed pleased with these comments (see "information on strengths" in Appendix 8).

Recording information

During this session we created a PowerPoint presentation to record all the information we had gathered. Jo enjoyed using my iPad to gather information and pictures of his autism heroes. When it came to writing about the strengths of autism, Jo's attention began to wander. He found it difficult to remember some of the strengths so needed help to recall them. I helped him to summarise these in the PowerPoint presentation.

I decided to talk about some of his interests and as we talked I related these interests to his strengths. When he added a picture of a mineral to his PowerPoint presentation, for example we talked about how he was able to focus on the detail and this might be why he is really good at noticing the difference between some crystals. Jo also really enjoyed

finding pictures from the Internet and adding them to the PowerPoint presentation. At this point he wanted to learn how to put the pictures into the presentation himself.

Focus on supportive strategies

I asked Jo to identify some of the things that he finds hard. I did not want to prompt him in this area, as I did not want others to make assumptions about what he perceived to be challenging. Jo came up with difficulties, such as being easily distracted, working in groups, and loud noises. We added these challenges to the PowerPoint presentation in the form of pictures and he said at this point "I prefer to use pictures to describe things". I linked this to the strength we had previously discussed, that people with autism are often good at visualising things.

I then went on to think about some of the things that others could do to help him with those difficulties. Jo found this really hard and needed some support to think of things that others could do to help. I supported Jo by asking him questions, for example, "if you like it when it is quiet, what could other people do in the classroom to help?" Finally, I helped Jo to add the pictures of these things to the PowerPoint presentation.

I asked Jo if he would like to share the presentation with his mother and his TA. He agreed to this readily.

Sharing the information

I arranged a meeting with Jo's mother and his TA. I talked through the presentation about autism and the theories of autism, focusing on the strengths and positives (see Appendix 11). Then Jo talked through his PowerPoint presentation (Appendix 12). He seemed happy to share it with others and became especially animated when he discussed his interests. The content of his presentation prompted lots of discussion about the things that he was good at. For example, we talked about how Jo enjoyed collecting succulent plants and how this might be linked to his systemising ability of collectible systems (Baron-Cohen's (2008) systemising theory was previously discussed in the introduction in chapter 5). I asked about whether he would like to share it with anyone else and he said "maybe".

Generalising information at school and at home: Jo shared the PowerPoint presentation with his family and carried out some work on it with his TA. They added some personal aspects to the strengths such as "sense of humour" and "enjoying playing chess".

Self-disclosure

Jo shared his PowerPoint presentation at his annual review (a yearly meeting carried out with school and parents to discuss Jo's progress in school) and spoke about himself in front of a room full of people. Jo also decided to share the presentation with his peers as he felt they would have a better understanding of him. I ensured that all the supportive factors from the model were in place to support Jo in the self-disclosure process.

Jo also made his presentation to six classmates. The PowerPoint presentation generated some discussion. When Jo said that he liked collecting crystals, for example, lots of the young people also expressed interest in collecting minerals and fossils. Peers also expressed amazement to hear that someone with autism had provided the groundwork for the invention of the computer (Alan Turing). When we came to the end of the presentation they generated some strategies that would help Jo, such as:

- Being careful not to make lots of noise around Jo

- Understanding when Jo needs a break out of the class

- Draw and play chess with Jo

- Asking Jo if he wants to play

- Understanding when Jo wants to be by himself

- Not pushing past Jo in the corridor

His interests then generated some discussion about cars and Top Gear. Jo returned to class discussing Top Gear with one of his classmates.

Jo's findings

Scaling

Before the intervention, Jo chose 3 out of 10 for his awareness of autism. He felt that the intervention had taught him more about autism, with this rating increasing to 5 out

of 10 afterwards. Jo felt that none of the other ratings had increased as a result of the intervention, with the ratings for being open about his diagnosis and self-advocating going down. Jo's scores show how negatively he perceived his autism and himself, as he chose 1 out of 10 where 1 is "very negatively". Jo felt that he was very aware of the difficulties that he had (9 out of 10) but not aware of the strengths (1 out of 10) (see Appendix 8 for further scaling results).

Jo's mother felt that Jo's understanding of autism had increased as a result of the intervention. She also rated his awareness of his difficulties as one scale higher and believed that his awareness of his strengths had not changed.

The TA had previously said she was not able to rate the young person's understanding of autism because she did not know. After the intervention she rated it as an 8. In completing the scaling after the intervention the TA questioned the accuracy of her scores before the intervention for Jo's awareness of his strengths, difficulties and how he felt about himself. She rated that Jo was more aware of his difficulties and felt more negatively about himself after the intervention.

Interviews

Jo said that he had enjoyed making the presentation and that he had learnt a lot about autism. Overall he felt that he had learnt a lot about autism but not much about himself. His feelings about autism had not changed and he described how he thought autism is a "massive disadvantage". Jo said that he felt sharing the PowerPoint Presentation with others had supported them in understanding more about him and he had enjoyed sharing it. Jo felt that it would be a useful thing to share with others in the future in order for them to "understand" him better.

Parents and TA

The three themes emerging from the post intervention interviews were: *'changing perspectives'*, '*increased awareness*' and '*continued support*'.

The theme '*increased awareness*' described how Jo's mother believed the presentation had supported Jo's teacher in having a better understanding of Jo and his autism. Jo also believed that he had learnt "a lot" about autism.

The theme *'changing perspectives'* encompassed the sense that the intervention had supported a positive change in the environment by helping the individuals around Jo to understand that autism is not something that prevents people from being successful. Jo's mother said:

> "It is very eye-opening to see the achievements that can be made and it is great to see that there is no reason they should be held back".

A small change of perspective was noticed in Jo and he was believed to be a little more positive. The TA discussed how he was now able to identify a few things that he was good at, for example, whereas she felt he would have struggled before. Jo felt that although he had learnt about the strengths many people with autism have and a lot about autism, he had not learnt anything about himself and he still saw autism as a massive disadvantage. The school and parents described their awareness of Jo's perspective of autism. Jo's TA said:

> "He still puts himself down and he is acting as if he hasn't done the work looking at the positives".

'*Continued support*' was a very important theme in this case study. It incorporated the realisation that Jo suffered from low self-esteem and the importance of ongoing support.

> "We are all trying to push and encourage him to realise what he has got to offer".

The TA spoke of her developing plans to support Jo to have a better understanding and celebrate the things he was good at, such as producing a joke book for him to share his humour with others and increased opportunity for him to do some gardening. Jo's mother summarised the intervention thus:

> "The basis of it is very good and it will be a case of building".

Self-disclosure

Most of Jo's classmates had heard about autism before the self-disclosure. When asked what their understanding of autism was, some of them described accurately some of the difficulties associated with the condition, including difficulty interacting with others and giving eye contact. One of the peers thought that autism was a disease. Jo's classmates had previous understanding about autism through different means. One had family who

were on the autistic spectrum; another had discussed autism with his mother, and the third had read a book about autism.

The overarching theme from the interviews was '*increased autism awareness*'. Jo's classmates described how they had a better understanding of the strengths associated with autism and were able to name many of Jo's strengths and interests that had been highlighted:

"I found out they were creative"

"I have also found out he likes Top Gear and cars"

"He also likes some of the people, celebrities with autism like the guy who when he is helicopter-riding, he draws a picture of it afterwards from memory".

They also described some of the things that Jo found challenging and identified ways in which they could adapt their behaviour to help Jo:

"We could not make loud noises, not touch him and we could play some chess and do some drawing with him".

"If people are being noisy tell them to just calm down and don't be so noisy because Jo doesn't like it".

Not only did many of the peers describe the intentions they had to support Jo, they also described some things they had already done in the week since the self-disclosure:

"Some people in class were being a bit noisy and a bit like monkeys really jumping around and stuff and I told them just to calm down".

"I think I have just been really kind to him as well".

"Earlier on I was reading The Diary of a Wimpy Kid book and Jo really likes them and it was one of the ones he hasn't read so I let him read a page with me".

Discussion

Overall the intervention did not have as much impact on Jo as I would have hoped. Before the intervention, Jo seemed to have a very negative understanding of autism and what autism meant for him. He believed that autism never made anything easier for him. Furthermore, Jo expressed that he felt very negatively about himself. It may be that his negative view of autism was impacting on his feelings about himself. Although the focus of the intervention was primarily on the positives and strengths, I found that at first Jo was unwilling to discuss these. He was, however, very quick to label all the challenges he faced which he felt were difficulties associated with autism. It is possible that he struggled to acknowledge his strengths and positives because they were not in line with his beliefs about himself. One positive change was that by the end of the intervention Jo was identifying his own strengths more. It was really encouraging to see him animatedly discussing his interests and abilities with his peers when he presented the presentation, for example. The PowerPoint presentation gave him the opportunity to identify and express them to other people and perhaps in verbalising his strengths to others, they began to become more real for him.

I felt the intervention had a very positive impact on the individuals supporting Jo at home and at school. Although the impact did not support Jo in changing his negative perception of his condition, the intervention did increase other people's awareness of Jo's negative perception towards his autism. When Jo carried out his presentation at the annual review meeting, his low sense of self-esteem became a focus. As a result, one of the outcomes developed on his EHC Plan was to improve his self-esteem. Strategies were developed in order to support Jo feeling good about himself, including support from an Emotional Literacy Support Assistant (ELSA) and extra-curricular activities such as karate, gardening, and creating joke books to share with his classmates. It seems that in highlighting Jo's feelings about himself and autism, others became aware they should take action and support him to increase his self-esteem.

I felt that the intervention was not as successful for Jo as I might have hoped for because his negative perceptions had become so entrenched with his sense of self and his autism. In terms of the model of supportive factors, this suggests that the individual's self-esteem was so low that he had difficulty acknowledging the 'celebratory' concepts I attempted to introduce. In terms of the Bronfenbrenner model, the 'person' concept at the centre is developed through experiences and support from

family and friends. In the previous phase of the research, the participants had commented that building positivity by focusing on the individuals' strengths was essential in helping them to feel good about themselves and their autism. While the intervention with Jo had not generated change at the individual level as I had hoped, it did generate a change of perspective at the micro and mesosystems level. It enabled both home and school to recognise how negatively Jo felt about autism and himself, which led to several practical changes to help Jo develop a more positive sense of self.

I believe that although the intervention did not help to change Jo's negative perceptions, it may have acted as a catalyst for his self-disclosure journey. It increased others' awareness of the support that Jo needed in order to build a more positive outlook on himself and his autism.

Jo's self-disclosure to his peers led to them having a greater understanding of Jo's strengths and the things that he was interested in and good at. His peers also demonstrated a desire to change their behaviour to support Jo and gave examples of how they had already put this into place.

David (Case study 2)

Background information

David was in year 8 at middle school. He enjoyed computer games and 'coding' on the computer. At school his preferred subject was maths. David described himself as having a big group of friends at school.

David felt that he had a good understanding of what autism meant. However, when I explored this I felt that he could not express the difficulties and strengths that he experienced in relation to his autism. Overall, David commented on the difficulties he experienced and seemed unsure about some aspects. One question he asked, for example, was "Is OCD to do with it? Because I have quite a lot of that". David made one positive comment about himself and his autism and that was his ability to focus on his computer.

David's mother felt that David saw autism negatively because it made him different. She described how David's behaviour had been misunderstood for years as 'naughty' and this had impacted on how he understood himself: "He does see himself as naughty and a bit of a problem a lot of the time".

She believed that David had a good understanding of his autism and what it meant to him. She suggested this understanding had been developed through lots of in-depth conversations with her. David's TA, on the other hand, described how David would sometimes use autism as an 'excuse' and how she had heard him telling his peers he had an 'illness'.

Intervention description

Autism Heroes

David was interested by the autism heroes, especially Albert Einstein, Alan Turing, Stephen Wiltshire and Andy Warhol. He read more about Alan Turing because he liked the idea that Alan was known as the "father of modern computing" (Elder, 2006, p.22).

Focus on strengths

David came up with a few strengths independently. He felt that autism was a good thing because it helped him to focus on specific things like computing for long periods of time. I then went through a few of the other things that people had said about his strengths. David recognised the positives and often gave examples of his strengths in particular areas. He told me about how he is really good at copying things in great detail in his art work, for example, and how friends often asked him questions about computers because he was very knowledgeable in that area (for more information on strengths see Appendix 9).

Recording the information

David started to create the PowerPoint presentation to record the information. I noticed that he focused on the detail in the presentation, adding lots of animation to make it interesting and fun. David was very particular about making the font the same all the way through. I discussed this with him and pointed out how carefully he was doing things and how he was paying attention to the detail in the PowerPoint presentation.

This strength is in line with one of the strengths suggested in Shore's list of strengths and challenges (Shore, n.d.).

David wrote his interests in the PowerPoint presentation and how he thought that autism helped him with these. David needed a little bit of prompting to remember all of the areas of strength we had talked about previously. He added the strengths that were important to him. We decided to take a photograph of a few pictures he had drawn to add into the presentation.

Focus on supportive strategies

David came up with lots of ideas for supportive strategies that would help him independently. He finished the PowerPoint presentation by adding these things.

Transition

David had recently transitioned to a new school. The move had been very positive and everyone reported that he seemed to be getting on really well.

David shared the PowerPoint presentation with his mother and the staff at the new school. He gave it as an informal presentation. He seemed quite shy, so I supported him with the presentation by helping him to describe some of the aspects we had explored together.

David's findings

Scaling

After the intervention, David scaled himself higher in the following areas: awareness of autism, awareness of how autism impacts on him, and awareness of his strengths and difficulties. He rated his scores lower on being open about his diagnosis and asking for help (see Appendix 9 for details of the scaling results). David had transitioned to a different school, however, so I was unable to carry out the scaling with David's former TA.

David's mother felt the intervention had increased David's understanding of autism and how autism impacts on him. She also rated David's awareness of his strengths and

difficulties as higher, but believed that David's awareness of his strengths had increased more than his awareness of his difficulties. David's mother felt one the biggest changes had been in how David felt about himself, with the rating increasing by 6 points. She also believed that David felt more positively about his diagnosis and was more likely to be open about the diagnosis. David's mother also reported that David was self-advocating more often. When she was scaling the section about how David felt about himself, she acknowledged that perhaps the intervention increased her awareness of how David felt.

Interviews

Overall, David said he had enjoyed making the PowerPoint presentation for two reasons: firstly, he had got out of lessons and secondly, he had been working on his computer. David said he might use the PowerPoint presentation in future to show people who may need to know about his autism. He felt that it would be useful if his teachers saw it.

David's mother's interview

Three themes emerged from the interviews with David and his mother: '*increasing autism awareness*', '*changing perspectives*' and '*continued support*'.

'*Increased autism awareness*' describes how the opportunity for David to discuss, reflect, and explore his own autism had been a positive thing. The PowerPoint presentation had given David the means to discuss his autism through a medium that he felt comfortable with.

A theme that developed from the interview with David's mother was *'changing perspectives'*. She felt the intervention encouraged both David and herself to celebrate his strengths and see autism in a more positive light. For example:

> "It made me realise the positive things what [sic] I would consider normal is actually quite a big deal and we need to celebrate those a bit more".

David's mother felt this change of perspective had allowed her to focus more on the positives and less on the negatives. She had begun to nurture his creativity by becoming more involved with his activities on his computer, for example, and spoke

enthusiastically about his computer skills. She felt that her change of attitude had enabled her and her family to begin to build more positive relationships with David.

Within the theme *'changing perspectives'* David discussed how the PowerPoint presentation had helped him to gain a more positive perspective of himself and his autism. He described how he had learnt about celebrities with autism and how discussing his strengths had helped him to notice his strengths in his new school. He provided examples of the strengths he had noticed, such as being able to complete the 3D shape work in maths because he was able to picture it in his head.

The theme *'continued support'* describes how participants felt the content of the PowerPoint presentation could be adapted as David got older and how it would really benefit teachers if David had the opportunity to share it with them.

Discussion

David's PowerPoint presentation supported his transition to the new school. A 'pupil passport' was created from the information on the PowerPoint presentation. David wanted to share it with his teachers so they had a good understanding of him.

Referring back to the supportive model for self-disclosure, this case study demonstrates how David's awareness of his autism grew, as did the strengths and challenges that he experienced. The PowerPoint presentation gave him the means by which to share this information with others in a manner in which he was comfortable.

This case study shows how the intervention can change others' perceptions of autism and the individual. In the supportive model of self-disclosure, this change was demonstrated in the mesosystem. Clarifying and celebrating the individual's strengths in this way reframed how others in the home environment perceived David in a positive light.

Laurence (Case study 3)

Background information

Laurence was in year 6 in primary school provision. He enjoyed anything to do with cars and learning about fish. At school Laurence preferred art as he enjoyed drawing, especially if he could draw something of his choosing.

In Laurence's interview he mentioned many things about his autism that he felt were negative. Laurence was scared of loud noises, for example; sometimes feeling that he wasn't liked by others, getting wound up easily and misunderstanding others when they were joking. The one positive comment he made involved his interests, i.e. telling people how cars worked and racing remote control cars (see Appendix 10 for strengths and challenges).

Laurence's mother believed that Laurence understood a little bit about autism. She identified that he was aware of aspects such as raised anxiety levels, a heightened sense of confusion and needing more time to complete things.

Laurence's teacher believed that Laurence had a good understanding of his autism. She described how he approached her and asked for help when he was confused or didn't understand something. She said that Laurence would not explicitly label his autism when asking for help, but he showed awareness of it. Sometimes he would say:

"because of what I have…."

Followed by a long pause, for example.

Intervention

Autism Heroes

Laurence liked learning about the autism heroes and he was interested to read about Benjamin Beneker and Isaac Newton in particular.

Focus on strengths

Laurence was keen to discuss the celebrities with autism and identified a few that he thought were interesting. When we discussed the strengths, Laurence was able to come up with some good examples of where the strengths applied to him. He felt like he could draw really carefully, for example, and he had a breadth of knowledge about cars.

Focus on supportive strategies

We revised the autism heroes. Laurence felt that the ones in the book were really old and he didn't know them. I said I would have a look and see if there were any autism heroes who specialised in cars like him.

We then started discussing the challenges Laurence faced. Laurence recognised that being distracted could sometimes be difficult for him in class. He told me how he could sometimes find things distracting in the environment. Thinking about his interests also distracted him.

Throughout our sessions I noticed that Laurence noticed noises outside of the room, for example, a whistle in the playground and a Subaru accelerating outside. These noises distracted him from whatever we were doing. This led to a conversation about how individuals with autism can be hypersensitive to noise and sounds and that he may find it challenging to block out background noise when he is working.

We then went on to think about some of the things that helped him in class. He spoke about a timer and having a quiet environment. He was aware of the things he found difficult, but struggled to think of ways he might support these difficulties. Laurence then went on to talk about how one TA talked to him. He felt that she wasn't speaking very kindly to him. I reframed this into something tangible that could help him: "for all teachers to use a kind voice when they are helping me".

Sharing the PowerPoint presentation

Laurence wanted to draw a picture to show his 'attention to detail' as part of the presentation. I read through the presentation and in the middle Laurence whispered:

"I can't stop smiling".

He spoke through the presentation really confidently. Laurence gave a few examples of the things we had been talking about. Within "I have a good sense of hearing" for example, he spoke about how he could hear and notice sounds. Being scared by loud noises prompted a conversation in which his mother clarified this, saying it was not necessarily loud noises, more sudden noises.

When Laurence finished the presentation he revealed a picture he had drawn to demonstrate good attention to detail. At the end I asked him if he would like to share the PowerPoint presentation with anyone else and he said he would think about it.

Laurence's findings

Scaling

Laurence rated his awareness of autism very highly before the intervention as a 9 out of 10, but his awareness of how his own autism impacts on him at a 6 out of 10. Laurence acknowledged that both of these scores had increased as a result of the intervention. When asked about his awareness of his difficulties, he experienced he rated his awareness of this at a 4 out of 10 and he rated his awareness of his strengths at a 2 out of 10. After the intervention he felt that his awareness of his strengths had increased to a 5 out of 10 and his awareness of the difficulties he experienced had not changed. Laurence also felt after making the PowerPoint presentation he felt better about himself, as this score had increased from an 8 to a 9.

Laurence's teacher and mother felt that his understanding of autism had increased, as well as his awareness of how autism impacted on him. They both felt that his awareness of his strengths had increased, but his awareness of his difficulties had not increased. Laurence's teacher believed that Laurence felt more positively about himself and his diagnosis. She also believed the intervention had meant that he was more open about his autism and asked for help more often.

Laurence

Laurence really enjoyed making the PowerPoint presentation:

> "It gave me something to look forward to and I really enjoyed it".

Laurence's teacher described how Laurence had approached her and been open about his diagnosis for the first time after one of the sessions.

Interviews

Four themes emerged from the interviews with all the participants. These were: '*changing perspectives*', '*boosting confidence*', '*increased awareness*' and '*continued support*'.

The theme '*changing perspectives*' showed that the overall impact had been to encourage Laurence to see autism and himself in a more positive light. Laurence's mother and his teacher felt that Laurence had enjoyed learning about the autism heroes and his strengths. They commented on the fact that the strengths had been the focus of the presentation and they believed as a result he was sounding more positive. Laurence's mother said: "It probably made him feel a bit special".

A second emerging theme was '*boosting confidence*'. Laurence's mother felt the presentation aspect of the intervention had not only boosted Laurence's confidence, but it had also raised her awareness of his confidence.

The emerging theme "*increased awareness*" referred to an increase of autism awareness. Laurence felt that he had learnt some things from the intervention, such as how sensitive individuals with autism can be to sound. He also named the racing driver Austin Riley. Laurence also stated that he felt he had learnt about his strengths from the sessions, such as being able to describe things really clearly. Laurence felt the intervention had helped him to clarify some of the things that help him when he finds some things difficult, like "needing a break". He gave an example about an incident earlier that day where he had become distracted in lessons by other children and he had asked to move to somewhere quieter.

All three participants felt the PowerPoint presentation had given Laurence an opportunity to educate his teacher about himself. Laurence felt more comfortable because he had been able to discuss his difficulties and strengths with her:

"My teacher knows more about me now. She has changed quite a lot since the presentation. She acts a lot more friendlier [sic] around me".

Laurence's teacher discussed how she had learnt several new things about Laurence from the presentation and had a growing awareness of Laurence's needs, such as regular breaks from work.

The theme '*continued support*' outlines how the PowerPoint Presentation could be developed in the future to continue to support Laurence:

"I can just keep working on everything and show all the teachers and it will just help them to get to know me and then I won't feel like the odd one out".

Summary

Referring back to the supportive model for self-disclosure, this case study shows how the intervention boosted the individual's confidence and his own awareness of autism. It also demonstrates that increasing understanding of the positives and strengths about autism can help an individual with autism to feel more positive about themselves and their label. In this case, the intervention led to the young person self-advocating more in the classroom. For this young person, the intervention therefore supported him in helping to clarify the challenges he faced and the strategies that could be helpful for him.

Within the microsystem of the supportive model, the impact of Laurence's self-disclosure increased autism awareness within the school by giving Laurence the opportunity to share the information they had learnt about himself.

Chapter 8

Discussion

The aim of the case studies was to demonstrate how an intervention developed for the purposes of supporting children with self-disclosure could be implemented in the school context. Such practice-based evidence is particularly useful for EPs and school staff in supporting them to understand the complexities in the process of self-disclosure. I will now share my reflections on the impact of the self-disclosure process, the intervention process itself, and finally, the impact of the research on general interventions for children with autism. I will do this by analysing the impact and use of the Bronfenbrenner model developed in Phase One. These reflections are designed to inform future researchers and educational practitioners.

As a social constructivist, I acknowledge that all the observations, analysis and interpretations from these case studies are influenced by my involvement in the research. As a researcher, I have been involved in creating the model used in the intervention. The model itself was developed through my interpretation of others' social constructions. During the entirety of the research, I was aware that my previous positive experience of self-disclosure in primary school may have an impact on my perceptions of events and others' perspectives. I was concerned that as a result of this previous experience I may have been biased in always interpreting self-disclosure in a positive manner. I therefore made a conscious effort throughout the research to include the aspects of self-disclosure that had not been successful. Although the research is influenced by my experiences and beliefs, I believe that my awareness of this has enabled me to provide a balanced account.

Impact of intervention

This research demonstrates how negative attitudes towards autism can be challenged through increasing understanding of the strengths and positives associated with individuals with autism. There is evidence to suggest that the process highlighted and emphasised the young people's strengths. The impact of the case studies also indicates that plans were implemented which enhanced and celebrated these strengths.

Each case study shows how positive attitudes can spread through the different systems of the Bronfenbrenner model, i.e. in both the home and school environments. The research implies that if young people with autism are given the opportunity to explore their positives and strengths, this could help them to reframe autism and help them to begin to see it in a more positive light. By providing an appropriate medium through which they can share this information with others, they can also educate others about their own strengths. The case studies show that for the young people who shared this information, awareness of their strengths can increase. Alfie's TA used the metaphor of ripples spreading through the water in a pond when a pebble is dropped to describe the impact of the positive attitude spreading across the different environments after self-disclosure.

The case studies also provide further insight into how the young person sharing information about their strengths helps others to celebrate and emphasise those strengths. In a few of the case studies, there was evidence of plans being made to enhance and further the strengths that had been identified. David's mother discussed ways David could use his IT skills, for example. Jo's TA talked about encouraging him to do more gardening at school. I think this demonstrates that the positive impact of the self-disclosure may be bi-directional, thus improving the environment for the child by encouraging the people supporting them to focus on their strengths. Supporting others to emphasise positives and strengths has previously been found to enhance parent-child interaction (Steiner, 2011). Steiner (2011) found that a strengths-based approach to parent education can improve parent-child interaction and parent wellbeing. The case studies presented in this research suggest that the strengths-based approach can also have a positive impact if it is carried out through the process of self-disclosure.

Including autism celebrities in the process of learning about autism was a powerful tool for a couple of the young people. David and Laurence mentioned it as something they had learnt from during the intervention. The autism heroes were particularly interesting to the young people if it was in an area of their special interests, or they had heard of the famous people before. David was drawn to learning about Alan Turing, for example, because one of his special interests was coding and Laurence was interested in Austin Riley, a go-kart racer with autism, because he loved cars. I think these 'heroes' with autism were particularly salient to the young people because they were successful in areas they could see themselves achieving in.

In Jo's case, the intervention did not have as much impact as I would have hoped. Jo's negative self-concept, for example, did not change much as a result of the intervention. This suggests that although learning about autism can have a positive impact on some individuals, this will nonetheless vary between individuals.

Jo reacted in a different way to learning about autism heroes than the other young people. Jo's mother suggested that learning about the autism heroes had been difficult for Jo, as they had made him feel inadequate. When Jo saw the drawing by Stephen Wiltshire, for example, he commented that he would never be able to draw like that. Rather than encouraging Jo to realise that autism did not have to hold him back, he seemed to feel that it had emphasised his feelings of inadequacy. If the intervention was carried out in future, I therefore think it would be important to include some more real life examples to show the spectrum of autism more accurately.

This experience with Jo could highlight the 'personal' aspect of the Bronfenbrenner model, in which personal characteristics such as motivation and emotional resources can have a role in the young person's ability to impact on their context (Tudge, Mokrova, Hatfield, & Karnik, 2009). Jo's negative perspectives may have been so entrenched that a short intervention looking at celebrities with autism was not enough to change them.

Regarding the chronosystem, the intervention did not measure the impact over time. It was not clear how long the positive impact of learning about autism lasted. In all cases, plans were made to continue with the work in all environments (both at home and at school), which shows that the intervention at least increased motivation for a change in behaviour.

During the intervention, I expected the schools to adapt and change the PowerPoint presentations with the young people. For all of the case studies I was dissatisfied by how little the young people had added to their presentations. There could have been many reasons for this; lack of time and difficulty with equipment were given as reasons in one school, for example. Another school had supported a young person to add information, but had only added one or two interests. It may also have been that the young people felt they had finished the PowerPoint presentation and had no more information to add. To increase the school's involvement in future, it might be

beneficial to support the school staff in carrying out the intervention themselves. If school staff were more involved with the process from the start, they might be more committed to the intervention and have a better understanding of what was required.

The self-disclosure process led to plans being made to support the young people with their strengths. I believe it would be necessary to review these after a period of time to ensure that these plans were actually put in place. I think that in order to continue to encourage the young people, their parents, peers and school staff to see their autism in a more positive light, it would be necessary to carry out regular follow-ups of the interventions. The schools and young people all spoke about how they could change and adapt their PowerPoint presentations in the future, so it might be important to return to them systematically in order to review and remind the young people and everyone around them about how they are developing.

Impact of self-disclosure

I felt that there were three main benefits to supporting the young people to self-disclose. I perceived that the young people felt empowered by the process of self-disclosure because of their reaction to the self-disclosure process. During Laurence's self-disclosure, he whispered to me:

"I can't stop smiling".

Jo happily declared to his peers:

"I have got autism. It is not a secret".

These reactions appeared to demonstrate how proud the individuals were of the presentation they had created and how pleased they were to have the opportunity to share it.

I also felt that the content of the self-disclosure was more powerful for those listening to it because it was delivered by the young people themselves. Jo's mother and teacher both had tears in their eyes when Jo presented the information at his annual review. Laurence's teacher expressed how interesting she had found it and how brave Laurence

had been in presenting it. If I had presented the information, I do not believe that it would not have commanded so much interest or attention.

Finally, Jo chose to share the PowerPoint presentation with his friends. This process demonstrated how peers' attitudes and behaviours can change as a result of learning more about autism from the individual with autism themselves. This provides further insight into previous research that suggests that educating children about autism has a positive impact (Silton & Fogel, 2012; Whitaker et al., 1998; Gus, 2000). It suggests that empowering individuals with autism to educate their peers can also be a successful method of facilitating understanding and increasing supportive behaviour.

Reflection on my research journey

I began my research journey wanting to explore self-disclosure. In the first phase, I found the interviews with the young people with autism inspiring and enlightening. The way they defined their autism was insightful. When asked what autism meant to them, the young people showed awareness of the difficulties they faced in the social environment, but also highlighted their own strengths. As a result of these interviews, I focused my work on self-awareness in order to support the self-disclosure process. I realised throughout my research journey that interventions supporting self-disclosure should not be focused on a one off self-disclosure event; instead, I now believe that the focus should be on supporting individuals with autism on their own journey of self-discovery. Specifically, all individuals with autism would benefit from being supported to gain a deeper understanding of their strengths and their needs in the different contexts they find themselves in. In enabling individuals to be more aware of their own needs and strengths, they will thus be more capable of self-advocating. In conclusion, the focus of any intervention in this area could concentrate on self-advocacy and empowering individuals to become more independent in supporting themselves.

In the second phase of the research it struck me how participants all described autism in a negative manner. When I asked about autism, all of the participants recounted the challenges and difficulties that young people with autism face. This disheartened me and encouraged me to reflect on the impact of labels on young people. Perhaps these attitudes reflect the medical approach to autism that has so far been the focus of research and understanding in the field.

Mackay and Parry, (2015) found that the behaviours observed in children with autism are often "pathologised" (Mackay & Parry, 2015, p. 1424) and "problematised" (Mackay & Parry, 2015, p. 1424). The narratives reflect what Mackay and Parry (2015) describe as an attitude that is "embedded" (Mackay & Parry, 2015, p. 1425) within the practice of autism. The theory is that such negative attitudes have developed from a history of interpreting autism from a medical perspective. Mackay and Parry (2015) go on to suggest that this approach to autism as a 'disorder' could impact on young people's ability to construct identities. This perspective is further supported by Humphrey and Lewis, (2008) who state that children with autism construct information about their identity through feedback from others. It is therefore possible that the descriptions used by both the parents, school staff, and the young people with autism themselves reflect the medical discourse around autism; it is possible also that this approach to autism has impacted on the self-concept of individuals in these case studies.

During the research, I returned to the diagnostic criteria for the autistic spectrum to find the words "Disturbances" "Difficulties" "Disorder" and "Deficit" (DSM V, p.52). Having completed this research, I find myself questioning the descriptive terminology in the diagnostic criteria. I have become more aware of the impact of this negative phrasing on the young people with autism. In a couple of the case studies, the words "illness", "disability" and "disadvantage" were used when talking about their autism, for example. I have gained further insight into how an individual's sense of self may be impacted by the negative terminology used to classify the condition. If these words filter through to the young person via parents' and schools staffs' assumptions about autism, this may be assimilated as part of their belief about themselves.

This raised awareness of how the language used to talk about autism may impact on young people has made me reflect on my own practice as an educational psychologist. I have now begun to research positive psychological approaches, such as the strengths-based approach. My psychology reports will now reflect this more positive strengths-based approach, highlighting and focusing on individuals' strengths and abilities.

Implications for the role of the Educational Psychologist

Promote and support the use of pro-active approaches to reduce the likelihood of problems occurring

Educational psychologists have many opportunities to change the perception of autism as a 'disability' and encourage people to understand autism as a 'difference'. Change can be implemented through education in all levels of the system identified in the model of self-disclosure. Perspectives can be influenced through parent consultations and workshops, joint work with other professionals, and training in schools, for example. Reframing the focus of interventions could be at the heart of this type of work. Currently, many interventions in schools emphasise the difficulties and problems faced by young people with autism, whereas this research suggests that the focus of interventions should involve acknowledging, encouraging and celebrating young people's strengths.

A positive attitude towards autism could also be achieved by increasing awareness of people to Baron Cohen's 'triad of strengths' (Baron-Cohen, 2004) and increasing awareness that the 'medicalised' language around autism can affect young people's identity formation and inadvertently lead to the young person feeling negative about themselves.

Another way that educational psychologists could reduce the likelihood of problems occurring could be to encourage school staff to focus on creating an environment of equality. For this research I have focused the intervention on the young person. However, as the model outlines, support can also be targeted at the level of the wider community (see Figure 5). Future research could explore the impact of interventions in the exosystem, to look at how changing attitudes in the wider cultural environment could impact on individuals' understanding of autism. It may be that although self-disclosure enables individuals to make positive changes to their immediate environments, without change at the cultural level it could be very difficult to sustain this change.

Adopt a psychological perspective to gain a deeper understanding of problems

In my experience, children with autism are often referred to educational psychology services due to the social difficulties they experience in the mainstream educational environment. My research has highlighted some aspects that could act as a barrier to young people with autism being socially included in mainstream school. If young people develop a negative perspective of the label of autism, this may increase their feelings of autism being stigmatised, which could thus impact on their social inclusion because they may feel like they have to 'hide' the label or distance themselves from it. The case studies presented here provide further information about the barriers to social inclusion by demonstrating that empowering the individual to understand and explain autism themselves can make them feel more positively about their label. This, in turn, could impact on their social interactions with their peers. Educational psychologists can use this information, to provide better support for individuals with autism because it gives a possible theoretical perspective of why individuals may be experiencing isolation in schools. It gives insight, for example, of how social isolation may be linked to being associated with a stigmatised label. This can help psychologists to increase others' understanding of possible causes of social difficulties and thus advance supportive strategies accordingly.

Use evidence-informed strategies to address problems and generate change

The model and intervention developed in this research could be shared with school staff to promote measures to support children with autism in understanding the impact autism has on them. This would provide the opportunity to challenge their own negative perspectives of their diagnostic label and gain further information about their strengths. The case studies provide evidence that change can be generated at all levels by empowering the individual to learn about and discuss their strengths and challenges in a positive and celebratory way.

Bronfenbrenner's model is intricate and multifaceted, therefore it can make the process of evaluating the situation a very lengthy and complex one. On a practical level, school staff might find the process of gathering all the information in the different systems complicated and time-consuming. The primary focus of schools is on the academic progress of students, therefore it can sometimes be hard to encourage school staff to

carry out interventions focused on social inclusion. There is a possibility that the complexity of the model might put them off using it themselves without support.

Another disadvantage of using the Bronfenbrenner model to understand the process of self-disclosure is that it does not give any clear explanations of the self-disclosure process (Bronfenbrenner, 1979). Whilst I have been able to gain a much better understanding of how different systems might impact and interact around individuals, it is incredibly challenging to identify the importance of each of these factors and how they interact for each individual (Hook, 2009). The model itself does not provide any support in trying to work out how individuals might react or the hierarchy of specific support factors for individuals. The model also provides answers for every eventuality, which makes it very difficult to disprove.

The main criticism of the Bronfenbrenner model is its complexity; however, I think this criticism is also its main advantage. The Bronfenbrenner model does not underestimate the intricacy of impacting factors of the environment on an individual's development. I think that Bronfenbrenner's theory has allowed me to remain open to influences from all the possible different contexts. The model has therefore supported the process of gaining more insight and information into the process of self-disclosure for each individual. Rather than narrowing down the focus, it expands the areas where support could be increased and therefore reflects the real environments that individuals find themselves in.

In order to overcome the complexity of the model, I have created a version that could be shown to school staff or parents. This model is accompanied with a sheet explaining the different supportive factors within the Bronfenbrenner model making it more accessible to individuals who do not have prior understanding of the model developed by Bronfenbrenner (see Appendix 13).

Implications for further research

Further research could look at the long-term impact of the self-disclosure process. This could involve measuring the impact of the process and how best to carry out follow-up support in schools and at home. It may also involve carrying out longitudinal research for individuals who self-disclose to explore how this changes and develops over time

and in different contexts, for example, exploring the self-disclosure process in college or work environments.

An essential goal for all children in autism is self-advocacy. Self-advocacy and self-disclosure are considered to be linked and there is evidence in a few of the case studies presented to demonstrate this. However, it wasn't clear from the research what the relationship was between self-disclosure and self-advocacy. This research has also highlighted that even when autistic people feel they have a good understanding of their autism, they might find it hard to verbalise how other people can help. Interventions may therefore need to focus on supporting the young person to develop self-advocacy skills. Future research could explore the connection between self-disclosure and self-advocacy in order to understand how self-advocacy could be better supported through the process of self-disclosure.

Finally, it must be noted that the self-disclosure might be a very different process for young people from different cultures, age groups, contexts and genders. Self-disclosure might also be a very different process for individuals with different labels. Self-disclosure is an individual process for every person in every environment. Although no generalisations can be made from this research, the supportive model nonetheless provides a starting point from which self-disclosure can begin to be explored.

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APPENDIX 1   INFORMATION GIVEN TO PARTICIPANTS

- Example of ethical consent form
- Example of information sheet given to the participants

Ethical consent form for young person:

I have been fully informed about the aims and purposes of the project.

I understand that:

I do not have to be part of this research project.

If I choose to be part of this research project I can change my mind at any time.

This research may be published.

If this research is published I can decide whether I am happy for information about me to be shared with others.

Any information which I give will only be used for this research project.

The information I give may be shared with people helping with the research (but only once my name has been removed so they do not know it is me).

The information I give will be protected and kept safe.

All information I give will not be shared with anyone else.

The researcher will make every effort to make sure that no one can work out who I am from reading there research.

...............................………………..
        ....
(Signature of participant)   (Date)

…………………………

(Printed name of participant)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher

Contact phone number of researcher: ▮▮▮▮▮▮▮ (work) OR ▮▮▮▮▮▮ (mobile)

If you have any concerns about the project that you would like to discuss, please contact:

Andrew Richards: Programme Director of the Professional Doctorate Training in Educational Psychology, Exeter University.

Martin Levinson:

Information for the parents/carers:

Exploration of self-disclosure for children with autism
Jess Pares Landells

Self-disclosure is when children have shared information with their friends and classmates about their autism.

The participants involved in this research will be helping to develop a model that can be used in schools as a guide for good practice. Their voices will be used to support others with autism in mainstream schools.

Aims of the research:

- I want to understand more about what happens when young people with autism talk about autism with their friends.
- I want to understand how and why this happens.
- I want to understand whether you think that telling people about their autism changed anything for your child in school.
- Finally I want to understand more about what you feel helped your child in this process.

This will involve:
- I will carry out interviews with your child in order to understand the self-disclosure process from their perspective. I will follow good practice guidance from the Autism Education Trust (AET) using visuals such as a time line and other methods to ensure your child understands. I will speak to individuals who know your child first in order to adapt the interview appropriately. I will also use Heather Moran's drawing the ideal self to explore how your child sees themselves. Finally I will use the Autism Identity Scale developed by Jarratt (2014) which explores whether or not they see autism as a part of their identity.
- I will then interview you about your understanding of your child's autism. I also want to find out about self-disclosure from your perspective.
- I will also interview a member of staff from the school who was involved with the process to gain further understanding

How these interviews will be used:

I will analyse the data. This will group together any themes emerging from the interviews. These themes will be used to create a model which will then provide a visual that will demonstrate environmental factors that were considered supportive in the self-disclosure process.

I envisage this model then being used in schools as a model to guide good practice, demonstrating all the supportive factors necessary for identity development for children with autism in school.

Ethical consent:

I have gained ethical consent from the school of University of Exeter's ethics committee. I will obtain informed consent from all the participants involved in the research, including parental consent for the young people with autism. All participants will have the right to withdraw from the research at any time.

All information collected during the research will be kept entirely confidential and anonymised for reporting.

APPENDIX 2   INTERVIEW MATERIALS

- Developing the interview schedule
- Original interview schedule
- Adapted autism identity scale

Developing the Interview Schedule:

Initial analysis of the domain:

A clear conception of the domain interest in order to ensure the research is systematic. Constructivist insights imply the need for researchers to make explicit to themselves the nature of their own construal of a topic domain (Tomlinson, 1989).

Interviews with young people with autism

Conception of self-disclosure process

Factors influencing self-disclosure process

    Environments perceived as influential

        School

        Home

        Other

    Individuals who were influential in the self-disclosure process

        Family

        School staff

        Other individuals with autism

        Friends

    Sources of information used in the self-disclosure process

        Books

        Internet

        Other individuals

Impact of self-disclosure process

Impact of self-disclosure process on self

Impact on identity

Autistic or non-autistic

Impact on individual with autism's own understanding of autism

Knowledge of the diagnosis

Knowledge of how autism impacts on them

Impact on individual's sense of self

Self-esteem

Confidence

Self-advocacy

Impact of self-disclosure process on others

Impact on others' understanding of autism

Peers knowledge of autism

Impact on behavioural attitudes towards individuals with autism

Staff's knowledge of autism

Impact on behavioural attitudes towards individuals with autism

Selection of Research Interview subdomain

Identify which aspects of the topic I wish to discover the interviewee's construals and reactions.

For individuals with autism:

All of the above apart from impact on identity – feel like this issue would be difficult to cover in an interview.

For Staff member:

All of the above

For parent/carer:

All of the above

Construction of interview agenda

Construct an agenda of questions that will cover these and provide a structure to guide the ordered focussing of actual queries in such a way to maximise the open-endedness of the process.

The interviews will be conducted in a hierarchical way. However the AET good practice guide suggests that children with autism benefit from structure. It is also suggested that individuals with autism benefit from the use of visual support. In order to support the young people with autism a timeline will be used. This will give the interview a clearer structure and will support the young person in remembering the events. As they give me information I will mark on what they are saying onto the timeline. The language was kept as simple as possible and will be checked with people close to the young person in order to check that they will understand all the questions.

Conception of self-disclosure process:

- **What did the process of self-disclosure of autism involve?**
    o When did you find out that you were autistic?
    o What began the process of self-disclosure?
    o How did it happen?
Would you do anything differently if you did it again?

Factors influencing self-disclosure process:

- **During this process of self-disclosure what supported you?**
    o Was there a particular place that you found helped you with self-disclosure?
        ▪ School
        ▪ Home
        ▪ Other
    o Were there people who helped with self-disclosure?
        ▪ Family
        ▪ School staff
        ▪ Other individuals with autism
        ▪ Friends
    o Did you get any information that helped you?
    o Where did you get this information from?
        ▪ Books
        ▪ Internet
        ▪ Other individuals

Was there anything that didn't help you with this process?

Would it have been better if you had more help in any of these areas?

Impact of self-disclosure process

What sort of impact did the process of self-disclosure have? (how did self-disclosure affect you?)

Did you learn more about autism through self-disclosure?

Did you learn more about how autism affects you through the process of self-disclosure?

Did self-disclosure have any impact on how you feel about yourself?

- Did it affect your self-esteem?
- Positively
- Negatively
- Did it affect your confidence?
- Positively
- Negatively

Did it affect your ability to let others know what help you might need?

- Positively
- Negatively

Did self-disclosure have any impact on people around you?

Do you feel it affected others' understanding of autism?

Do you feel like self-disclosure had any impact on your friends and classmates understanding of autism?

- Positively
- Negatively

Do you feel like it made any difference in how classmates and friends acted around you?

- Positively
- Negatively

Do you feel like self-disclosure had any affect on staff's knowledge of autism?

- Positively
- Negatively

Did it affect how staff acted towards you?

- Positively
- Negatively

2. The Autism Identity Scale (Jarrett, 2014)

Instructions:

The scales below include a list of statements about how you see yourself and what you like to do. If you strongly disagree, tick the box. If you disagree with the statement, tick this box. If you neither agree or disagree, tick the 'neutral' box. If you agree, tick this box. If you strongly agree, tick this box. There are no right or wrong answers. Please complete scale 1 and scale 2.

Only tick one box for each statement. If you do not want to answer a question, that's fine, just leave it blank.

<u>**Scale 1**</u>

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
<u>Cultural Identity</u>					
I call myself autistic or say I have Asperger syndrome.					
Being involved with people who have autism or					

Asperger syndrome is an important part of my life.					
Being autistic or having Asperger syndrome is an important part of who I am.					
I feel that I fit in with other people who have autism or Asperger syndrome.					
I am comfortable with other people who have autism or Asperger					

syndrome.					
Cultural involvement					
I enjoy reading books/magazines/information written by authors who are autistic or have Asperger syndrome.					
I enjoy going to events/parties/gatherings for people with autism or Asperger syndrome.					
I enjoy talking to other young people with					

autism or Asperger syndrome.					
I enjoy taking part in activities that promote the rights of people with autism or Asperger syndrome.					
Cultural preference If you could have your way, what would you prefer the following situations in your life to be like?					
I would prefer my education to be at a school with only people with autism or Asperger syndrome.					

I would prefer my closest friend(s) to have autism or Asperger syndrome.					
I would prefer my family members to have autism or Asperger syndrome.					
Cultural competence					
I know lots of other teenagers with autism or Asperger syndrome.					

	Strongly	Disagree	Neutral	Agree	Strongly
I know lots of names of well-known people who have autism or Asperger syndrome.					
I know lots about important events in the history of autism or Asperger syndrome.					
I know of clubs run by and for people with autism or Asperger syndrome.					

Scale 2

Statement	Strongly	Disagree	Neutral	Agree	Strongly

	disagree				agree
Cultural Identity					145
I don't call myself Autistic or a person with Asperger syndrome.					
Being involved with people who do not have autism or Asperger syndrome is an important part of my life.					
I often wish I could become non-autistic or not have Asperger syndrome.					

I feel I fit in with other people without autism or Asperger syndrome at school.					146
I am comfortable with people without autism or Asperger syndrome.					
Cultural involvement					
I enjoy reading books/magazine/information written by people without autism or Asperger syndrome.					
I enjoy going to					

events/parties/gatherings with people who don't have autism or Asperger syndrome.				147
I enjoy talking to other young people online without autism or Asperger syndrome.				
I enjoy taking part in school events with people who don't have autism or Asperger syndrome.				
Cultural preference
If you could have your way, how would you prefer the following situations in your				

to be like?					
I would prefer my education to be at a school with people with and without autism like now.					148
I would prefer my closest friend(s) to not have autism or Asperger syndrome.					
I would prefer my family members to not have autism or Asperger syndrome.					
Cultural competence					
I know lots about teenagers without autism or					

Asperger syndrome.					
I know lots of names of famous people without autism or Asperger syndrome.					
I know lots about important events in world history.					
I know of clubs run by and for all young people					

Thank you for completing this questionnaire!

4. Feedback to CS2

Summary:

Process of self-disclosure:

Alfie was 8 years old when he found out that he was Aspergers. In primary school he felt that everyone knew that he was different. At this time he would mention that he had Aspergers in conversation if he felt it was appropriate. Alfie's interest in finding out about Asperger syndrome grew between the ages of 9 and 11 and the transition to secondary school in year 8 spurred him on to find out more about Aspergers. At this point Alfie did not want people to know that he had Aspergers and he was very selective about who he told. However, the new environment in secondary school proved to be a challenging one. Alfie describes finding himself in "awkward social situations". In a year 8 public speaking assignment Alfie chose Aspergers as a topic.

The following is a diagram that has been created out of interviews with the young person, his mother and a member of the school staff who supported the process:

Each of these strands represents themes that arose out of these interviews.

Reasons for self-disclosure:

Reactive reasons refer to themes which described why there was a need for self-disclosure. These included the transition to secondary school, some social difficulties that occurred in the new environment secondary environment and others' negative feelings towards difference.

The proactive strand refers to a desire to create a more positive environment for the young person. This included wanting to change their peers' attitudes towards differences. This was done by explaining why there may be differences in behaviour and giving them more appropriate strategies to enable a more supportive and understanding environment.

How self-disclosure happened:

Within the theme "how self-disclosure happened" the "content of the self-disclosure" was discussed. "Focussing on the individual" was considered important as well as ensuring there was an overall celebratory attitude towards the autistic spectrum condition. This was done by celebrating successful individuals on the autistic spectrum and teaching peers about the different abilities individuals with autism can develop. Some of the young person's difficulties were also discussed alongside giving supportive strategies for peers.

Impact:

The impact was considered to be very positive:

"oh yeah, I had people who knew and people who listened to me and that's all I ever wanted."

It was considered to have a positive impact in many different ways. There was a feeling that others at school had more acceptance of difference. It encouraged others to see past the differences and get to know the individual. Others were also more aware of the young person's strengths. It encouraged openness about difference and increased discourses about the autistic spectrum. Finally self-disclosure also gave peers a better understanding of how to support the individual at school.

The ripple effect describes how positive attitudes spread like ripples in water when a pebble is dropped into a pond. It was felt that once the self-disclosure had a positive

impact on those who had been present, this had a positive impact on the wider environment.

Supportive factors:

There was an overall sense that having a positive and can do attitude particularly supported this young person's self-disclosure. All the individuals involved discussed how they believed it was essential to ensure that the autistic spectrum was not considered a barrier. This was done by having a positive attitude, celebrating autism and building the individuals self esteem through a focus on the young person's strengths. It was also considered essential for the young person to have a good understanding of themselves and their Aspergers. Support from school was considered essential. This support included good communication between the parents and the school, the school having experience and a good understanding of the autistic spectrum and teaching and advice for the young person being readily available. Another thing that was considered important was for the young person having a trusting relationship with a member of staff at the school.

APPENDIX 4   DATA ANALYSIS

- Example of transcribed interview (Alfie)
- Example of transcribed interview (Alfie's mum)
- Description of data analysis
- Example of interpretive codes
- Emerging codes for each case study
- Final codes emerged

Transcribed interview (Alfie):

JPL: So, first of all I just want to find out a little bit about how you feel about Aspergers. What is it to be Aspergers?

X: What is it to be Aspergers? A very common question I get. For me it's a different perspective on things. Particularly socially, because that's an area that people have discrepancies about. For me it was certainly difficult I'm not going to go and say, oh you know, it was jolly good fun. It was difficult at first, you know, sort of, the whole integration process, socially, it was difficult. That's sort of one part of it though, for me Aspergers is a conundrum and its one part of who I am, it's a combination of things … what's identified with Aspergers?... sometimes an extended memory, advanced vocabulary, limited social skills and response to, sort of, stimuli, whether that be social interaction with other people..

JPL: So you said that sometimes it can cause difficulties socially, and that also it can give you an extended memory and good vocabulary. Anything else you want to add to that? Remember there's no right or wrong answers, I'm just asking your perspective.

X: Yeah, my perspective, I don't know, for me, it's made me more observant if anything.

JPL: Ok, yeah, in what sort of way? What are you more observant of?

X: I'm more observant with things that I like and I'm a bit more, with history. I like history, it's one of my good subjects, I like looking at historical facts, i research dates. I'm very observant I'm very analytical sometimes.

JPL: Ok

X: I can be creative but I am analytical a lot of the time.

JPL: So analytical and creative, and you got special interest in history as well.

X: Yeah, that among other things, yeah. I'm basically calling myself a nerd now.

JPL: And what sort of other things?

X: Um, film, media, drama, acting particularly. Yeah, I try to be a varied person.

JPL: So now we're gonna look at the process of disclosure. So let's talk about first when you found out that you had Aspergers, can you tell me a little bit about that.

X: Yeah. Well like I said before, it's hard to explain really because I didn't find out about it until I was eight, I was having difficulties in school, I'd been having difficulties from the age of six, six is when my parents found out I was diagnosed. They said 'yeah your son has Aspergers.' And I knew even though I didn't want to admit it, there was stuff like, I was hiding under tables when it was too noisy, i was rushing around I did socially awkward things, I would mutter to myself sometimes. I was a bundle of joy though, I didn't really care what happened, i was quite happy to do anything and everything. I found out properly when I was eight. Dad said just say to people I've got Aspergers syndrome I've got a learning disability. And I was like what is that what are you talking about Dad I don't understand. and it was sort of, that that started this journey of self discovery for me and just sort of venturing into the weird world of Aspergers and autism and just finding out what it is and what it's doing for me.

JPL: Yep, so you really began to find out about autism from the age of eight

X: Yeah, slowly, it didn't come straight away, but then again not everything does, so yeah it was finding out through TAs, I mean you know obviously they helped me, I had support in lessons, because I was rather distracted, I mean I was an enthusiastic and I would say maybe polite student. But I did get distracted very easily, needless to say.

JPL: So that was one of the difficulties that you had

X: Certainly, and conforming

JPL: And you had support with that?

X: Yeah I had support, I may not have appreciated it in the most obvious way possible but I'm very grateful for all those who tried to help, in every single way, so that would be my teachers, TAs, parents obviously. But yeah and I think it was years 5 to 7 that my interests grew...I can't really be...

JPL: Interests grew for...?

X: Just finding out about it, I can't be any more specific, I suppose, interesting things...I've had a busy life but that's all I can selectively remember to be honest, all I can remember is wanting to extend my interest in it. Year 7 particularly because I was moving to secondary school and I didn't realise how big of a thing it would be and the whole thing sort of made me oh ok, I'm gonna integrate into a bigger school environment.

<u>Transcribed interview (Alfie's mum):</u>

P: I think A***** was more relaxed. Finally he is out. There is no hiding from it. I think he got more friends. He got more from girls friends but he has a good bunch of male friends. I think he started to see.. I think people started to listen to him and see what his interests areand then realise actually we have loads in common and they build those relationships. So he is really very got respect from others. I think that's one thing the teachers use and Mrs Ayres says.. A***** is very well respected by adults and by children. They all come to him and look up to him. And see actually he is a normal person. He is a great listener and you can go to him. Its made his confidence. His confidence has come really you know.. he walks standing up straight.

R: You think that process impacted on his confidence.

P: I think so.. I think once he came out… there is no pretending to be someone else. When A***** joined year 8 (St E******) he tried to fit in sometimes by trying to be someone else and I said.. 'That's not you A*****.. you are not going to be happy doing that. You might think you are being happy because you are fitting in.. you're not.' You should be yourself. You know who you are. Be yourself and people will accept who you are. I think that's when he, actually, this is who I am. I can do this and you can either take it or leave it. Not everyone is going to laugh at your jokes. It doesn't matter. Not everyone laughs at my jokes. I think that's what it took for A***** to.. actually this is who I am. Gaining confidence in himself to try things like join a drama group and join the school show. actually I can do this and he hasn't stopped. Actually he has to believe in himself. Actually I can do this… why cant I do this? Who said I cant do this. The only person stopping you doing this A***** is yourself. If you set your mind to it you can do it. So go for it. Actually I am A***** I have Aspergers. I can do that and that's the way it should be. If someone else doesn't want to help you with something. they are not your real friends. They don't accept you for who you are. And I they don't accept you for who you are that's fine. You don't get on with everyone in life. The more we talked about it.. I always tried to tell him to have a go. You are going to disagree with someone someone is going to disagree with you. That's life.. I think Maturity as well. I think maturity came into it.

R: How did maturity come into it?

P: He became less angry. When something happened he wouldn't have a fit or shout and scream or something. He would say.. actually.. this has happened.. 'can I talk to you about something?' 'yeh, you can talk to me about something.'I think that's when maturity came because he actually said actually I don't have to throw my dummy out of the pram. I can actually talk about it.

R: Which came first? The maturity or being able to tell others about his aspergers?

P: I think he was probably was talking about Aspergers before he started becoming more mature. I think he spoke about it and then as the progress matured. I think it is a process of time. Everyday we would see something different in A*****. I think its with time. I think the skills he was picking up.. his reading.. we buy him books about body language and all those things that A***** picks up he reads. Matures because he is picking up skills. And he is mature in the way he approaches. So all the things that we take for granted comes very hard to A***** like reading body skills and A***** like I

said is a great reader and the best tool for A***** is books. He will take it all in. Not just about Aspergers but about self development. And his maturity of understanding the books as well. If I gave him the same book the same one about body language three years ago it would be no good for him because he wouldn't be able to understand but now he can. So he can read and he can actually.. that's why now.. when he does drama. His body language comes with his character. He really gets into a character and he can actually become that character. Because he learns to get the body language right.. all that is from talking to us and many of the things is from reading. Its amazing what A***** gets from books.

R: So I suppose its about looking at about their interests and thinking what would be a good tool..

P: I think it helps if the child likes to read because there is so much information in books.. and A*****. Where ever we go .. at the airport.. we always end up in a book shop. A***** just gets so much out of books so we are lucky in that way. I suppose a if you got a child who doesn't really get books then it will be a lot about actually you reading the books and passing that information on.

R: So being the transmitter of that information?

P: Another thing they did in school was a course on social skills and development. That is important. Every school should be offering that. That when they join, especially secondary school because that is important for them to have that help with how to interact. To know about personal space because when you come from a small school and you grow up there. Like A*****'s been to primary, middle school and the same school they saw him growing they accepted and they wouldn't try to break his space and they would just let him get on with it.. where… when he joined secondary school all the kids in his class came from all different schools so he wouldn't be aware of their personal space and they wouldn't be aware that it is normal for him to invade their personal space. We don't like it because we don't know him. So that is important for them to use that extra curriculum lesson that they do to help them develop their social skills and interact because I think that is the biggest problem as well because in classrooms they can have the support of the TAs whereas in the playground they haven't got any support there. So you have to let them… because if you are standing by them it will make the even more noticeable but you need to give them the skills for them to be able to come in the playground and I think it is important for those classes to be there for them to develop their skills to interact with others. I think as well a lot of it is disclosing yourself to them it will make them aware actually.. you have to have understanding as well. If that person is like that they are not doing that just for the fun of it. They need their space.. give them their space. If they don't know and you have a fit… 'why you having a fit?' 'I don't know why you are having a fit.' You are actually fuelling.. putting more fuel on the fire. So that is why it is important to disclosure yourself and develop your social skills in conjunction.

Description of data analysis

I started by reading through the interview transcript in full. In stage one I produced descriptive coding of one set of interviews (child, parent and school staff). I then recognised that the data fitted under certain headings;

- Reasons for self-disclosure
- Content of self-disclosure
- Impact of self-disclsoure
- Supportive factors for self-disclosure.

I grouped the data under these headings and then began to develop interpretive codes by looking for emerging themes and clusters in the descriptive codes. I carried out this process for the each of the case studies one at a time (see mind maps in appendix 5 for an example). After I had analysed each of the case studies in this manner I compared the interpretive codes to see if there were any similarities. At this point I adapted the names of the interpretive codes to encompass the similar interpretive themes from each case study. This process allowed me to see more general interpretive codes for the data as well as identifying differences between the separate case studies and differences between the different participants in each case study. I created a detailed picture of the themes emerging in each case study of which there were 40 and above. I recognised clusters of themes and grouped them a final time to form the final overarching themes.

When I then looked at the themes again I realised that the four overall headings above did not remain appropriate because there were so many aspects that overlapped. I then merged the themes under the following headings "reasons for self-disclosure", "Content of self-disclosure" and "Supportive factors for self-disclosure". This left me with two main headings:

- Self-disclosure process
- Impact of self-disclosure

Example from CS2 of the interpretive codes:

Red is the young person
Blue is the young person's mother
Black is the young person's TA

Impact of self-disclsoure:

Encouraging openness about autism:

If he wanted some help.. he could go to his peers to say 'you know what sorry.. is that an Aspie thing to say?'

During the course of these lessons the other child who no one knew had aspergers.. said 'I have got aspergers too as a matter of fact.. other kids in the class both disclosed that they had cousins and one of them had a brother with autism.

once ****** made a disclosure.. I got **** coming up and asking 'whats all this about aspergers?' one or two of the kids would come and ask me about it.

Also curiosity.. that is where this young lad (friend of ******'s) used to come up and say… 'Miss I have got a question for you. Why does ******….'

I think people said actually we can approach him. Especially the girls are more interested and they will go and ask him questions and because they are quite deep and emotional where boys are a bit more.

But now I'm very open about it, people say, if I tell people they'll be like oh I didn't know you had it you covered it up really well, I'll be like oh, sometimes I try sometimes I don't

yeah we can joke about it! I loads of those jokes, I get slagged off all the time, it's funny! I don't care anymore. They can make a joke about me,

we can joke about it, I joke about my Aspergers and there has been a bit of banter, I like making jokes, I try to be a comedian it doesn't work out all the time, I've got friends who rip into me sometimes, like my friends...assistants to the classroom...X's poohed himself again. You know, the really harsh sort of, jibes at the ribs and stuff like that, but...I don't take it personally at all, I know that they don't mean it, obviously. They wouldn't...if they did then that would be another matter but I know and teachers know, and we've all established, and it's not consistent, I dish it back as well, I make decent jokes, while I can.

it wasn't massive, you know it wasn't massive it wasn't like oh my gosh I feel like the best feeling in the world now but you know, it was something that...you know it was a convenience, and it was convenient that I did so. Because they need to know sooner or later,

When he feels comfortable he does. And sometimes he doesn't say until a long time… in just a normal conversation. I know that he has done his street dancing for a while and he goes to the girls group next door and they were doing a fund raising for autism and he actually said. Actually I and my sister have autism. And everyone said.. 'What you?' and he said 'yeh' so he is actually happy to say it. He is not ashamed..

Seeing past the label

When you know somebody you value them. The more you know about a person the more you value them and the more you are able to forgive their faults because they know that the reason you do this is because of this.. that and the other

Greater knowledge brings greater understanding and respect. And that's something that children do not give automatically. You have to earn it and he did . He earned it.

I think he started to see.. I think people started to listen to him and see what his interests are and then realise actually we have loads in common and they build those relationships.

So he is really very got respect from others. I think that's one thing the teachers use and Mrs Ayres says.. A***** is very well respected by adults and by children. They all come to him and look up to him. And see actually he is a normal person. He is a great listener and you can go to him.

I think he got more friends. He got more from girls friends but he has a good bunch of male friends.

I personally believe.. about positive behaviour reinforcement. In some respect it is not just about getting children to do what you want.. its also to get teachers to do what you

want in terms of changing their attitudes towards… 'oh my god.. we have got another autistic child….'

Acceptance of differences

I wanted people to accept me as an equal not to pity me or to feel sorry for me. But obviously you have to make them understand how it feels, but it's about making them understand not making them feel sorry for you cause otherwise they look you in a completely different way and they sort of look down on you and no one...i hate being looked down on I despise it that's one thing I'm paranoid about the most. But I think self-disclosure helps, it may not be the best idea for everyone but it's helped me.

And I think he got a lot of understanding I think especially from girls. I think they were a bit more open minded and said actually 'its fine' I think he got more friends out of girls than actually out of boys. I think boys that age are less interested in things like that.

Actually he is just a person like us.. and he gets a bit emotional and a things like that.. they learnt to accept that sometimes it gets too much and he just leaves the classroom because he needs to get his head together and that's it.

I think they liked that and they appreciated it by like sort of accepting me into the groups

then you know they understood me they tried to accept me as well as they could

I think it made the teachers understand him a lot better because he got better support from the teachers and I think they are not frightened of A***** .. I think some particularly didn't know how to deal with it. He said 'this is who I am' and they recognised that when that happens he needs to take time out and recognise that that is fine.

Emerging codes with the following headings:

o Reasons for self-disclosure

o Content of self-disclosure

o Impact of self-disclsoure

o Supportive factors for self-disclosure.

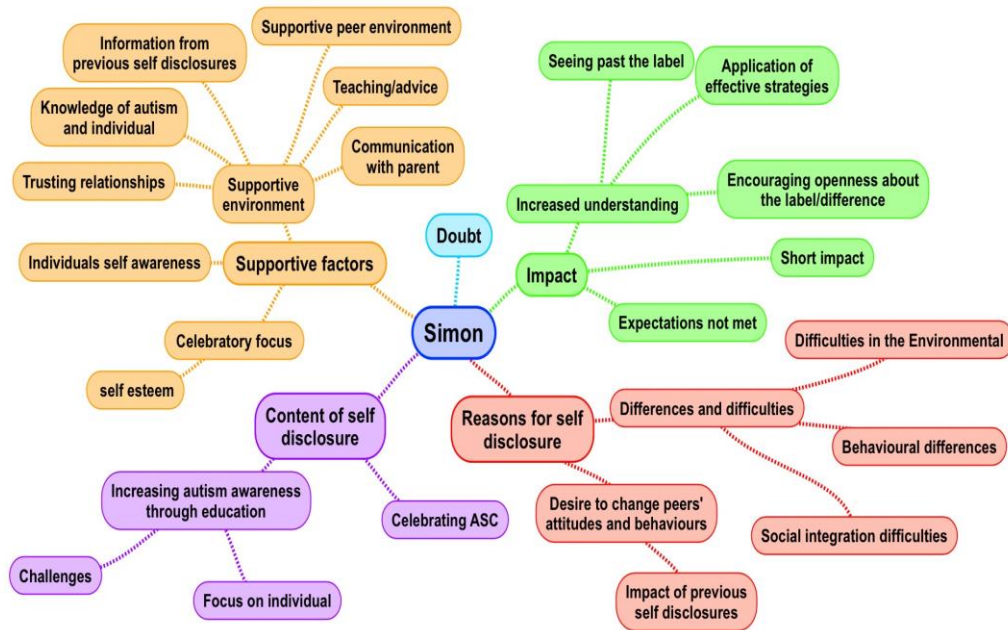Mind map of emerging themes for Finley:
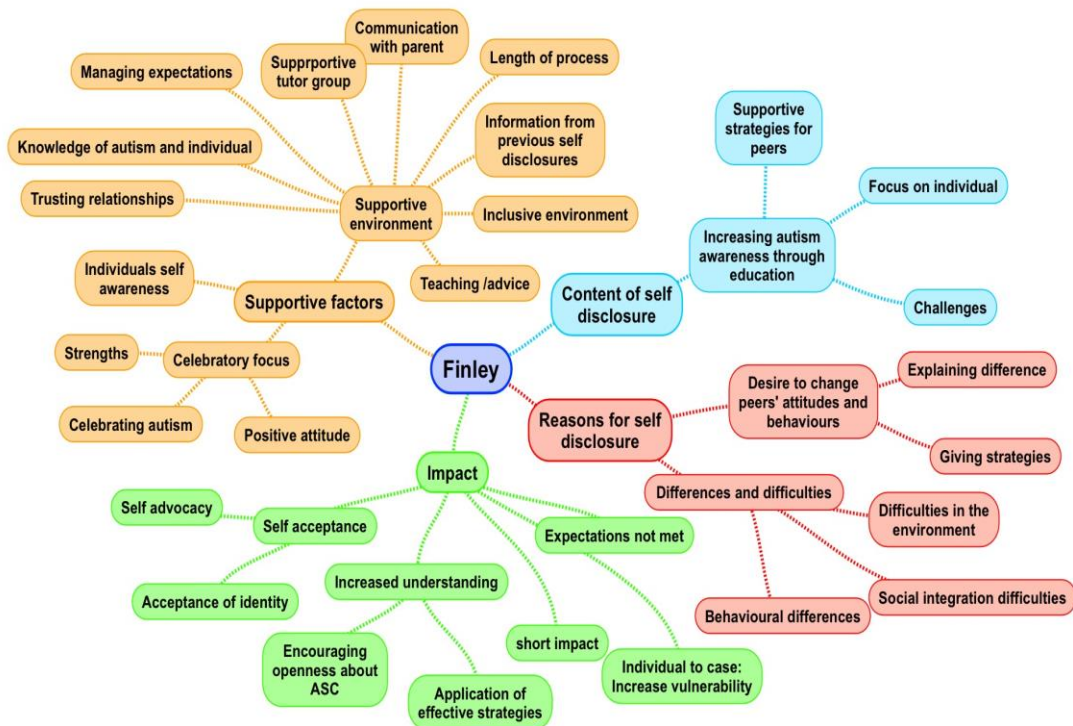
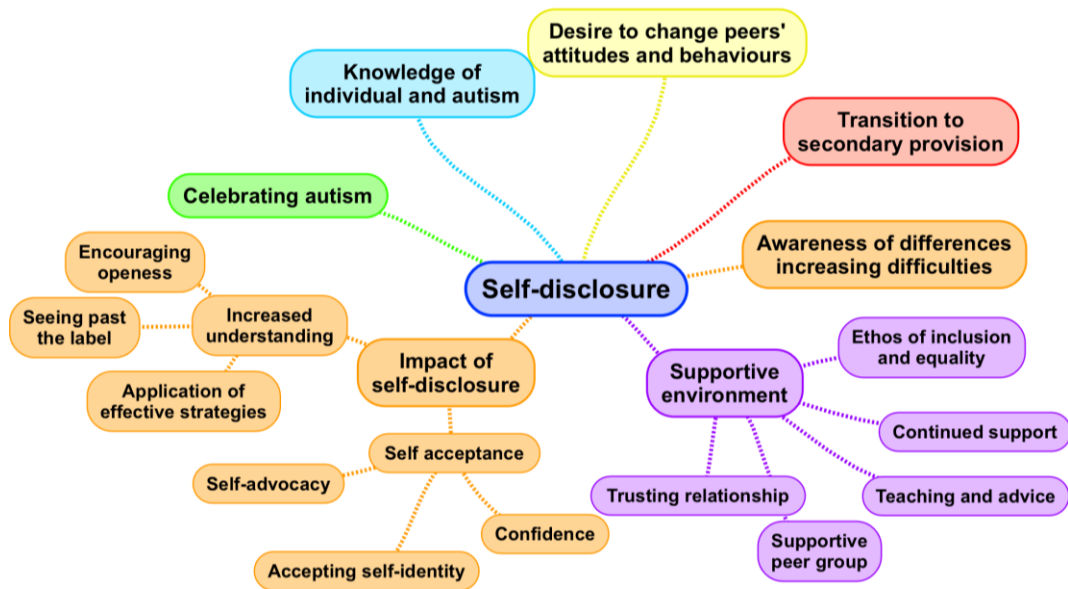Mind map of emerging themes for Alfie:

Mind map of emerging themes for Matt:

Mind map of emerging themes for Simon:

Emerging final themes:
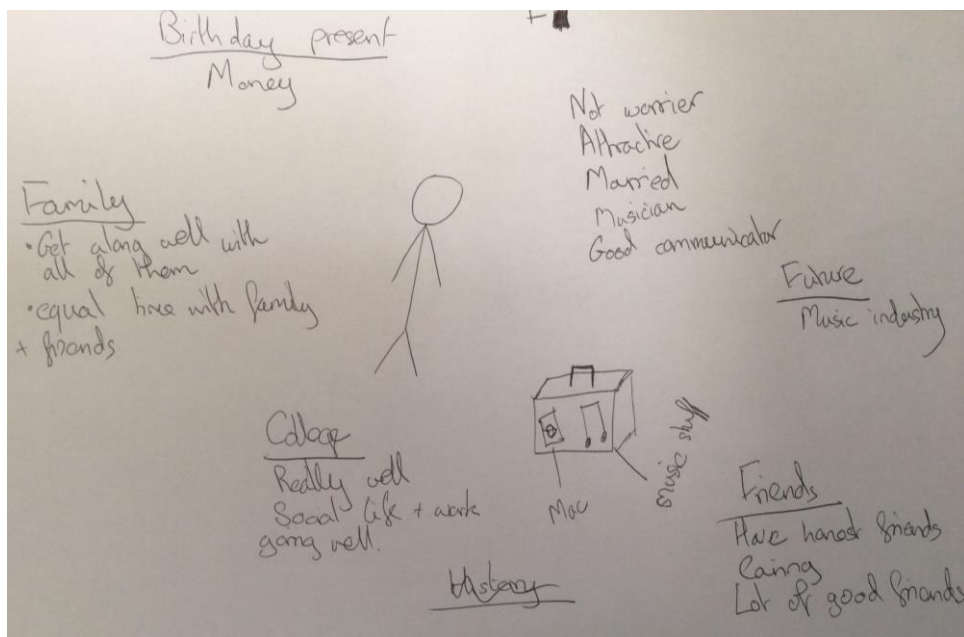
APPENDIX 5   FINDINGS

- Finley's "ideal self"
- Alfie's "ideal self"
- Mat's "ideal self"
- Simon's "ideal self"

Finley's "ideal self"

Ideal self:

The person Finley would least like to be:
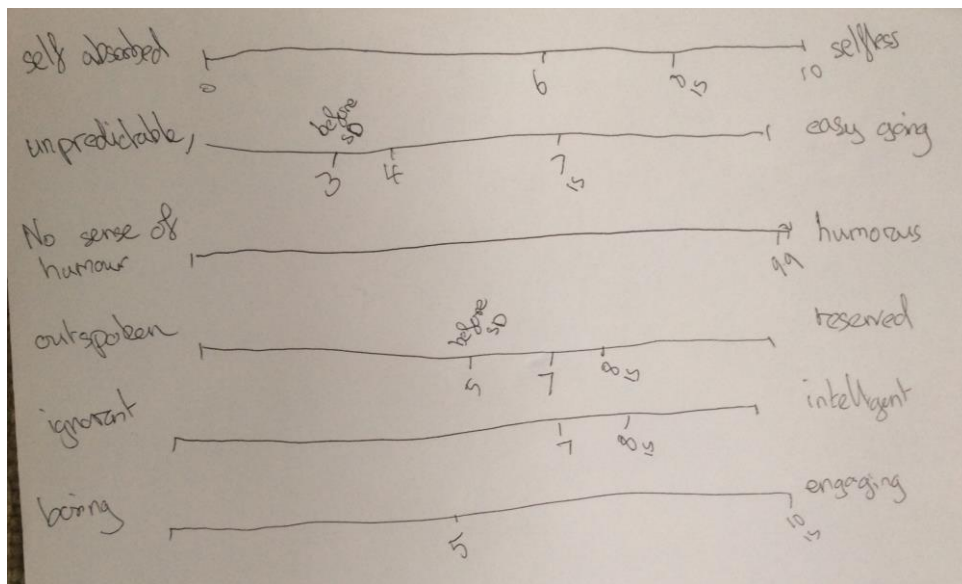
Scaling:

Alfie's "ideal self"
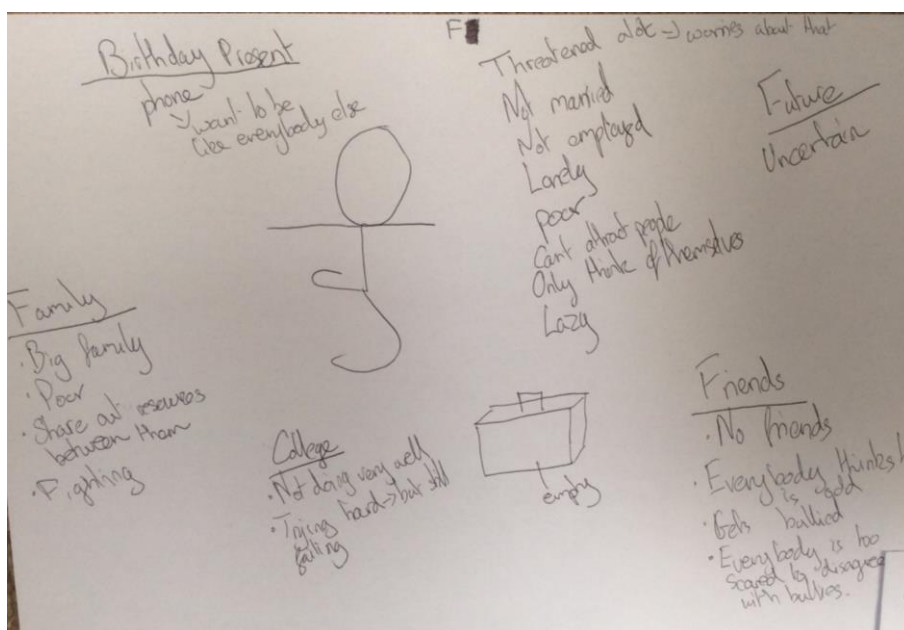
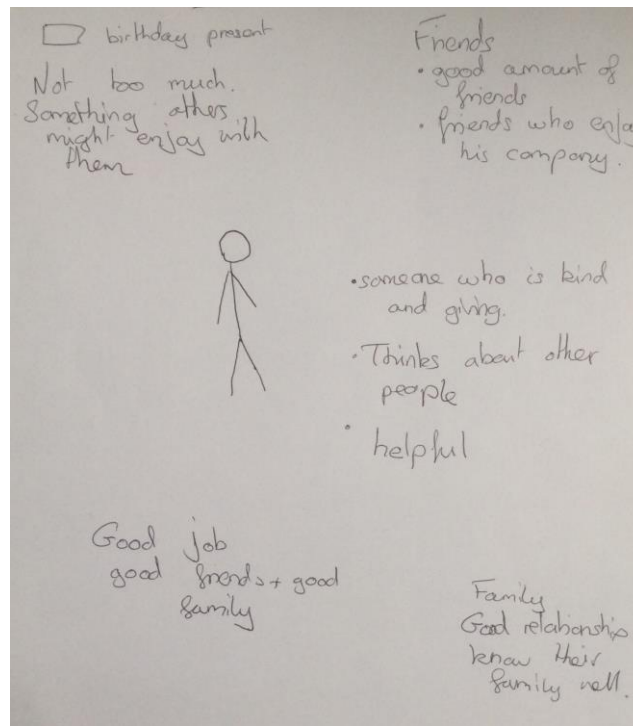"Ideal self":
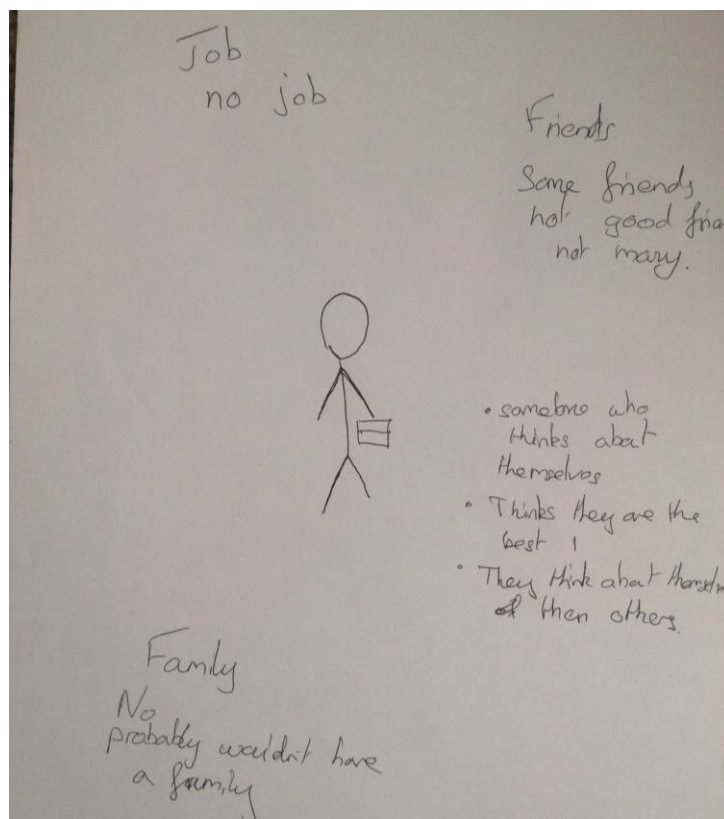
The person Alfie would least like to be:
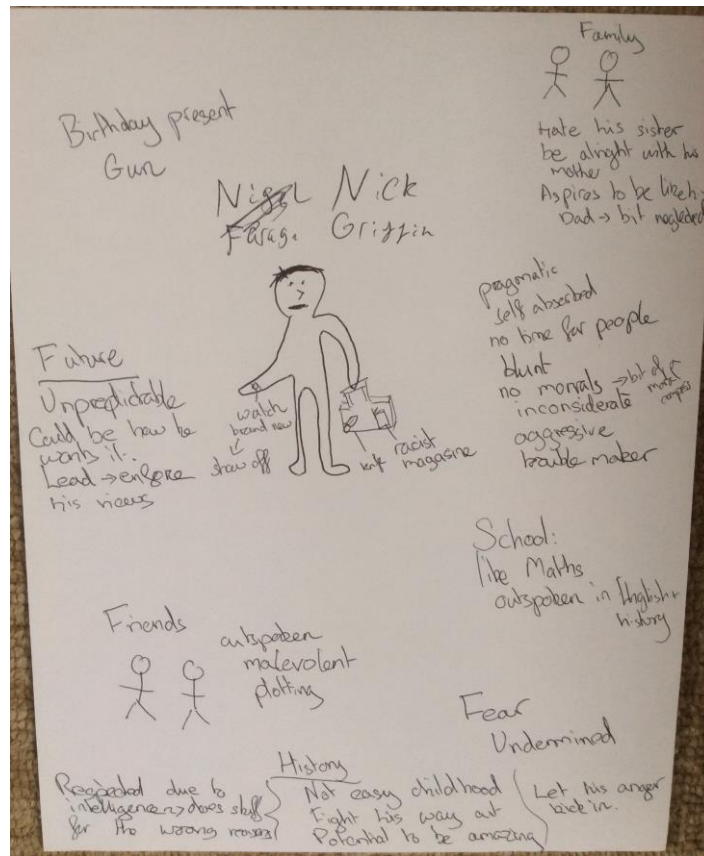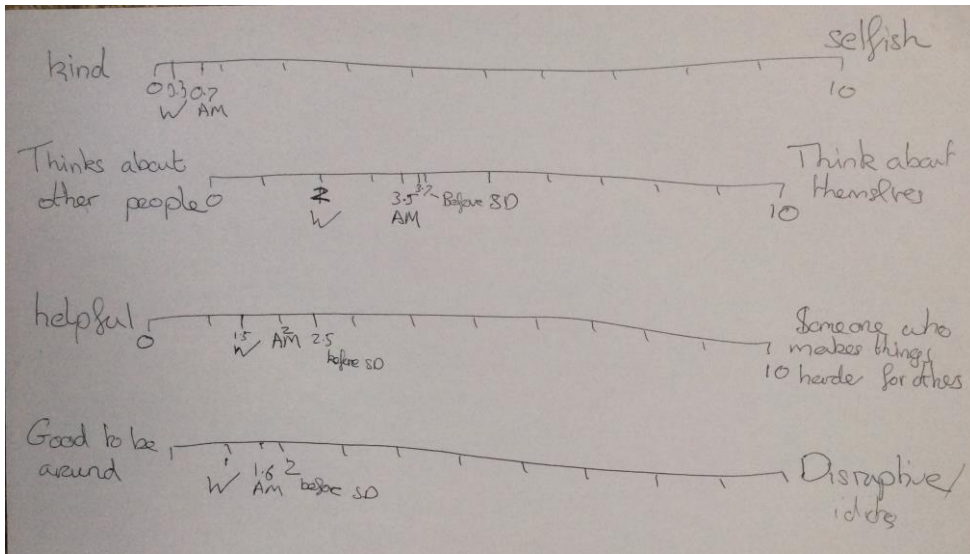

Scaling:

Mat's ideal self

Ideal self:

The person Mat would least like to be:
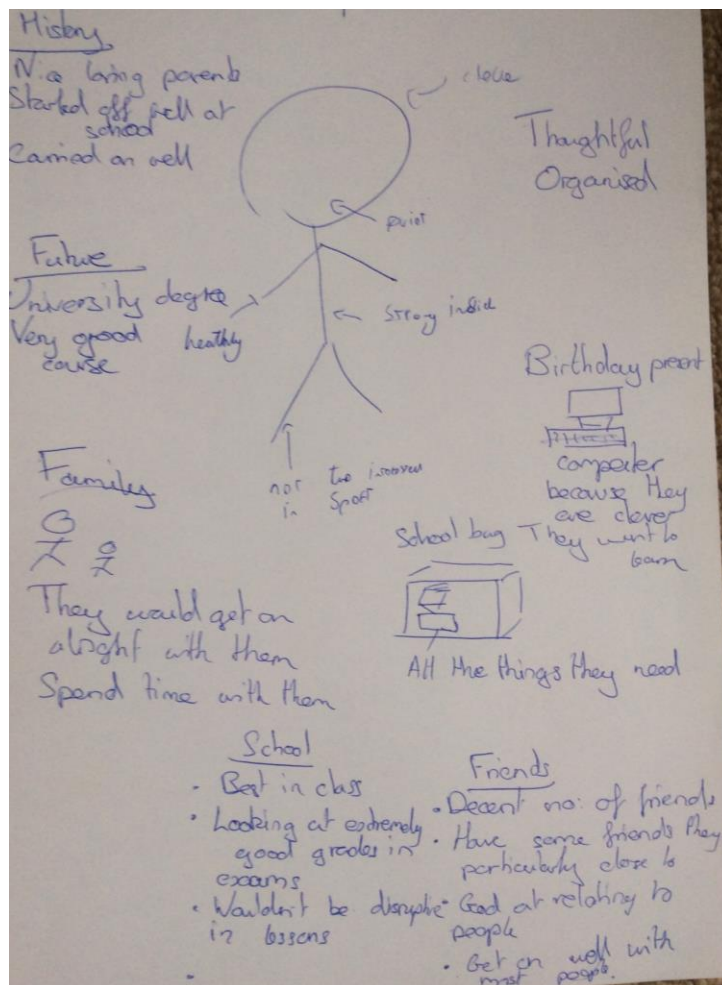
Scaling:

Simon's "ideal self"

"ideal self":

The person Simon would least like to be:
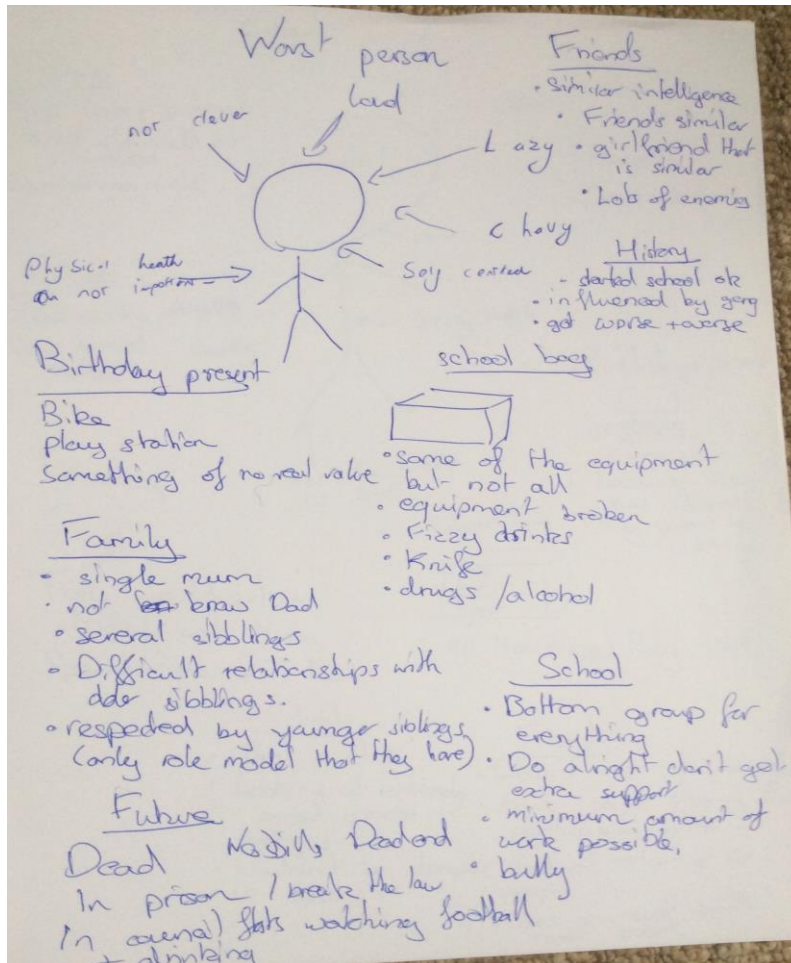
Simon's scaling:
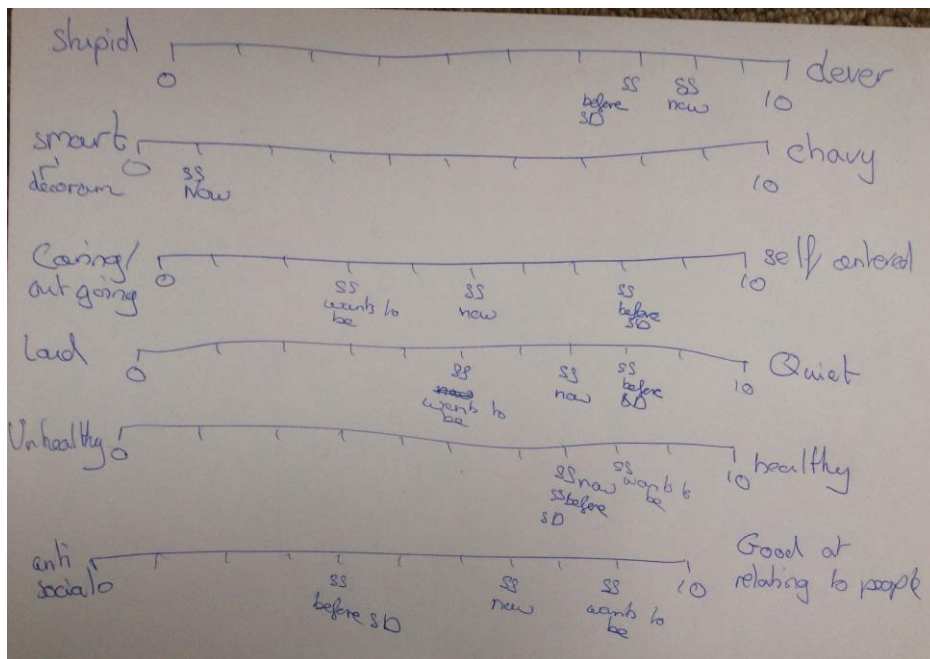
APPENDIX 6   PHASE TWO RECRUITMENT MATERIALS

- Introductory letter to parents
- Introductory meeting plan
- Summary page of research for parents
- Letter to parents of peers for self-disclosure involvement

Introductory letter to parents

University of Exeter,

Graduate School of Education

St Luke's Campus

Dear ……..

I am a trainee educational psychologist currently on placement for the Educational Psychology service in ▮▮▮. Previously I worked as a SENCo assistant in a mainstream school focussing on supporting children on the autistic spectrum in this setting. I have also completed a post graduate course on teaching children with autism.

I am currently carrying out research in schools. My focus is on researching the provision in mainstream schools for children on the autistic spectrum condition. I have completed the first part of this research. This involved interviewing children with autism in mainstream schools about their perspective of the support they received throughout their school years. With this information I intend to produce a model that will be used in schools to support other children. This model will be used to inform good practice. It will outline activities and strategies that have been reported as successful by these young people and the people who have supported them.

Here are a few examples of the activities this may involve:

o   Staff training to increase understanding

o   Educating peers to increase understanding

o   Individual work with the young person

o   Enhancing the schools inclusive ethos

I would like to work with █████████ for this project in September 2015. I will be contacting you in September to discuss this further. If you have any questions please do not hesitate in contacting me on the details below.

Jess Pares Landells

Trainee Educational Psychologist
Exeter University

Contact details:
██████████

Andrew Richards: Programme Director of the Professional Doctorate Training in Educational Psychology, Exeter University.
Martin Levinson:

Data Protection Act: The University of Exeter is a data collector and is registered with the Office of the Data Protection Commissioner as required to do under the Data Protection Act 1998. The information you provide will be used for research purposes and will be processed in accordance with the University's registration and current data protection legislation. Data will be confidential to the researcher(s) and will not be disclosed to any unauthorised third parties without further agreement by the participant. Reports based on the data will be in anonymised form.

Introductory meeting plan

Presenting it to parents:

I have been researching children with high functioning autism in secondary schools and interviewing them about their experiences.

With this information I created a model including all the things they found were supportive

Before I go into any more detail can I ask you a little bit about your child?

o When were they diagnosed?
o Do they know they have autism?
o When were they told?
o How did you tell them?
o What was their reaction to this?
o What is their understanding of autism?
o Do they understand how it impacts on them?
o Would they ever discuss their autism with others?
o If so in what sort of situations?

The focus of my research has been on individuals who have been open with their peers about autism.

Those that self-disclosed in my research discussed the positive impact of this on their peers and on themselves…

I have detailed the impact of this for you on a hand out so you can take it home and look at it in a bit more detail.

o It enabled others to understand difference
o Some individuals felt that it enabled their peers to see past the label and get to know them as individuals

- o It gave them the ability to self-advocate more in school
- o Allowed them to gain confidence
- o Feeling of accepting their own identity
- o One TA described how it had a positive impact on the whole school

What I have developed from this is the following model: (show simplified version of the model)

This model demonstrates all the things in place that supported this process.

What I would like to do is go through this process with your child and ensure that all this support is in place. I would like to facilitate in their developing presenting a video about themselves.

On a practical level this will be a 10 minute video where they can talk about themselves, their strengths and some of the difficulties they have.

Primarily this video can be used to help them have a better understanding of themselves. This video could then be used in the future to help educate others about themselves.

Any questions..?

<u>Summary page of research for parents:</u>

Summary of the research:

I would like to work on an individual basis with a young person and help them understand autism in more depth. Within this work I will be encouraging them to celebrate autism by focussing on the positives. Part of this will involve researching famous individuals with autism and what they have achieved. I will also address some of the difficulties they experience as a result of autism and help them to come up with practical things that others could do to help.

This individual work will lead to the creation of a video which they will have ownership of. The young person will be given the choice of what to do with this video. They can either keep it private or, if all parties agree, it could be something they share with others.

Throughout this process there will be back and forth communication with parents. I would like to ensure the parents are very involved in the creative process.

Educating others about autism:

Previously research has found that educating peers about autism has had a positive impact on peers' behavioural intentions towards children with autism.

Gus carried out some research on educating peers about autism and found that the young person's peers did not know that he was autistic. They then educated the class about autism. The peers stated that it had enabled them to be "more sensitive, understanding and patient" (Gus, 2000, p.464).

Ask and Tell: Self-Advocacy and Disclosure for People on the Autistic Spectrum is a book written by adults with autism (Shore, 2004). Many argue that self-disclosure is necessary in order for individuals to self-advocate. The reasoning behind this is that in order to make sure that an individual receives the provision and adaptations they need, it is essential to be prepared to give a reason why.

Impact of self-disclosure in my research:

Those that self-disclosed in my research discussed the positive impact of this on their peers and on themselves. They felt the self-disclosure process:

- enabled others to gain a better understanding of autism
- enabled their peers to get to know them better
- enabled peers to use more effective strategies to support them
- encouraged peers and the individual to talk openly about autism
- It gave them the ability to self advocate more in school
- Increased their confidence
- Gave them a stronger sense of self

The support staff also talked about how self-disclosure had a wider impact on the school. The 'ripple effect' describes how the improved confidence of the individual and openness and understanding within the class impacted the whole school environment.

Gus, L. (2000). Autism: Promoting peer understanding. *Educational Psychology in Practice*, 16(4), 461–468.

Shore, S. M. (Ed.). (2004). *Ask and Tell: Self-Advocacy and Disclosure for People on the Autistic Spectrum.* United States: Autism Asperger Publishing Co.

Letter to parents of peers for self-disclosure involvement

Dear

Thank you for giving your consent for your child to take part in a small research project at ███████████ School.

I am a Trainee Educational Psychologist who is currently on placement in ███. I am carrying out some research into supporting children with autism. The purpose of this research is to educate children about autism and evaluate the impact of this education on their understanding towards their peers with autism.

The project will involve a 15-20 minute presentation about autism from myself and another student. I will carry out a brief interview of all the children involved before and afterwards to explore the impact of this presentation. The presentation will be recorded and shared with the student's parents.

The information that I gather will all be anonymous and confidential. The results will then be written up as part of my thesis.

Please do not hesitate to contact me if you have any questions. I would be very grateful if you could you sign the enclosed form and return it to me by Friday 5th February.

Telephone: ███████

Many Thanks,

Jess Pares Landells

APPENDIX 7   PHASE TWO PRE AND POST INTERVERTION INFORMATION GATHERING MATERIALS

- Scaling for young person
- Scaling for staff and parent
- Example of pre-intervention interview
- Example of list of strengths and difficulties
- Example of post interview

Scaling for young person

Do you understand what autism is?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

No understanding   Full understanding

Do you understand your own autism?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

No understanding   Full understanding

Do you think autism makes things harder for you?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Never   All the time

Do you think autism makes things easier for you?

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Never										All the time

How do you think/feel about yourself?

	1	2	3	4	5	6	7	8	9	10
Very negatively										Very positively

How do you feel about having autism?

	1	2	3	4	5	6	7	8	9	10
Very negatively										Very positively

Do you tell other people that you have autism?

	1	2	3	4	5	6	7	8	9	10
Never										When appropriate

Do you feel you can ask other people for help at school when you need it?

	1	2	3	4	5	6	7	8	9	10
Not at all										When appropriate

<u>Scaling for staff and parent</u>

What is the young person's understanding of autism (in general)?

 1 **2** **3** **4** **5** **6** **7** **8** **9** **10**

No awareness   Full awareness

What is the young person's awareness of how autism impacts on them?

 1 **2** **3** **4** **5** **6** **7** **8** **9** **10**

No awareness   Full awareness

How aware is the young person of the difficulties they have?

 1 **2** **3** **4** **5** **6** **7** **8** **9** **10**

No awareness   Aware of all the difficulties

How aware is the young person of the strengths they have?

 1 2 3 4 5 6 7 8 9 10

No awareness   Aware of all their strengths

How does the young person feel about themselves?

 1 2 3 4 5 6 7 8 9 10

Very negatively   Very positively

How does the young person feel about their diagnosis?

1   2   3   4   5   6   7   8   9   10

Very negatively   Very positively

Is the young person open about their diagnosis?

1   2   3   4   5   6   7   8   9   10

Not at all   When appropriate

Does the young person self-advocate? (tell others when they require help/support)

1   2   3   4   5   6   7   8   9   10

Not at all   When appropriate

Example of pre-intervention interview schedule:

Parents interview

Understanding of autism in general:
- Could you tell me what your current understanding of autism is? (what does it mean to you?)
    o How has this developed (training, research, working with other individuals?)
    o Could this be developed further?
    o How could this be done?

Understanding the young person's autism:
- What impact does autism have on this young person? (ie your understanding of this young person's autism)
    o What are the young person's strengths?
    o What are the young person's difficulties?
- Could this be developed? And how?

How do they feel about their autism?

How do they feel about themselves?

The young person's understanding of themselves and their autism:
- what is the young person's understanding of autism?
- Do they understand how autism impacts on them?
- How has this been developed so far?

Schools understanding of autism:
- what is the parents understanding of autism?
- Do they understand how autism impacts on the individual?

Peers understanding of autism:
- Do his peers/ classmates know that he has autism?
- What is there understanding of autism?

Supportive environment:

- Do the school promote an ethos of inclusion and equality?
- How do they do this?
    - o Could anything be done in this area to support the young person further?
    - How is this maintained?
        - o Regular communication? (how)
    - Does the young person have someone that he can trust and turn to at school?
        - o Who supports them?
        - o How are they supported?
    - Is the peer group supportive of him?
        - o What is his social inclusion like?
        - o Does he have friends?

    - Does the young person receive any teaching around the areas they find difficult?
    - What does this involve?

Together look at strengths and difficulties list by Stephen Shore and identify whether or not the child shows those.. with examples.

Example of list of strengths and difficulties:

Challenges	
Grasping the "big" picture	
Uneven set of skills	
Difficulty in developing motivation to study	
Difficulty perceiving emotional states of others	
Perceiving unwritten rules of social interaction	
Difficulty summarising important information for a conversation	
Sensory integration problems where input may register unevenly, distorted, and difficulty in screening out background noise	
Generalisation of skills and concepts	
Difficulty expressing empathy in ways that others expect or understand	
Executive functioning resulting in difficulties planning and organisation	

Strengths:	
Attention to detail	
Often highly skilled in a particular area	
Deep study resulting resulting in encylopedic knowledge on areas of interest	
Tendency to be logical (helpful in decision making where emotions may interfere)	
Less concern for what	

others may think of them	
Usually visual processing (thinking in pictures or videos)	
Can give clear detailed descriptions	
Direct communication	
Loyalty	
Honesty	
Nonjudgmental listening	

Example of post interview schedule:

Parents/staff interview

Their perspective of the impact on the young person:

Do you think (name) learnt anything from the PowerPoint Presentation?

What did they learn?

Do you think this will be useful for them in the future?

How do you think it will be useful for them?

Impact of PowerPoint Presentation on the individuals around the child

Have you learnt anything from the PowerPoint Presentation?

What have you liked about it?

Is there anything you didn't like about it?

Have you learnt anything about autism?

Have you learnt anything about the young person?

Have you learnt anything about how autism impacts on them?

Impact on the other adults it was shared with (staff /parent):

Do you think anyone else learnt anything from the PowerPoint Presentation? (staff or parents)

Reflection:

Is there anything that you think could be done differently next time?

APPENDIX 8   JO'S FINDINGS

- Strengths
- Challenges
- Results from scaling

<u>Strengths</u>

Strengths:	Mother	School staff	Young person
Attention to detail	Can identify the differences between birds (for example buzzards) Looks at the detail of things in nature Can identify differences between minerals 'snow flake obsidium'	Pays attention to detail in drawing Tidy – pays attention to where things should go	Lego building Keeping things tidy and in order Attention to detail in shells/minerals and fossils (noticing differences) Reading – able to skim read text quickly and understand detail
Often highly skilled in a particular area	Very quick reader Good geographic knowledge Good knowledge of history Good knowledge of vehicles (tanks and	History (horrible histories) Geography Shapes understanding Knowledge and	Very fast reader History (remembering facts- for example about tanks) Geography – for example explaining how

	planes)	understanding of films	stalagmites are formed
			Space (can identify the planets)
Deep study resulting resulting in encylopedic knowledge on areas of interest	History Sea life Pokemon Fantastic memory Helps when other people are struggling to complete crosswords	Whimpy books	History Geography Cars Space Shells
Tendency to be logical (helpful in decision making where emotions may interfere)	Not appropriate (Jamie can often become anxious and it is felt this can interfere with decision making)	Thinks logically Helps with maths problems	Maths
Less concern for what others may think of them	Does not seem to bother	He does show concern and will say he is embarrassed	
Usually visual processing (thinking in pictures or videos)	Visual learner Good at seeing shapes in 3D		Helps in maths when picturing shapes Playing computer games
Can give clear	Can talk in a lot of		Very good at

detailed descriptions	detail about topics of interest		describing things
Direct communication	Good at saying what he means	Yes will be direct about how he is feeling	
Loyalty	Expresses how he cares for others	Strong sense of right and wrong	
Honesty	Cannot tell lies	Never gets in trouble

Is always honest | Cant lie |
| Nonjudgmental listening | Not appropriate | Not appropriate | |
| Average to above average abilities | He is doing well academically | Works hard | |

Challenges

Challenges	Mother	School staff	Young person
Grasping the "big" picture	Personal care – needs help in braking it down	Needs things being broken down into small steps	
Uneven set of skills	He is better in some subjects than others	Doesn't like writing

Can have difficulties expressing himself

Sometimes goes | |

		blank	
Difficulty in developing motivation to study	Particularly in writing	Has difficulty completing things he doesn't want to do	In writing
Difficulty perceiving emotional states of others	Yes		Prefers to be by himself
Perceiving unwritten rules of social interaction	Yes	Can learn if taught	Prefers to be by himself
Difficulty processing in non-favourite modalities such as aural, kinaesthetic etc	Yes		
Difficulty summarising important information for a conversation	Sometimes he tells you irrelevant information	Yes	
Sensory integration problems where input may register unevenly, distorted, and difficulty in screening out background noise	Noisy environments can be difficult He does not eat certain food textures	Sensitive to all senses	Sensitive to loud noises
Generalisation of skills and concepts	Standard of work is very different at home to at school. Struggles to generalise these skills to home environment	He does generalise once he has learnt a skill	

	Yes		
Difficulty expressing empathy in ways that others expect or understand	Yes		
Executive functioning resulting in difficulties planning and organisation	Difficulty remembering day to day things	Needs small steps to help him sequence and organise	Easily distracted

Results from scaling

	Jo			Staff			Parent		
	Pre	Post	Diff	Pre	Post	Diff	Pre	Post	Diff
What is the young person's understanding of autism? (1= no understanding, 10 = full understanding)	3	5	+2	NA	8		5	8	3
What is the young person's awareness of how autism impacts on them? (1= no understanding, 10 = full understanding)	2	2	0	NA	NA		5	7	2
How aware is the young person of the difficulties they have? (1 = no awareness, 10 = full awareness)	9	9	0	2	6	+4	7	8	1
How aware is the young person of the strengths they have? (1= no awareness, 10 = full awareness)	1	1	0	9	9	0	6	6	0
How does the young person feel about themselves? (1= very negatively, 10 = very	1	1	0	9	5	-4	3	3	0

positively)									
How does the young person feel about their diagnosis? (1= very negatively, 10 = very positively)	1	1	0	NA	NA		3	3	0
Is the young person open about their diagnosis (1 = never, 10 = when appropriate)	10	9	-1	2	7	+5	1	5	4
Does the young person self advocate (1 = never, 10 = when appropriate)	4	3	-1	1	1	0	2	5	3

- Strengths
- Challenges
- Results from the scaling

Strengths:

Strengths:	Mother	School staff	David (after intervention)
Attention to detail	Notice if something is missing Photographic memory for some things. This helps him to recognise things accurately	PowerPoint Presentation Presentations - huge attention to detail	Produces high quality of work in some areas due to being able to identify small mistakes Good at editing other peoples work (can spot mistakes) Makes PowerPoint Presentation Presentations different and exciting
Often highly skilled in a particular area	Very good at drawing and art - Really good attention to detail and gets all the ratios correct	Visual strength IT Creating PowerPoint Presentation	Programming on the computer Creating things (drawing, PowerPoint Presentation

| | | Presentations | Presentations, mine craft, building things, art)

Can help others in IT |
|---|---|---|---|
| Deep study resulting resulting in encyclopedic knowledge on areas of interest | Minecraft

Lego ninjago | Minecraft

ICT

Mario | Programming on the computer

ICT

English (spelling) |
| Tendency to be logical (helpful in decision making where emotions may interfere) | Stays calm when other people are stressed (helps him to make good decisions at busy times)

Stay focused on important bits when rushed | Focuses on facts

Can remain calm in stressful situations | Good at remaining calm

Able to focus on the facts |
| Less concern for what others may think of them | NA | NA | NA |
| Usually visual processing (thinking in pictures or videos) | Very visual – this is used to support him with routines | Net shapes

Visual strength

Quicker than others at building things | Helps when understanding shapes (net 3d-2d)

Minecraft

Building things and making things

Art |

Can give clear detailed descriptions	Can go into minute detail and tells others every step of the process very clearly	Good at describing things in detail	Good at describing 'interests'
Direct communication	Says things that need to be said	Doesn't beat around the bush	Say it how it is
Loyalty	Loyal to friends (even sometimes when they don't deserve it)	Challenges teachers if he thinks they are being unfair to his friends Sticks up for his friends	Get involved when others are in trouble in order to help them
Honesty	Very honest even when he knows that maybe he shouldn't be Says that he cannot lie	Very honest and finds it very difficult to lie	Cant lie Have to tell the truth
Nonjudgmental listening		Doesn't judge others	Good at listening

Challenges:

Challenges	Mother	School staff	David
Grasping the "big" picture	Sometimes focussing on the detail in things means that he misses the bigger picture	NA	Sometimes frustrated by the small things

Uneven set of skills	Physical ability is poor (gross motor) Can be clumsy and hates PE	Numbers confuse him	
Difficulty in developing motivation to study	Negative behaviours begin when he is expected to do something he doesn't like Cant motivate himself	Yes	Difficulty concentrating unless it is on the computers
Difficulty perceiving emotional states of others	Never been able to support others when they are upset (used to put hands over ears when others were crying)	Na – gets sad and concerned if others are sad	
Perceiving unwritten rules of social interaction	Doesn't realise when others are getting angry until they raise their voice Sometimes doesn't realise peers want him to stop – doesn't get the subtle signals that suggest they have had enough.	Can pull funny faces sometimes (not aware he is doing it)	
Difficulty	Has difficulty	NA	

summarising important information for a conversation	giving summary – will often give lots of unnecessary information		
Sensory integration problems where input may register unevenly, distorted, and difficulty in screening out background noise	Noises bother and distract him (for example the sounds of the fridges in tesco or a baby crying a few aisles away) Tends to notice noises that we are not normally aware of	Noise is a distraction	Easily distracted Difficulty with sitting still for long periods of time (unless it is on a computer)
Generalisation of skills and concepts	NA	NA	
Difficulty expressing empathy in ways that others expect or understand	Does not react to others emotions	NA	
Executive functioning resulting in difficulties planning and organisation	Organisation skills Needs visual support (in the same way you would use a recipe)	Improving	Difficulty keeping everything tidy (unless it is my room)

Scaling results:

	David			Parent		
	Pre	Post	Diff	Pre	Post	Diff

What is the young person's understanding of autism? (1= no understanding, 10 = full understanding)	8	9	1	5	8	3
What is the young person's awareness of how autism impacts on them? (1= no understanding, 10 = full understanding)	8	9	1	8	9	1
How aware is the young person of the difficulties they have? (1 = no awareness, 10 = full awareness)	3	6	3	8	10	2
How aware is the young person of the strengths they have? (1= no awareness, 10 = full awareness)	4	5	1	5	9	4
How does the young person feel about themselves? (1= very negatively, 10 = very positively)	6	6	0	2	8	6
How does the young person feel about their diagnosis? (1= very negatively, 10 = very positively)	5	6	1	5	8	3
Is the young person open about their diagnosis (1 = never, 10 = when appropriate)	7	3	-4	3	9	6
Does the young person self advocate (1 = never, 10 = when appropriate)	9	6	-2	2	8	6

APPENDIX 10   LAURENCE'S FINDINGS

- Strengths
- Challenges
- Results from the scaling

Strengths:

Strengths:	Mother	School staff	Young person
Attention to detail	Remembers dates and times of events that happened years ago. Amazing memory for tiny details	NA	Good with science Cars/ fish/ space Amazing memory for details – ie the day and all the details of buying a fish tank
Often highly skilled in a particular area	Cars Fish Drawing art	Maths Drawing things that he is interested in	Art/ literacy and certain areas of maths
Deep study resulting resulting in encylopedic knowledge on areas of interest	Reads lots of books about cars and fish	Fish Cars	knows how cars work How parts of the engine move Knows what to look out for when buying a new car How to service

			cars
			Name the different types of fish and which are tropical fish and which are ocean fish
Tendency to be logical (helpful in decision making where emotions may interfere)	NA	Very literal understanding Strength in maths Good when topics are factual	Helps when doing maths problems
Less concern for what others may think of them	In some ways – for example he doesn't care what he is wearing	NA	NA
Usually visual processing (thinking in pictures or videos)	Visuals help him Good at building engines	Likes things to be represented visually (timer)	Can picture things in my head like my dog and my cat Can draw cars and fish
Can give clear detailed descriptions	Yes can give detailed descriptions of his dog	Very good at describing things	Good at giving detailed descriptions or cars and fish
Direct communication			
Loyalty	Very loyal to friends and family	Sticks by his close friends	

Honesty	Truthful and honest	He is very honest	
Nonjudgmental listening	Doesn't judge and considers everyone an equal	NA	
Average to above average abilities		Yes – he is doing well at school	

Challenges:

Challenges	Mother	School staff	Young person
Grasping the "big" picture	Needs things to be broken down into steps	NA	
Uneven set of skills	Is not very good at reading other people and understanding the subtleties of language Sometimes doesn't understand when people are joking	Weaker in some areas	
Difficulty in developing motivation to study	Needs prompting if he does not find the topic motivating – and will often try to change the subject to something he does find	Yes – can be difficult to motivate Concentration is not as good in the topics in which he is not	

	motivating Needs the curriculum tailoring to his interests to increase motivation	motivated	
Difficulty perceiving emotional states of others	He can pick up on obvious emotional states but finds it really hard to identify subtle emotions	NA – he is good at perceiving others emotional states	
Perceiving unwritten rules of social interaction	Doesn't pick up on the differences of meaning between tones of voice	NA	
Difficulty processing in non-favourite modalities such as aural, kinaesthetic etc		Yes – sometimes struggles to respond to teaching	
Difficulty summarising important information for a conversation	Finds it difficult to sumarise how his day was at school	Yes	
Sensory integration problems where input may register unevenly, distorted, and difficulty in screening out background noise	Very sensitive to noises and will jump and flinch. Doesn't like traffic noises or some children's voices	Heat Distractible	
Generalisation of skills and concepts	NA	NA	

Difficulty expressing empathy in ways that others expect or understand	Can say things to upset people without realising it will upset them	NA							
Executive functioning resulting in difficulties planning and organisation	Needs to be told what he needs before a task

Always does things last minute | Difficulty in organising himself | | | | | | | |

Results from the scaling:

	Laurence			Staff			Parent		
	Pre	Post	Diff	Pre	Post	Diff	Pre	Post	Diff
What is the young person's understanding of autism? (1= no understanding, 10 = full understanding)	9	10	1	5	8	3	5	6	1
What is the young person's awareness of how autism impacts on them? (1= no understanding, 10 = full understanding)	6	8	2	6	7	1	7	8	1
How aware is the young person of the difficulties they have? (1 = no awareness, 10 = full awareness)	4	4	0	7	7	0	6	6	0
How aware is the young person of the strengths they have? (1= no awareness, 10 = full awareness)	2	5	3	6	8	2	3	5	2

How does the young person feel about themselves? (1= very negatively, 10 = very positively)	8	9	1	4	7	3	4	4	0
How does the young person feel about their diagnosis? (1= very negatively, 10 = very positively)	10	10	0	5	7	2	4	4	0
Is the young person open about their diagnosis (1 = never, 10 = when appropriate)	5	5	0	3	9	6	5	5	0
Does the young person self-advocate (1 = never, 10 = when appropriate)	10	10	0	2	6	4	4	4	0

APPENDIX 11   INTERVENTION MATERIALS

- Session plans
- Example of notes from each session
- PowerPoint Presentation for sharing with adults

Session plans

Session 1

Aim:

Increase awareness of famous people with autism

- Introduce 'autism heros'
- Increase awareness of autism as a strength
- Identify a few hero's that the young person is interested in
- Learn a bit more about your heros (research or reading in the autism heros book)

Content:

Introduce the idea that people with autism often have areas of strength and things they are really good at.

Discuss and look through the autism hero book. Drawing attention to the fact that all these individuals were thought to have autism and they have been really successful in certain areas.

Encourage the young person to read about these famous individuals. Discuss their areas of strengths.

Research and explore a few individuals that the young person has a particular interest in.

PowerPoint Presentation:

- Add autism heros of interest into a PowerPoint Presentation

Session 2

Recap of session one:

- Can you remember who we learnt about?
- What were they good at?

Aim:

- Identify some of the strengths the young person has
- Look at some strengths that other people with autism often have
- Increase their awareness of their own strengths
- Identify how these strengths might help you

Content:

Identify the young person's strengths (what they are good at and what they enjoy doing)

Identify common strengths that people with autism often have

- Go through the strengths identified by Stephen Shore
- Give examples from the information collected from parents and teachers

Find practical examples of how these strengths help

Start making the PowerPoint Presentation:

- Young person's strengths and examples
- Include the young person's special interests to increase motivation

Session 3

Recap of session 1 and 2

Aim:

- Identify the difficulties that the young person experiences
- Alongside these difficulties focus the discussion on things that help

Content:

Discuss some of the things the young person finds difficult (do not use information from other sources at this point. This information should just come from the child).

Focus the discussion on strategies that others can use to support young person with these difficulties.

Think of practical examples of things that others can do to help

PowerPoint Presentation:

- Finish aspects of the PowerPoint Presentation

Example of notes from sessions with young person:

Session 1:

Jo was very interested by a few of the autism heros.

We looked through the book and he was particularly interested in Benjamin Banneker, Albert Einstein and Stephen Wiltshire.

I gave him one of the prints of Stephen Wiltshire's work and he said he would take it home with him and show it to his parents.

Session 2:

Jo remembered some facts about some of the autism heros without being prompted.

Jo seemed to find it hard to talk about his strengths. It felt like he began to lose interest in the conversation. I think this is because he found it difficult to identify things that he was good at. Perhaps it was because he did not feel that the things I was pointing out were strengths for him.

I spent a bit of time pointing out what others had said about his strengths. He did not contradict me with these and it seemed like he was taking some of these on board.

I ended the session before we had finished all of them because I felt he was losing interest before the end.

Session 3:

We began to create a PowerPoint Presentation. He enjoyed using my ipad and finding pictures of the relevant autism heros to put into the PowerPoint Presentation. He chose relevant information to write about each of these autism heros.

When it came to write about the strengths of autism he again began to lose attention. He had found it difficult to remember some of these so needed some prompting to recall

some of them. I helped him to summarise these in the PowerPoint Presentation (he wanted me to write at this point as I felt that this was not very motivating for him)

We then decided to talk about some of his interests and relate these to his strengths. He really enjoyed finding pictures from the internet and adding them to the PowerPoint Presentation. At this point he wanted to learn how to put the pictures into the PowerPoint Presentation himself which showed that he was very motivated by this activity.

He added lots of his interests and wanted to continue doing this in the next session

Session 4:

Looked together at some of the things that he finds hard.

I did not want to prompt him in this area as I did not want others to put words into his mouth about the things he found hard. He came up with a few things such as; easily distracted, working in groups and loud noises. It seemed easier for him to think of the things that he found hard.

We added these to the PowerPoint Presentation in the form of pictures (showing that he has a visual strength) and he said at this point… 'I prefer to use pictures to describe things'

I then went on to think about some of the things that others could do to help him with those difficulties. I found this really hard and needed some prompting to think of things that others could do to help.

Shared with parent and staff:

I talked through my PowerPoint Presentation about autism and the theories of autism, focussing on the strengths and positives.

Then Jo talked through his PowerPoint Presentation. He seemed happy to share it with others and became especially animated when he discussed his interests.

When asked about whether he would like to share it with some others he said 'maybe' and it was agreed that we would let him think about this.

In the meantime he used the PowerPoint Presentation at an annual review to talk about himself.

Autism

Jess Pares Landells

Focus on the difficulties that some people with autism experience

POSITIVE THINKING

NEGATIVE THINKING
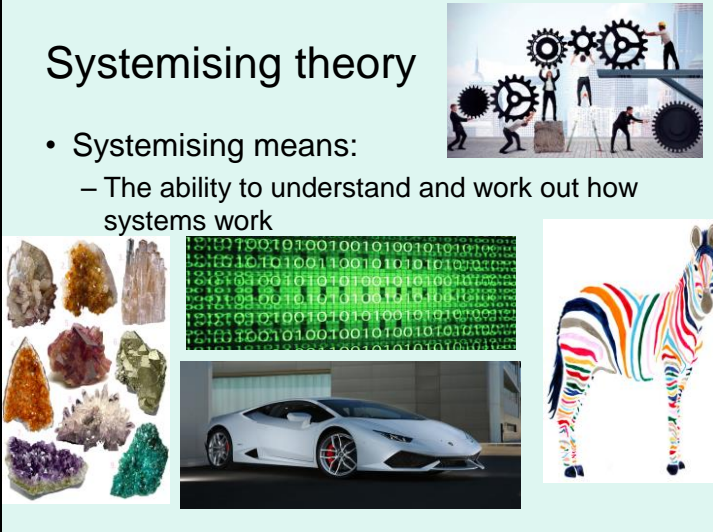
Focus on the positives and strengths that people with autism experience

People used to focus on autism as something that made things harder for everybody

Recently however researchers have realised that there are lots of good things that come with being autistic

Systemising theory

- Systemising means:
  - The ability to understand and work out how systems work

Many are very talented at something he calls systemizing.

This means their ability to understand and work out how systems work.

Systems always follow rules and being good at systemising involves being able to understand and apply those rules.

For example – being able to distinguish the difference between different types of minerals is called collectible systemising
Being able to understand computers and coding is called mechanical systemising
Abstract systems describes how art and music also follow rules

Triad of strengths

- Good understanding of systems

- Specific areas of strength

- Repetitive behaviour

These are the three areas in which individuals with autism usually have particular strengths.

Good understanding of systems – like we talked about
Specific areas of strength – often related to systems thinking or perhaps a special interest
Repetitive behaviour – as we all know practice makes perfect so this can be a real benefit and can enhance those areas of strength even more

Simon Baron Cohen is a famous researcher who works in the area of autism… he does lots of research and tries to understand autism more

He has worked out that although most have difficulties with emphasizing.. That means sometimes they find it hard to imagine what others might be thinking

Many people with autism have difficulties in these three areas..

Sometimes they do not understand other people's body language and sometimes they do not know what someone else is thinking.

But if they are given the right help and strategies to support them with these things then these difficulties don't have to act as a barrier to them in whatever they choose to do

Things that people with autism can find hard:

- Very sensitive to noises: Loud noises can actually feel like they hurting

- It can be difficult to understand other people: sometimes it can be difficult to tell whether or not other people are joking.

Autism is a difference

- Autism is not something that holds you back from doing what you want to do:
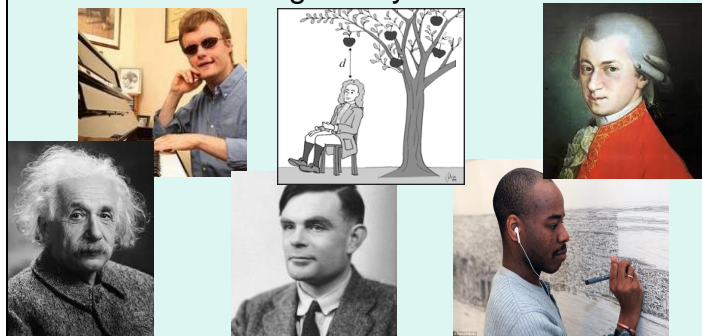
Remember

Autism means that you see the world in a slightly different way

Being different is a good thing because no two people are the same

It is good to understand autism because then everyone can recognise the positives and strengths

It is good to understand autism because then everyone can help with the things that can be hard

Some quotes:

- "I like being autistic because it helps me appreciate life's simple pleasures"

- "I Like Being Autistic Because I have a photographic memory, I have obsessions that bring me joy, and I'm a Unique and Fun person to be around."

- "Well, I'd say your brain is like a bunch of gears moving all together and all those gears make your brain function. Autism basically just changes the direction of all those gears, to make you think differently. Just changes the way.. how your brain works, how you process information. That's how I see Autism, it just changes the way you think."

APPENDIX 12   POWERPOINT PRESENTATION PRESENTATIONS

Jo's PowerPoint Presentation

Stephen Wiltshire

Stephen went on helicopter rides and drew pictures from memory.
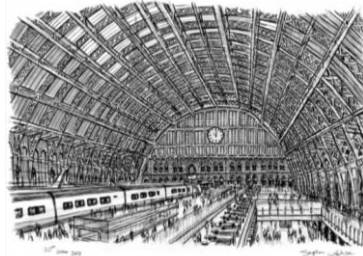
Albert Einstein

He was famous for his work in physics ,his work changed the way we think.
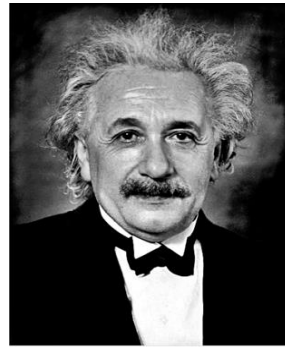
Strengths of Autism

- Attention to detail
- Often highly skilled
- Deep study in areas of interest
- Good at visualising/imagination
- Honest
- Loyal
-Good at describing things in detail
-Good sense of humor
-Good at telling jokes
-Polite

my interests (personally)
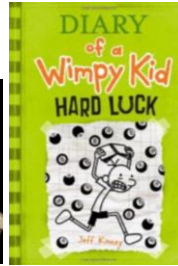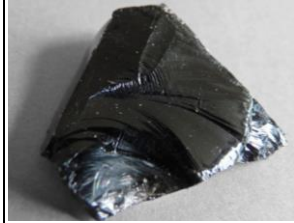
My Interests (personally) continued

Lego
Tanks
Cacti & succulents

Disadvantages: Get very frustrated

Help

Busy places

Drawing [hobby]

Chess [one of my favourite games]

David's PowerPoint Presentation

ASD

Autistic   Spectrum   Disorder
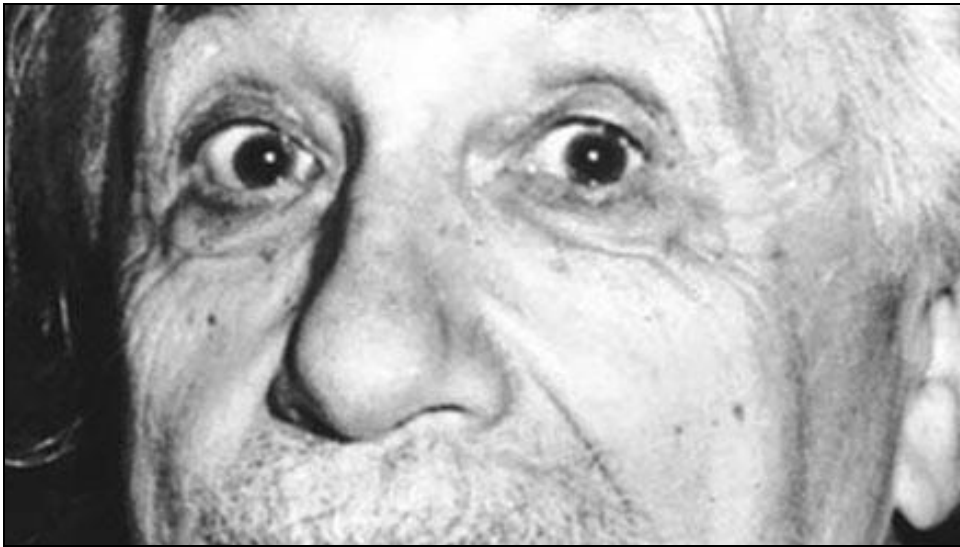
Also, Stephen Wiltshire had a similar condition.
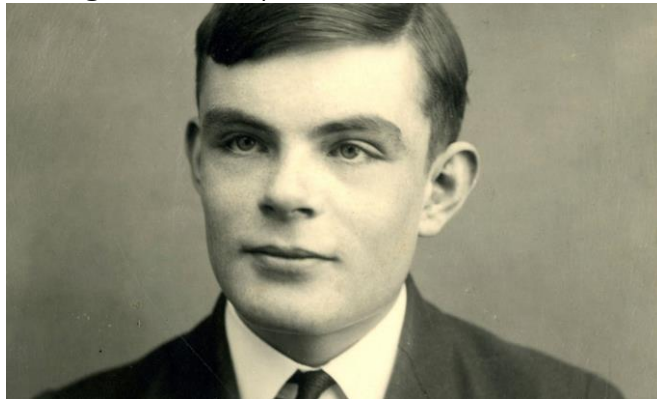
And he produced
Some amazing
Artwork!

He would spend 20 minutes on a chopper, then, from memory, he would draw it all out!

And Alan Turing was the Father Of Modern Computing, because autistic people can be better at working with computers!

Without Him, we Wouldn't Have PCs! And that Would be Terrible!

Strengths people with ASD have

Good attention to detail

Can be highly skilled in particular areas

Visual processing (Picturing things you have seen)

Good at describing things

Honest & loyal

Good at things they enjoy

ME!

My interests

I think I am good at using computers and programming.

I am pretty good at drawing.

I am a pretty good gamer.

I find it very hard to lie!

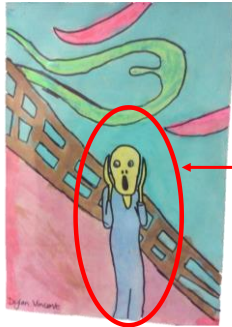Sometimes I say my thoughts out loud!

Making this PowerPoint

Very good at spelling

I notice small mistakes.

MY PICTURES!

More pictures!
(Painting)

Things I find hard

- Concentrating (Unless it's on computers!)
- Listening and staying focused
- Sometimes I get frustrated at small things
- When I do something like drawing everything has to look right
- Leaving things in a mess (Unless it's my room!)
- Putting sentences together BEFORE talking
- Sitting still for ages with nothing to do (Unless it's playing my laptop)

Things to help me

- Fiddling with LEGO
- Having things explained simply
- People checking that I know what to do
- Moving around and not just sitting doing nothing
- Doing things in a way I like (Using the computer)

Lawerence's PowerPoint Presentation
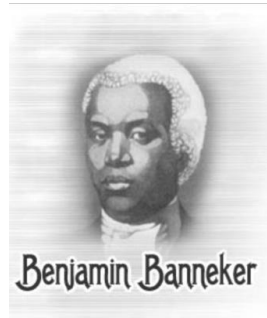

All about me

Laurence's PowerPoint Presentation

Autism heros:

- Some people who have autism have become famous for lots of different things.
- They have become famous for:
  - Inventing new things
  - Discovering new things
  - Being amazing musicians and artists

Benjamin Banneker

Benjamin Banneker

- Benjamin studied the solar system..
- He knew more than his teacher about maths
- He took a watch apart and put it back together by himself

Isaac Newton

- The most famous scientist.
- Discovered gravity
- Surprised the apple didn't knock him out! (fruit isn't always healthy especially if it falls on your head!)

Austin Riley

- Austin riley is the racing driver for racing with autism and races karts.
- His favorite cars are the mclaren mp4-12c and the lamborghini aventador.
- He talks about his career and rases autism awareness

Things I am good at:

•Good attention to detail: around interests such as cars, cats, dogs and fish.
•Art: Paying attention to detail in art makes me feel good about what I do.
•Highly skilled in a particular area: I am good at remembering things events that happened ages ago.
•Deep knowledge in certain areas: I know alot about cars because I like researching things about cars (help people make descisions about cars)

•I am good at picturing things in my head (helps me understand how things work)
•I can describe things really clearly: This can be really helpful
•I am very loyal to friends and family: I stay close and support them
•I am good at being honest: prefer to tell the truth (makes me anxious if I dont tell the truth)
•I have a very good sense of hearing: I can always hear things happening that other people don't notice!

Things i am interested in

Smart 450 brabus (2003)

- This is a 2003 Smart fortwo 450 brabus.
- bhp output: 84
- weight: just over 500 kgs
- price: 3,000 to 5,000£s
- I like this little car so much beause of its 0-60 time of 9.1 seconds and its top speed of 91mph which is very fast for a little smart

Honda S2000 (1999)

- The Honda S2000 is to this date one of the best sports cars ever made
- bhp output: 240
- This "ragtop" uses honda's ledgendery VTEC engine which uses two sets of camshafts which engage at different moments. When this system kicks in, it adds a massive boost in bhp's.

hpiracing: micro rs4

- this is a hpi micro rs4.(the smaller one)

  its to my oppinion the best rc out on the market

  i like this so much because you can modify it however you like to.

Things I find difficult:

- I find it hard to concentrate when the teacher talks alot
- Distracted by things going on around me
- Distracted by thinking about things that I like (for instance I think a lot about my remote control car at the moment)
- Sometimes I just want to talk about the things I am interested in. Sometimes it is hard for me to focus when other people are talking about the things they like.

Fears

- scared by loud noises (like motor bikes.. i have to put my fingers in my ears)
- sometimes i feel left out by some people and i can feel that people don't like me.
- can take me longer to do things because i get so distracted

Things that help me:

- Time me helps me to concentrate. A time deadline helps me know when things should be finished
- I need a quiet classroom- less distractions the better
- It helps if teachers to make sure I understand what i am doing
- For all teachers to use a kind voice when they are helping me
- Sometimes I need to have a break - regular breaks help me focus

That is all you need to know about me!

APPENDIX 13   SUPPORTIVE MODEL OF SELF-DISCLOSURE

Process of self-disclosure:

Self-disclosure is the process whereby an individual shares information about their diagnosis with others. My research has shown this can support them in developing a positive sense of identity and increase others understanding of their strengths and the challenges they face.

Interventions should be put in place to support the young person in understanding their strengths and needs. Self-disclosure should only be supported if the young person expresses the desire to share the information about themselves with others.
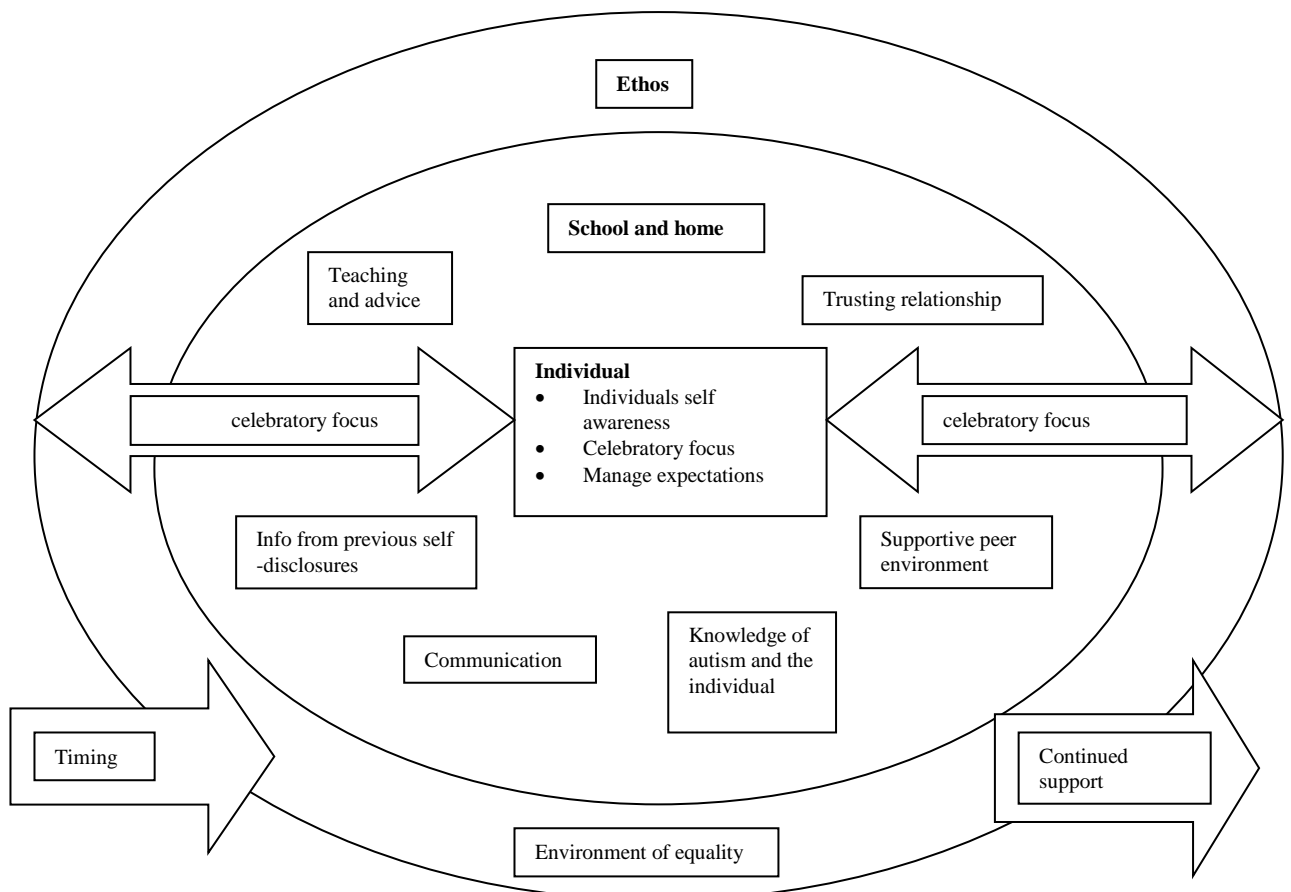
The model demonstrates all the supportive factors that have been identified as important for the process of self-disclosure. These factors were identified through interviews with individuals who had self-disclosed themselves, their parents and a member of school staff who supported the process.

The circles in the model reflect different contexts and environments with the young person at the centre. I will now give a brief explanation of the supportive factors at each level:

Individual (young person at the centre):

Self-awareness – the young person needs to understand their strengths and the challenges they face and be able to express these clearly through a medium they are comfortable with (laptop, writing, drawing or talking).

Celebratory focus – the focus should always be on their strengths and their abilities thus supporting their self-esteem.

Manage expectations – Supportive individuals should help the young person to understand that self-disclosure might not 'fix' all their problems.

School and home environment:

Knowledge of individual and autism – staff and parents should be supported in understanding the individual's needs including their strengths and the challenges they face

Communication – maintaining regular contact between home and school helps build a positive relationship with information is shared

Supportive peer group – the impact of the self-disclosure will be more positive if carried out to a group of peers who are considered supportive

Trusting relationship – provide one member of staff at school who can take a little time getting to know the young person so they have someone to turn to if they need advice or support

Teaching and advice – social communication groups can help the young person to develop skills in social interaction

Information from previous self-disclosures –information about the outcome of previous self-disclosures can help individuals considering self-disclosure to understand what to expect

Celebratory focus:

Strengths and abilities should always be the focus of any intervention in supporting young people to understand themselves and their diagnosis. A positive 'can do' attitude which identifies that young people with autism can do whatever they put their minds to can support the young person to feel positive about their diagnosis.

Ethos:

Environment of equality – develop a community in school whereby everyone understands that everyone is equal and different.

Timing:

Timing: Self-disclosure is a journey which begins with self-discovery and self-awareness. This journey can be supported through intervention in school by helping the young person to discover their own strengths and needs in relation to their diagnosis. Once the young person has been supported in gaining a better understanding of themselves then it is their choice what they do with that information. They may, for example, chose not to self-disclose at all, or they may want to tell a few close friends, or perhaps just their teachers.

Continued support: Self-disclosure is a lifelong process and may change and adapt in different contexts and with different people. Therefore, after any intervention regular follow ups are necessary in order to revisit and update the personal information.