

An exploration of autistic adolescent female's educational experiences within mainstream

secondary school

by

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Abstract

Research exploring education and autism has become oversaturated with the perspectives of non-autistics (Nicholas et al., 2019; Richards & Crane, 2020; Tesfaye et al., 2019). Previous studies have highlighted the unique challenges autistic adolescent pupils' experience within mainstream secondary school (Symes and Humphrey, 2011; Brede et al., 2017; Moore, 2006; Humphrey and Lewis, 2008). Moyse and Porter (2015) explored what it was like being an autistic girl within regular primary education, however limited studies have solely concentrated on the voices of autistic adolescent females. The project explored the following research questions: -

1. What is school like for autistic females in a mainstream secondary school?
2. How can personal experiences and knowledge of autism support the development of a fully collaborative research approach to allow the voices of autistic females to be heard?
3. How can creative and personalised approaches be used to engage autistic participants

This topic is particularly important to me, as an autistic female I really struggled in mainstream education. I believe that this doesn't have to be the case for the next generation of autistic females.

A group of 4 autistic adolescent girls from a mainstream secondary school within the UK took part in the project. A mixed method approach was utilized, adapted to the individual needs of the girls. A variety of data was collected and analysed using thematic analysis.

The data gathered from the girls provided a unique insight into their school experiences at the time of this study. Interestingly all the girls were talented in various areas of creativity, providing them with stress relief, expression of self, as well as escapism. All the girls reported the importance of having friends, however, they often felt misunderstood by their peers and staff.

Worryingly, the girls reported bullying and stigmatisation, it was clear that this had a detrimental impact on the girl's well-being. An unexpected finding was the solidarity found in meeting and interacting with other autistic girls, as well as having an openly autistic teacher within the school.

Keywords: Autistic adolescent females, education, creativity, empowerment

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Gratitude

I would firstly like to thank the collaborators who took part in this project, I feel honoured to have been able to meet such inspiring autistic females, I wish you all every success in the future. I would like to thank my loving fiancé and beautiful daughter for encouraging and supporting me throughout my studies. Finally, I would like to thank my supervisor Dr Alison Ekins and chair of studies Dr Judy Durrant, both are incredibly inspirational women, who worked with my strengths as an autistic student.

Chapter 1

Autism, research, and me

I am a white autistic female, and like many autistic females I was misunderstood throughout childhood and adolescence until I received my diagnosis at 21 years old.

Adolescence can be a precarious time for autistic girls (Cridland et al, 2014), in addition secondary school can be challenging for autistic pupils (Symes and Humphrey, 2011).

This was particularly the situation for me, and my experiences as an autistic individual have guided the research that I have completed. Through my experiences I have understood the need to prioritise the voices of autistic adolescent girls, so that we have greater insight into their experiences and ensure the right support is provided in schools.

This research project is therefore focused on highlighting the autistic females' educational experiences within mainstream secondary school and has explored the following research questions:

- What is school like for autistic females in a mainstream secondary school?
- How can personal experiences and knowledge of autism support the development of a fully collaborative research approach to support the voices of autistic females to be heard?
- How can creative and personalised approaches be used to engage autistic participants?

Before introducing the broader context underpinning the research, it is helpful to have an understanding of my own experiences and understandings of the education system and ways that this has influenced and guided the research that I have undertaken.

Autism, education, and me

I hated school, from an incredibly young age I felt an overriding sense that I just did not fit in. It felt as if I were trapped within a glass cube, I did not know I was trapped, the world could see me, and I could see the world, but the walls of the glass cube kept getting in the way of meaningful interactions. All I knew was that I was alone, I was different, and the world did not make any sense. I remember years of difficulties consisting of trying to make and maintain friendships, but for some reason I just could not navigate this maze of unspoken complexities.

In primary school I managed to make one friend, but I became very dependent on that friendship and if said friend decided to play with another child it had a distressing effect on me, she left before the end of junior school, which meant I had no friends. I was already experiencing bullying and I would spend most play times alone or hiding in the toilets. I told my parents how difficult school was and that I was being bullied, they tried to raise their concerns with the school, but nothing changed. I became internally distressed, around 9 years of age dying felt like the only option, life was simply too painful.

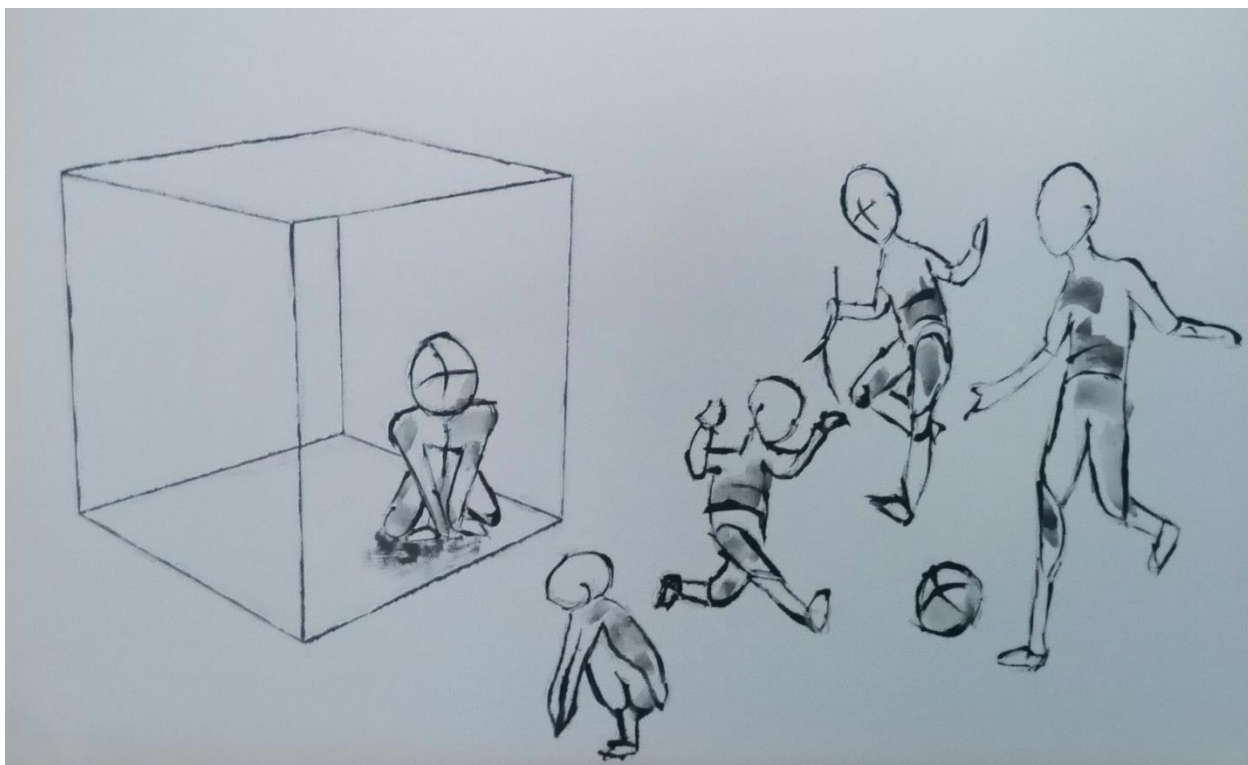


Figure 1 Experiencing school within a glass cube, artwork by Esther Whitney

Research suggests that autistic females use various techniques, consciously and or subconsciously to hide their autistic difficulties, some refer to this behaviour as ‘camouflaging’ or ‘masking’ (Hull et al. 2017a; Hull et al., 2020; Lai et al. 2011). I was adamant that I did not camouflage, ever. I was wrong, looking back I did, and I still camouflage to this day. I realised that when I was a child, I would watch a lot of American television series involving 'popular girls', I would try to mimic their behaviour, style, and attitudes to fit in. I recall this back firing on many occasions, I could not articulate myself fast enough to respond to the quick pace social exchanges, which often did not happen exactly as they did on the television shows.

I often plan my social exchanges; before attending any social events my brain automatically runs through all the possible conversations which could take place and my responses. It is draining and I end up being exhausted before the social event has even started.

After the event, my brain scrutinises each conversation and response, this causes sleep difficulties because my brain will not shut down until it has done with its analysis. This was a particular problem at school, social exhaustion. My brain continually working in overdrive, bombarded by far too much social data to digest and file in its database.

I enjoy learning, however at school I learnt extraordinarily little, thus I was classed as stupid and slow, this label followed me for the entire time I was in the educational system. While at school I was quiet and very well behaved, this was a different situation at home when I would take off the 'mask' and let a days' worth of distress out. Teachers would often describe me as a polite and well-mannered girl but just very slow, this was a surprise to my parents as at home I was a nightmare.

Primary and junior school were tough but secondary school was absolute hell. Fundamentally I could not cope in mainstream secondary school, I was literally eaten alive. I had no friends, the bullying continued, I was perceived as 'weird'; I did not understand the social constructs within secondary school life, which left me very vulnerable. At lunchtime I took refuge in the library, as I was less likely to be bullied there.

The school classes were large, I was quiet, I got overlooked and fell behind in my studies, this meant I was placed in the bottom sets, with pupils that were disruptive; I fell further behind. The teacher spent more time managing challenging behaviour, than teaching the class.

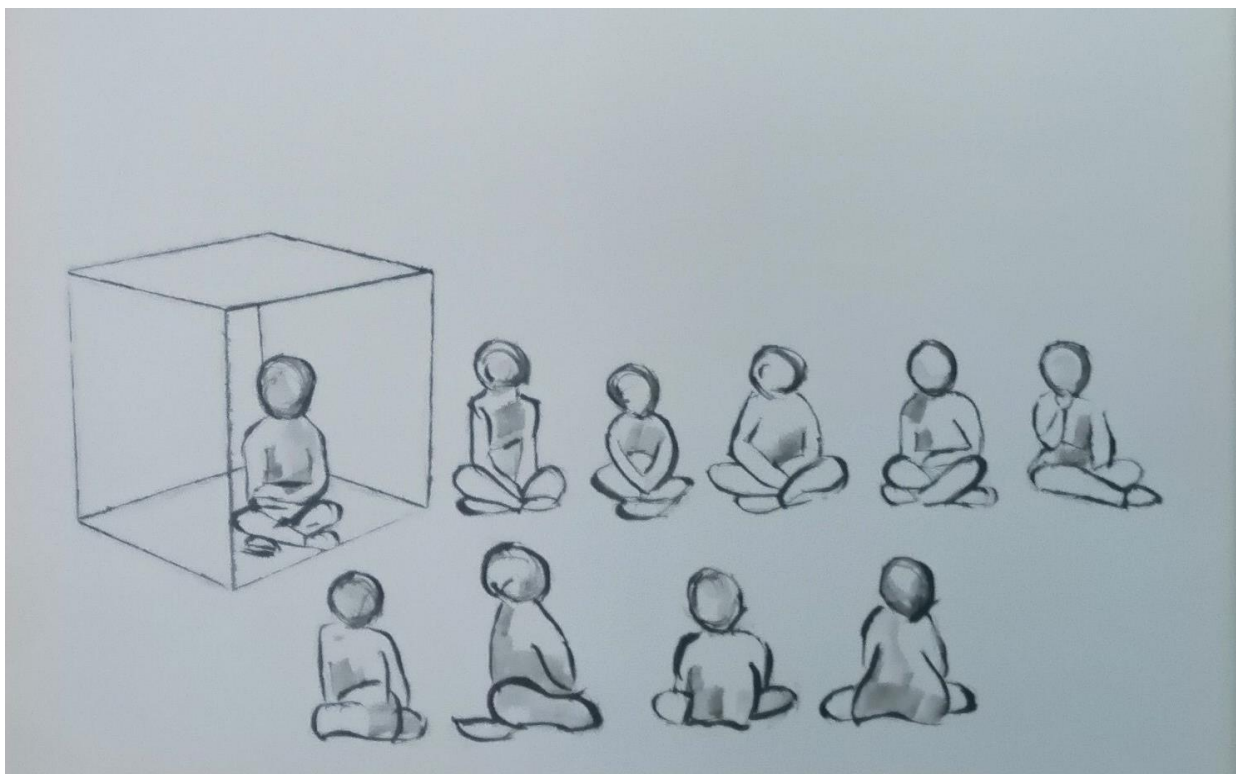


Figure 2 Experiencing school within a glass cube, artwork by Esther Whitney

Sitting in the classroom inside the glass cube, I am visible but cannot connect with my peers and they cannot connect with me. No one can see the glass that is between us, but we know it is there. There is no real explanation for why it is in the way, they become frustrated with me, and I become frustrated with myself. My teachers try to teach me, but it is very difficult to hear and learn when you are sitting in a glass cube, I try hard to study but the glass walls prevent this.

I managed to survive up until year 9 of mainstream secondary school. Unfortunately, the impact of not having an autism diagnosis during my school years got the better of me. I did not understand why I felt so different; I concluded that there was something fundamentally wrong with me, that I was a worthless person and life was just too painful. I attempted to take my own life at school, thankfully I survived. However, my story is not unusual, research has found that

autistic females are more likely to die by suicide than autistic males (Hirvikoski et al., 2016; Kirby et al., 2019; Holden et al., 2020).

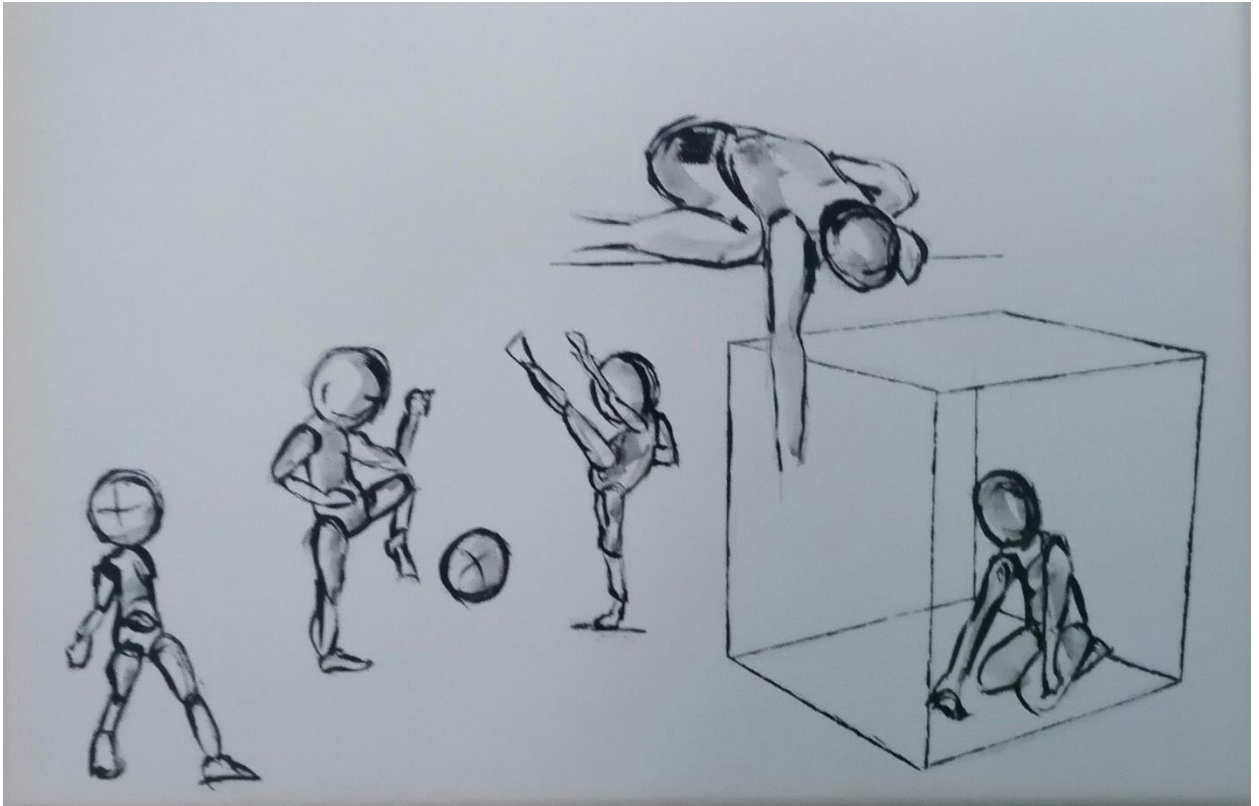


Figure 3 Experiencing school within a glass cube, artwork by Esther Whitney

It was decided that I would not return to mainstream education, so I went to a specialist school for pupils with a variety of needs. Attending a specialist school was the best thing to have happened to me during my time in the UK education system. It was like someone reached inside the glass cube I had spent my entire school years in and connected with me. The school was small, I was almost taught one to one. The school realised my gifting in art, so the art teacher spent time encouraging me in developing my artistic skills. This encouragement gave me the confidence to try and understand other subjects. The teachers adapted their approach when I did

not understand, this was something I had never experienced before, instead past teachers had become frustrated and made me feel stupid.

I completed my secondary education and sat my GCSES. The support the specialist school gave me meant I could go to college, something that seemed impossible when I was in mainstream school. Sadly, I am not the only autistic person who struggled with the educational system; In a survey conducted by Parsons, (2014); investigating the educational experiences of autistic adults, found that, several participants struggled throughout their education. Due to late diagnosis some participants did not receive the right support and felt that they were written off by the education system. It is rather troubling that the educational system has resulted in negative experiences for some autistic people.

Receiving my diagnosis of autism was enlightening because I could understand that there was nothing fundamentally wrong with me. Nevertheless, the diagnosis itself raised many questions, as well as often being misunderstood, I was diagnosed over 15 years ago, at this time there were few autistic females with an official diagnosis. Being one of the few in a community which was dominated by autistic males was lonely. Furthermore, as an autistic female I felt overlooked, it appeared that the world was preoccupied with autistic males. For a few years I went into the post autism diagnosis abyss, a seemingly never-ending tunnel of enlightenment, confusion, disempowerment, empowerment, and depression. This led me on a journey, seeking an answer to the question... what does my autism mean to me?



Figure 4 Art by Esther Whitney, A Thimble Full.

Despite my negative experiences of education, this has not prevented me from continuing my studies. Since leaving school at 16 I have completed a vocational course in art and design, an apprenticeship in childcare and teaching assistants. I have achieved a BA Hons in Art and Design which I focused on creating artwork relating to my experiences of having autism. I now wish to dedicate my life to pursuing a career in autism research, because greater knowledge is empowering.

I have endeavoured to gain deeper insight into autism particularly female presentation, this has led to a greater understanding of myself. However, at times this has come at a cost; knowledge and understanding of my autism and how it impacts my life has not always been well received by professionals, many of whom have inaccurate presumptions. Over the years autism awareness has increased, although this has not always been beneficial as it has encouraged, the portrayal of autistic stigma and stereotypes. Furthermore, this stereotyped representation can become problematic for professionals, who perceive the stereotype as a literal representation, forcing me back into the glass cube.

Sometimes I do feel that as an autistic woman; society has often, silenced me because I am deemed as too difficult or too complicated to engage with. This is not the case, as an autistic woman I have a lot to say, and I have a unique insight into my autism and the impact of a rigidly constructed society.

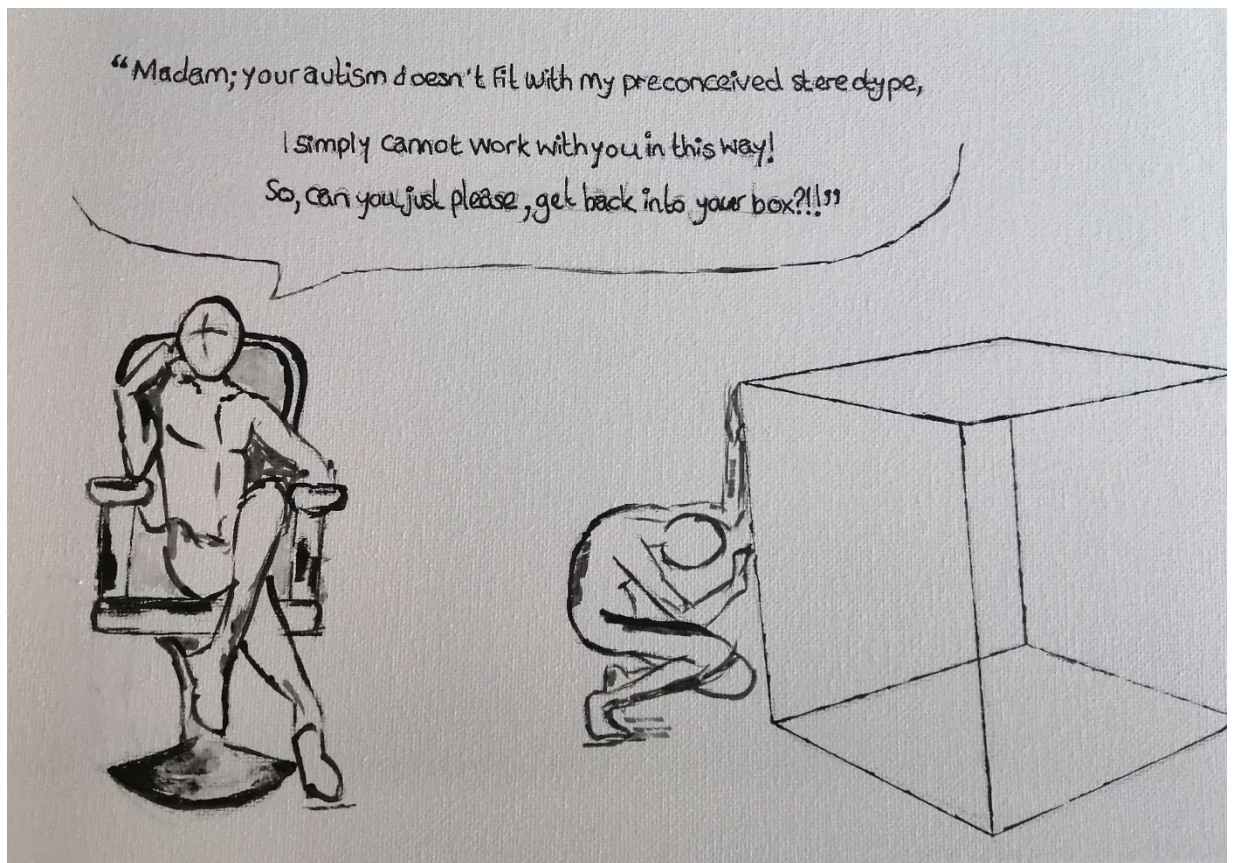


Figure 5 Please return to your box, by Esther Whitney

Over the recent years there has been more awareness around autism, however autism continues to be stigmatised (Giwa Onaiwu, 2020). I have experienced the ‘let us focus on your deficits’ as well as the belittlement of autism, countless times others have said, ‘well - we are all on the spectrum somewhere.’ or ‘we are all a little bit autistic’. In addition, any difficulties in communication or interaction, it is me the autistic person who needs the intervention, although emerging evidence for example Milton’s (2012) double empathy theory, which radically

challenges the deficit view of autism, by advocating that both autistic and non-autistic individuals uniformly have difficulties understanding each other (Mendelson et al., 2016; Mitchell et al., 2021).

Despite times of disempowerment, I have equally had times of empowerment. Times when professionals had taken the time to get to know me and in turn understand my autism. I have been able to take part in webinars giving insight into being an autistic female; the feeling of being listened to and respected because you are sharing your lived experience to give others insight into your world, is an honour.

My passion is to provide autistic adolescent females with a voice, I understand the turmoil caused when you are, overlooked, silenced, or dismissed, this has certainly been the case for autistic people within autism research, particularly autistic females. I welcome these discussions personally and professionally; society including academia have not been kind to the autistic community. For example, academia has excluded autistic people from taking part in autism research, centring studies on the perspectives of non-autistics, as well as ignoring requests from the autistic community about conducting research that makes positive contributions to the lives of autistic people and their families (Nicholas et al., 2019; Richards & Crane, 2020; Tesfaye et al., 2019; Kara, 2020; Grant & Kara, 2021; Botha & Cage, 2022).

Autism research needs to be empowering, focused on listening to autistic people and their experiences within the construct of today's world. As an autistic autism researcher, I will be approaching this research project from a unique 'insider' perspective. Therefore, I intend to conduct an exploration into the lived experiences of a small group of autistic adolescent girls within a mainstream secondary school, utilising my experiences and understanding of autism and the challenges within education to design a study that is fully adaptable.

Chapter 2

Literature review

This study explores the experiences and perspectives of autistic adolescent females in a mainstream secondary school. Central to the research have been key issues including, what is autism, gender disparity, inclusion, and the dearth of participatory autism research.

What is autism?

Historically the medical model has defined autism as a series of deficits. Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and the presence of restricted interests and repetitive behaviours (DSM-5). Leading one to assume that there is a ‘normal’ neurotype, which perpetuates the ‘othering’ of the autistic community and implies that the predominate neurotype is superior. Armstrong (2015 p. 348) established, ‘there is no such standard for the human brain. Search as you might, there is no brain that has been pickled in a jar in the basement of the Smithsonian Museum or the National Institute of Health or elsewhere in the world that represents the standard to which all other human brains must be compared’. A growing body of literature argues that autism should not be categorised as a bunch of deficits and that the social model of disability is required. Samaha, (2007, p1251) defines it as ‘A social model of disability relates a person’s disadvantage to the combination of personal traits and social settings.’ Beardon, (2017, p19) refers to autism as a neurotype that leads to;

- A cognition that is qualitatively different from that of the predominant neurotype in the way that information specific to communication, social interpretation and interaction is processed and understood;

- And to a perceptual reality of the sensory environment that differs considerably from one individual to the next.

Gender Disparity

There is acceptance within the autism research field that there is gender inequality in relation to research focusing on autistic females. D'Mello et al., (2022) found that studies often overlook or ignore autistic females.

Historically there have been difficulties in diagnosing autistic females, without cognitive impairment (Shattuck et al. 2009). Some studies indicate that because research has centred around autism in males, many diagnostic guides have been developed based on the autistic male presentation (Lundin et al., 2020). It could be suggested that because diagnostic tools have been developed based on the autistic male presentation, autistic females are often misdiagnosed with mental health difficulties or diagnosed later in life compared to autistic males (Fusar-Poli et al., 2020).

I think currently it is difficult to quantify the autistic male to autistic female ratio, although Loomes et al., (2017) proposes it maybe to three to one. Regardless, it is widely accepted that there is a gender disparity. That said, what has not been agreed upon within the literature is why there is a gender disparity within autism.

Some research suggests that it could be possible for females to have the 'female protective effect' reducing the likelihood of developing autism (Hull et al., 2020; Zhang et al., 2020). Other research has identified that autism might go undiagnosed in females because autism could present differently in females; autistic females show interest in friendships and socialisation (Head et al., 2014; Baron-Cohen et al. 2011), their special interests appear to be within the context of the 'social norm' (Grove et al. 2018; Mandy et al. 2012; McFayden et al.

2018; Nowell et al. 2019). As the current diagnostic tools are sensitive in detecting the male presentation of autism, it could be an explanation as to why autistic females maybe falling through the gaps (Hull et al., 2020; Nasen, 2016).

Autistic females are more likely to suppress their traits and difficulties (Leadbeater et al. 1999). This could have a big impact within educational settings, as autistic females may blend into the background (Hull et al., 2020) resulting in teaching staff not being able to recognise autistic related challenges in their female pupils (Posserud et al., 2006).

In a study which looked at the experiences of autistic girls within mainstream primary schools conducted by Moyse and Porter (2015), identified that teaching staff lacked understanding around how autism presented in autistic females resulting in their needs not being fully met.

It has been recorded, that there is an absence of autism training for teaching staff (Brede et al., 2017; Robertson et al., 2003; Dybvik 2004; Humphrey and Symes, 2011) despite studies highlighting the importance of autism training for teaching staff (Humphrey and Symes, 2013). However, the debate regarding what training is beneficial continues; disparities in the knowledge and awareness of autism have been highlighted throughout the different stages in mainstream education (Ballantyne et al., 2019). Some studies report that basic autism awareness training can equip teaching staff with the tools to be able to support their autistic pupils (Symes and Humphrey, 2012). Other studies recommend that teaching staff require more specialised autism training (Symes and Humphrey, 2011). Humphrey and Lewis (2008) argue that it is deeper than just ‘autism training’; an individualised approach to autism inclusion is much needed (Humphrey and Lewis, 2008).

Inclusion and Autism

Research implies that autistic pupils can benefit from mainstream school settings (Symes and Humphrey, 2012). Equally, school can make or break an autistic child (Beardon, 2021, p68). The current educational pathway is a linear one (Beardon, 2021, p69) this can be problematic as autistic children's needs will be ever changing throughout their educational journey. Emphasising that, inclusion within mainstream education is not straight forward for autistic pupils. House of Commons Education & Skills Committee (2006) highlighted the unique complexities of meaningful inclusion for autistic pupils. What does Inclusion mean: students' presence without the use of withdrawal from classes; participation, acceptance, and achievement (Symes and Humphrey, 2012).

What does Inclusion mean: to be able to meaningfully participate in education, prompting acceptance and achievement (Symes and Humphrey, 2012). As highlighted by Ravet (2011) there is two differing viewpoints around inclusion. The first point is that of a child's 'right' to be able to access education without discrimination. The second point is that children with additional needs require the educational provision to fully meet their unique needs. However, this is rather a simplistic view and in reality, it is far more complicated due to the uniqueness of each autistic person's autism. The school environment can cause discomfort to many autistic pupils, furthermore mainstream school has been designed for neurotypical children; some autistic pupils, struggle with neurotypical demands and expectations being placed on them. Teaching styles used don't tease out autism related strengths, this can lead to autistic pupils incorrectly believing that they are 'stupid' negatively impact their well-being. Many autistic pupils struggle navigating the social complexities that come with mainstream education further impacting their wellbeing. Some argue that autistic children need to be able to cope within mainstream education in order to prepare them for living in the 'real world' however many autistic adults are not coping in the

‘real world’ due to experiencing significant trauma as a result of negative educational experiences (Fulton et al., 2020).

Studies have highlighted that inclusion for autistic pupils with mainstream secondary schools can be significantly challenging (Symes and Humphrey, 2011) particularly for autistic pupils who experience sensory differences, the overwhelming environmental aspect of secondary school can be problematic for autistic pupils (Humphrey & Lewis, 2008; Moore, 2006) resulting in sensory trauma (Fulton et al., 2020). Due to autism being a ‘hidden’ condition as well as the use of ‘masking’ teaching staff aren’t always aware an autistic pupil is struggling (Brede et al., 2017) in addition many incorrectly believe that because an autistic student is educationally proficient, they are able to succeed within the mainstream environment with little or no support (Moore, 2006; Humphrey and Lewis, 2008). Furthermore, it has been reported that autistic pupils disproportionately experience bullying, social isolation, and social rejection, as well as school exclusion, resulting in the development of mental health problems (Humphrey and Lewis, 2008), this appears to be still the case with little success in anti-bullying strategies (Sproston et al., 2017; Goodall, 2021).

Adolescence is challenging for most people regardless of neurotype (Seifert, K. et al. 2000) however, autistic people experience adolescence differently and this can be rather traumatic. Studies have highlighted that for autistic girls’ adolescence has its own unique complexities, it can become harder for autistic girls to ‘mask’ their autistic traits (Dean et al. 2016; Lai et al. 2016; Mademtzi et al., 2017) resulting receiving an autism diagnosis in adolescence (Begeer et al. 2013; Bolick, 2001). Throughout adolescence friendships become difficult to navigate (Bauminger et al. 2008; Carrington et al. 2003) resulting in bullying and social rejection (Solomon et al. 2012; Sullivan and Caterino 2008) bring to the surface their

social differences (Solomon et al. 2012). Furthermore, during adolescence autistic girls can experience mental health problems, disguising the underlying autism (Nasen, 2016) adding additional challenges and complexities.

Unfortunately, some of the current literature paints a concerning picture of the educational experiences of autistic children and young people (Goodall, 2020; Heyworth et al., 2021; Humphrey & Lewis, 2008; Makin et al., 2017; Williams et al., 2019). Furthermore, autistic pupils are more likely to experience non-attendance, whether that is through exclusion, parental withdrawal, or school avoidance (DfE, 2019; John et al., 2022). This appears to be further compounded by the complex and lengthy system parents have to navigate to secure the right support in the form of an EHCP. Emerging evidence suggests that parents fighting this complex system for the right support for their disabled children often experience parental blame (Cerebra, 2021).

Inclusion can only be effective if the right support is put in place in a timely manner before crisis point, however studies have highlighted that this is far too often not the case and pupils are left without the right support for too long, resulting in crisis (Gray et al., 2023). Unless support and resources are put in place, inclusion for autistic pupils will be very difficult to achieve. Worryingly the House of Commons Education Select Committee (2019) admitted that there was not enough funding available within the SEND system to provide the adequate support and resources for SEND pupils.

Participatory autism research

There is a lack of autistic participatory research and qualitative data collection, yet the value of listening to autistic peoples lived experiences has been highlighted within the literature (MacLeod, 2019). This hasn't always been the case, historically autism research has focused on

listening to non-autistic people creating distrust between the autistic community and the autism researchers (Fletcher-Watson et al., 2018).

As highlighted within Tomlinson et al., (2019) systematic review of the school experiences of autistic girls, this area of research is lacking the voices of autistic girls. More participatory autism research will help researchers to understand the impact that being an autistic female has on an individual at any given time (Beardon, 2017, p19). Conducting research, where the primary focus is on the views of autistic children and young people, can raise specific challenges in the way the research is conducted due to the nature of autism (Rasmussen and Pagsberg, 2019). This could explain why there is limited participatory autism research, due to reluctance from researchers within the autism field.

Research exploring the opinions of autistic children are largely non-existent (Preece and Jordan, 2010; Parsons, 2014). Despite the valuable insight children can offer research about their experiences (Rasmussen and Pagsberg, 2019). Conducting research, where the primary focus is on the views of autistic children and young people, can raise specific challenges in the way the research is conducted due to the nature of autism (Rasmussen and Pagsberg, 2019). This could explain why there is limited participatory autism research, due to reluctance from researchers within the autism field.

Research has identified areas where autistic participants might have difficulties with engaging in research. Questionnaire based research methods have been reported as problematic (Stacey & Cage, 2022) difficulties with concentration, the demand to answer the questions quickly, as well as limited explanation around the questions can be challenging for autistic people to effectively engage.

Interview-based research has also been highlighted as challenging for autistic participants, due to differences in communication styles as well as not always being aware of non-verbal cues (Kenworthy et al., 2008; White, 2013; Milton, 2012). The pressure to process information quickly can mean that autistic people's voices aren't fully heard because they are not afforded enough time, limited structure within questions can also cause difficulties in engagement (Maister et al., 2013; Gaigg & Bowler, 2018). However, research has suggested that autistic people are able to communicate effectively with other autistic people, giving weight to the autistic researcher advantage (Crompton et al., 2020; Sinclair, J., 2010).

Alexithymia

Some participatory autism research has based data collection on semi-structured interviews which could be problematic for a participant who has coexisting alexithymia. Research suggests a large proportion of autistic people may have coexisting alexithymia (Griffin et al., 2016, Ola and Gullon-Scott, 2020). Alexithymia is when an individual struggles to identify and verbally articulate their feelings (Farina et al., 2021). If relying on words alone, this could result in the participant not being able to fully engage. However, some research advocates the use of non-verbal communication or expression which can support alexithymics in sharing their feelings (Meijer-Degen and Lanssen, 2006). Therefore, it is important for non-verbal opportunities to be made available to collaborators who might struggle verbalizing their experiences.

Concluding Comments

This Literature Review has identified that autistic pupils can benefit from mainstream school settings (Symes and Humphrey, 2012) although it is not clear whether this is an assertion made by the neurotypical community or from the autistic community. Emerging research has highlighted that some autistic individuals have negative educational experiences within mainstream educational settings as well as struggling with a curriculum that is designed to teach pupils multiple topics in a school day (Beardon, 2021, p77). Some studies suggest that inclusion within mainstream secondary school is more complicated for autistic pupils (Symes and Humphrey, 2011), assigning culpability on the nature of autism Jordan (2008), rather than the rigidity of the current mainstream educational system, as well as neurotypical demands, environments and expectations being placed on autistic pupils. Another side to the literature indicates that the mainstream environment can be a significant barrier for some autistic pupils, Dr Luke Beardons 'Golden equation' $\text{Autism} + \text{environment} = \text{Outcome}$ (Beardon, 2021, p 4) places importance of an autism friendly educational environment, however a move away from a 'one size fits all autistic pupils' approach is much needed.

It is agreed that in autism research there is a gender disparity, females have generally been overlooked (D'Mello et al., 2022; Fusar-Poli et al., 2020; Fusar-Poli et al., 2020; Loomes et al., 2017).

Exploration into designing research methodology which is flexible enough to adapt to each autistic participants needs, is required to help address the gap in autism participatory research, developing adaptive approaches could support rebuilding the distrust between the autism research community and the autistic community (Fletcher-Watson et al., 2018; MacLeod, 2019). Autistic people communicate effectively with other autistic people giving weight to the autistic researcher.

The educational experiences of autistic females is a vast subject matter and there are many areas that require further research; however, this project is on a very small scale, and I feel that it is vital to build a firm foundation before embarking on a large-scale piece of research. Therefore, I have chosen research questions which will provide the insight and knowledge which would be required for larger-scale studies. I have chosen the following research questions.

- What is school like for autistic females in a mainstream secondary school?
- How can personal experiences and knowledge of autism support the development of a fully collaborative research approach to allow the voices of autistic females to be heard?
- How can creative and personalised approaches be used to engage autistic participants?

These research questions will provide a good starting point in ensuring that autistic girls are able to fully participate with research and their voices are being heard.

Chapter 3

Methodology

Principles and values underpinning the Methodological Approach

A large proportion of autism research has focused on ‘fixing’ or ‘curing’ autism, often driven by non-autistic people in power (Kara, 2020; Grant & Kara, 2021). Botha & Cage, (2022) highlight problematic research and approaches within the field of autism.

“Autism researchers can be ableist, including by talking about autistic people in sub-human terms (dehumanisation), treating autistic people like objects (objectification), and making othering statements which set autistic people apart from non-autistic people, and below in status (stigmatisation).” (Botha & Cage, 2022:1)

As an autistic autism researcher conducting a literature review can, at best be disempowering at worst offensive and traumatising; it is understandable that there is distrust within the autistic community. Damaging dehumanising autism research has become embedded within societal institutions and services. I have personal experience of being treated as subhuman because I am autistic, and this topic is often explored within my artwork.

Although organisations such as shaping Autism Research UK and The Participatory Autism Research Collective (PARC), have been advocating for changes in the way autism is researched; Botha, (2021) argued that discussions around whether the autism research field is truly welcoming to the autistic community, appears to be absent within the literature, subsequently opening discussions, challenging past treatment of autistic people within research. Highlighting the need for empowering participatory autism research and this was the foundation block of this research project. Based on lived experience as the ‘researched’, I am aware how

research outcomes can create prejudice within wider society, and the implications research has long term on the 'researched', advocating a need to change.

The Autistic Advantage as an Autistic Researcher

Within the autism research field, many autistic researchers have hidden their autistic identity (Dwyer et al., 2021). Being openly neurodivergent within a professional context, can be associated with negative stigma and classed by some as 'professional suicide'. However emerging research has offered a different perspective, autistic autism researchers have many strengths as well as lived experience (Dwyer et al., 2021). As an autistic autism researcher, I am able to approach participatory autism research from an inside perspective because of my experience of being 'the researched'. Considering the autistic advantage in the context of an autism researcher as a notable part of the methodological approach, might seem unorthodox however for this project it is significant.

As an autistic individual who has participated in various autism studies over the years, I was able to use this experience within the development of the methodological approach, this has been highlighted as a strength autistic autism researchers have within the literature (Dwyer et al., 2021). Research suggests that autistic people have a better understanding and empathy for other autistic people (Russell et al., 2019, Dwyer et al., 2021, Grant & Kara, 2021). Autistic people have unique traits however depending on the context or environment these traits can become advantageous or disadvantageous (Russell et al., 2019). Due to my own lived experience and understanding, developing a fully adaptable methodology from an insider perspective creates an accessible and empowering research project.

Discussions took place with my supervisor and the school around how my autistic needs would be met, such as ensuring that I had recovery time after visiting the school environment

and wearing strong perfume to mask the overpowering smells within the school environment. Furthermore, it was really important that my own experiences as an autistic female did not overshadow this research project and that I maintained an objective approach throughout. Discussions took place with my supervisor, and I went through a process of bracketing my lived experiences within education as an autistic female. This process allowed me to put my experiences to one side, acknowledging that every autistic individual is different and so will their experiences.

The project was conducted within the guidance outlined by Shaping Autism Research UK; it was centred around these three principles which are recommended; trust, mutual respect, listening and learning (Pellicano et al., 2017). The project was conducted as a collaboration rather than a 'study', thus with this in mind I will not refer to the people taking part in this project as participants but as collaborators, an approach endorsed by Pellicano et al., (2017).

The purpose of this research is not on generalities, its function is for an in-depth exploration into the lived experiences of the small group of autistic girls taking part. This study aims to address the lived experience gap within the literature as highlighted by Nicholas et al., (2019); Richards & Crane, (2020); Tesfaye et al., (2019) who suggest that lived experience research has primarily fixated on the views of non-autistic people. Therefore, within the context of this small research project I will be only seeking the voices of the collaborators. All collaborators fulfilled the research criteria, discussions with the gatekeeper around vulnerability were sought before any girls were put forward (BERA, 2018).

It has been recognised in a recent study by Dwyer et al., (2021) that autistic autism researchers bring a set of unique strengths to the field, which has enabled autism research to

become more accessible and inclusive towards autistic people. This challenges past researchers who would often blame disabled participants when they were unable to fully engage with participatory research projects, rather than relooking at whether their methodological approach was causing the barriers (Booth & Booth, 1996).

Dwyer et al., (2021) highlighted that many of the autism networks and services we have today, were developed by non-autistic people. What is emerging from the literature is the importance of autistic researchers within the autism field (Dwyer et al., 2021). As highlighted by Milton, (2012) that non-autistic people and autistic people equally find it difficult to understand each other. As suggested in Dwyer et al., (2021) autistic autism researchers have an advantage as they are able to understand by experience, potential communication, and methodological barriers, I will be reflecting on this throughout the project.

Creativity and the Multimethod approach

The research project was designed as a multimethod exploratory case study; designed to explore a complex issue in great detail in order to develop multidimensional understanding (Crowe et al., 2011). As stated previously this project is not about generalities, I will be looking through a phenomenological lens at the experiences of a small group of autistic adolescent girls within mainstream secondary school over a period of 7 months.

As outlined within the literature review this is an area that has been sparsely researched, Mayer & Greenwood, (1980); Yin, (1984) suggest that when an area of interest lacks extensive exploration, an exploratory case study is the most appropriate approach. The purpose of the project is to give the autistic girls a voice so they can share their experiences and what that means to them, as highlighted previously autism research has not been actively seeking the voices of autistic people (Nicholas et al., 2019; Richards & Crane, 2020; Tesfaye et al., 2019).

Applying an exploratory case study approach to understand the experiences of a small group of autistic females could be used to formulate potentially productive lines of future research (Ogawa & Malen, 1991). Highlighted by Milton, D. and Bracher, M., (2013) that large numbers of the autistic community are advocating change within the autism research field, campaigning for the voices of the autistic community to be heard and included in all aspects of autism research (Pellicano et al., 2014).

Crowe et al., (2011) suggests that applying a case study approach enables the researcher to capture information exploring ‘how’, ‘what’ and ‘why’; this fits in well with my research questions. ‘How can personal experiences and knowledge of autism, support the development of a fully collaborative research approach to enable the voices of autistic females to be heard?’. The approach provides in-depth exploration of ‘What is school like for this small group of autistic females at the time of the study?’ along with ‘How can creative and personalised approaches be used to engage autistic participants in research?’ and ‘why’ this needs further exploration.

Adams & Ingham, (1998) suggest that research with children needs to be carefully thought out to ensure the flexibility of the data. Using a multimethod approach would provide the flexibility required for this project as outlined by Lewis-Beck et al., (2004). Flexibility and adaptation were key to this project so that approaches could be personalised to support the engagement of the collaborators, due to the variety of research tools used a multimethod approach was implemented.

The Mosaic approach was developed as a methodological approach to support the engagement of young children within early years research (Clark, A. 2005), the key elements of the Mosaic approach as outlined in the study by Clark, A. (2005:13), fit well with the purpose of this project.

- ‘multi-method: recognises the different voices or languages of children.
- participatory: treats children as experts and agents in their own lives.
- reflexive: includes children, practitioners, and parents in reflecting on meanings, and addresses the question of interpretation.
- adaptable: can be applied in a variety of early childhood institutions.
- focused on children’s lived experiences: can be used for a variety of purposes including looking at lives lived rather than knowledge gained, or care received.
- embedded into practice: a framework for listening that has the potential to be both used as an evaluative tool and to become embedded into early years practice’ (Clark, A. 2005:13).

Although I did not apply the Mosaic framework as a methodological approach, the approach used in this project has similarities to the core principles of the Mosaic approach, along with the Mosaic approach stages (Clark, A, 2005:15): -

- ‘Stage One: gathering children’s and adults’ perspectives.
- Stage Two: discussing (reviewing) the material.
- Stage Three: deciding on areas of continuity and change’ (Clark, A. 2005:15).

My undergraduate degree is in art and design, I created thought provoking artwork, challenging the stereotypes that autistic people are somehow deficient in creative and expressive skills. I believe that creativity has the potential to break down barriers, support communication and connect people together. Using creativity allowed the girls to express their thoughts and feelings in a fun and empowering way; challenging past research on autism and creativity which implied that autistic people are creatively deficient (Kasirer & Mashal, 2014). Despite many

talented autistic artists, engineers, and scientists (Happé & Frith, 2009, Shaughnessy, 2013) and recognition that many autistic people are visual and pattern thinkers (Makhaeva et al., 2016).

In a study by Simonton (2001) states that creativity can be defined as the ability to bring about raw flexible ideas. Creativity is significant to this study on the basis that every autistic person has a unique experience. Autistic artist Rebecca Burgess depicts this in her piece, 'What people think the Autism spectrum looks like'. Applying a creative approach provided the project with the flexibility to adapt to meet the needs of the collaborators.

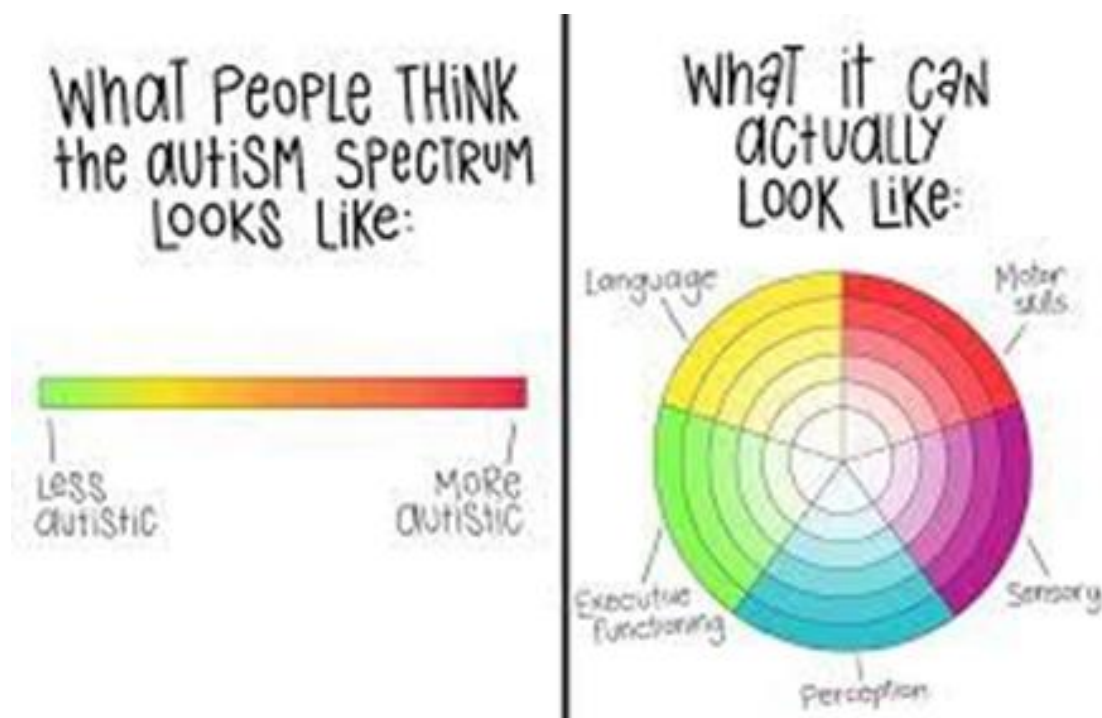


Figure 6 Graphic by Rebecca Burgess

Makhaeva et al., (2016) suggests that in order to ensure participants engagement is meaningful, the researcher must create a project that has structure but also allows freedom and flexibility. This concept became a point of reference throughout the project. The activities were simply a skeleton structure, as an autistic researcher my role was to use my knowledge and

understanding of autism to adapt the approach so that each collaborator was able to engage meaningfully.

Research Process

The research project I undertook was a multimethod exploratory case study, which took place in a mainstream secondary school setting, for a period of 7 months. Four autistic girls collaborated throughout the project, each engaged in an introduction meeting, group workshops, one to one workshop, a debrief and empowerment workshop.

Finding the right school was really important and this took several months. The school needed to be local to my home as I reside in Birmingham. Careful consideration went into searching for the right school to take part in the project, towards the end of September 2021 letters went out to a number of schools in the local area inviting them to take part. Around the time of the letters being sent out there were many unknowns in relation to COVID 19, I believe that this did have an impact on the research invitations and the school's willingness to participate.

The participating school

The participating school is a co-educational comprehensive secondary school, based within a predominantly affluent metropolitan county of the West Midlands, between Birmingham and Coventry. The school's pupil intake is around 1,000 pupils between 11-16 years of age. Alongside the school's mainstream provision, two additionally resourced provisions are on site which supports inclusive education for pupils with physical and sensory disabilities. For the purposes of this very small-scale research project, I had to narrow the sample criteria for the participants. I acknowledge that many autistic girls struggle with school attendance and that half of autistic individuals have cooccurring learning disability, however this was a 'test' piece of

research, therefore the criteria was narrowed. I worked with school staff who identified autistic girls who were in regular school attendance as this would provide the opportunity for them to have their voices heard and to test the methodological approach on a smaller scale. This study and methodological approach has built a foundation for future larger sample sizes to be used.

The research criteria for the project were clearly outlined within the letter to the schools:

- (1) Female
- (2) Post ASC diagnosis without learning disability.
- (3) Aware of diagnosis
- (4) Between the ages of 11-16 years
- (5) Regular attendee of mainstream secondary school
- (6) Able to verbally communicate.

Originally five collaborators consented to taking part in the project, however one collaborator left the school at the beginning of the study. Each collaborator was invited to create their own pseudonym; thus, the girls will be referred to as Beth, Poppy, Zakia and The Oracle.

Date:	Research Activity
September 2021	Letters posted to local schools
October 2021	Interest expressed by SENCO of participating school via telephone
October- December 2021	Failed attempts to arrange initial meetings with participating school, not knowing SENCO had left

December to January 2022	Search for school continues
January 2022	Emailed received by supervisor from participating school asking if they could still take part in the project, old SENCO had left project details were mislaid.
January 2022	Initial meeting with the participating school set up
End of January beginning of February 2022	SENCO and Autism Lead select collaborators based on research criteria
Mid- February 2022	Meeting with the autistic girls
Mid- February – July 2022	Meeting collaborators weekly for group and individual workshops until July 2022

Figure 7 Research Timeline

Research Tools

Trust, Mutual respect, Listening and learning (Pellicano et al., 2017) three principles recommended by Shaping Autism Research UK were considered when selecting the research tools used throughout this project. All the research tools selected had a degree of flexibility and creativity in order to adjust and adapt to each collaborators needs. Creativity was a fundamental building block within this project, despite some literature indicating autistic people may have deficient creativity, there is a plausible argument to be had in that autistic people are likely to have particular, exceptional creative abilities (Baron-Cohen et al.,2009).

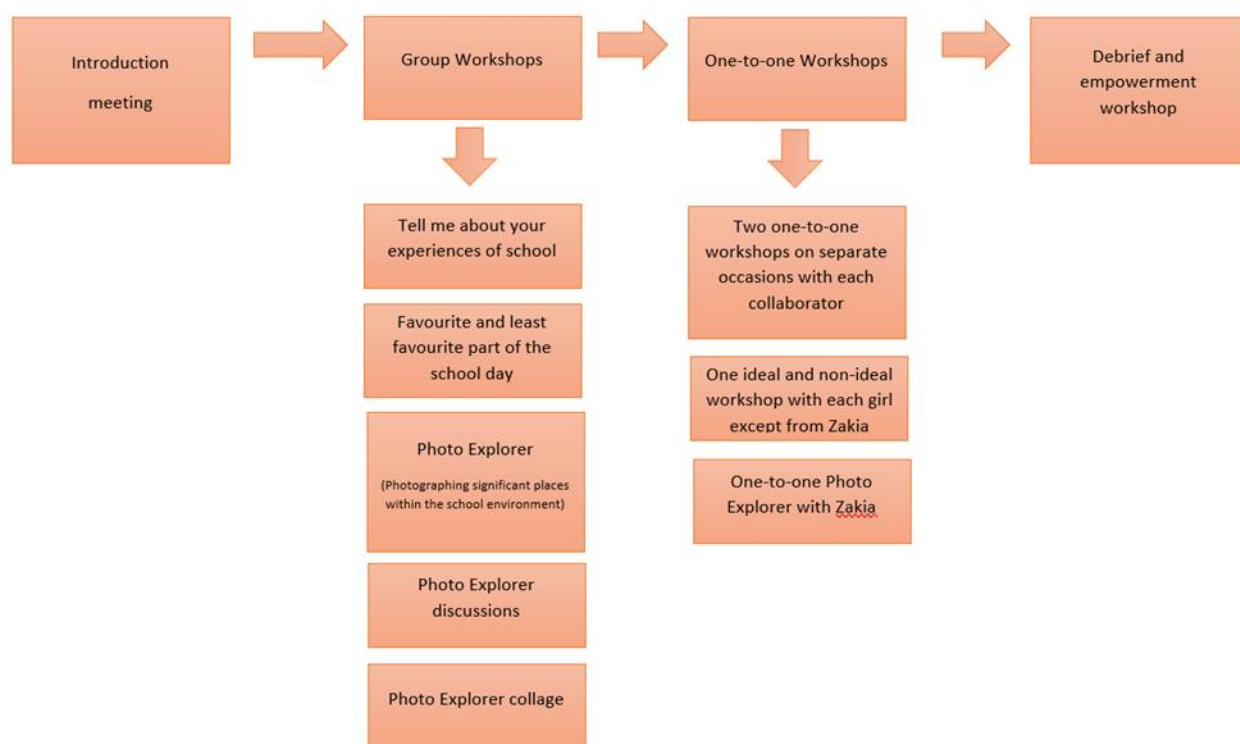


Figure 8 Research activities

The first tool was an introduction meeting with the girls this was to get to know the girls and discuss the project. The second research tool was group workshops which consisted of five workshops. The tools used referred to recommendations in a study by Clark, (2001) who suggests by allowing children and young people the prospect to gain insight into their own world

by contemplating and reviewing matters that concern them. By starting the project using creative group-based tools supported the development of a rapport between myself and the collaborators. This project was about collating rich data, Adams and Ingham, (1998:149) suggest that although surveys, audits, questionnaires, and interviews are good tools for collecting data, such tools are not always good at teasing out rich data.

Figure 8 shows the research activities which took place, each group activity was selected based on my interactions with the girls from the previous workshop. I reflected on the work by Rinaldi (2005) who suggests that by providing children and young people the chance to openly discuss and hear peers' opinions on matters that concern them would encourage rich data.

Group workshops

Tell me about your experiences of school- this activity was designed as an opening group activity, the girls shared their experiences of school through creativity, some of the girls shared similar stories which opened up a dialog between each other.

Favourite and least favourite part of the school day- this activity encouraged the girls to creativity explore different aspects of their school day which enabled them to reflect on 'What it means to be me within the context of school'.

Photo Explorer- research has highlighted the importance of using photography within participatory research, Walker (1993) suggest that the use of photographs enables children and young people to be heard without having to speak. Similarly, Photovoice, a research tool which allows people to explore their world through the camera lens (Wang & Burris, 1997) has been used as a participatory research tool within a wide range of minority communities. In a study by Teti et al., (2016) used Photovoice to engage young autistic adults in sharing the strengths using photo-stories. It was suggested that Photovoice was a complementary tool which supported

young adults to convey their perspectives (Teti et al., 2016). Due to Photovoice's flexibility (Wang & Burris, 1997) elements of this research method was incorporated within the photo explorer activity.

The third research tool was one-to-one workshops, these workshops were developed as a two-stage process. However, the one-to-one workshop stages were adapted for Zakia, photo explorer was completed as a group activity, Zakia was struggling to engage with the other girls.

One-to-one workshops

Stage One: Each girl was offered two one-to-one workshops on two separate occasions.

Stage Two: Each girl was offered My ideal and non-ideal school one-to-one workshop.

My ideal and non-ideal school developed by Williams & Hanke, (2007) to explore the opinions of autistic pupils' educational experiences. What emerged from these studies was the positive engagement of the participants and the rich data the activity was able to encourage without the use of complex questionnaires or long monotonous interviews.

Empowerment Debrief

During the project it became apparent that at times the girls expressed internalised stigma in relation to their autism diagnosis. It was important to end the project, with the girls feeling empowered and inspired about their autistic identity. Therefore, I contacted a number of autistic female professionals and asked the following questions:

1. What does your autism mean to you?
2. What is your Job title and how have your autistic strengths enabled you to become successful?
3. One thing that you would like to tell the next generation of autistic women.

Four autistic females answered the above questions (appendix 11), and one autistic girl contributed a poem she had written for autism awareness week.

Developing accessible research tools for autistic individuals

Transparency

All social science should be conducted with integrity throughout, employing the most appropriate methods for research purposes (BERA, 2018:4). Having participated in various research studies over the years the way researchers display the research information and consent forms can be problematic, large quantities of written information presented in black and white can be boring to read and difficult digest, as an autistic individual I tend to switch off, there is a risk of skimming the research information or not reading it at all. When thinking about how I would present the project information to the collaborators I was able to consider two perspectives:

- Researcher perspective, what information does the collaborators NEED to know.
- Researched perspective, please don't bore me with lots of written information and fancy words.

In accordance with guidelines set out by BERA, (2018:16) researchers should aim to be open and honest with participants. I provided the collaborators with the following:

- Project information booklet for the collaborators and an information sheet for the parents and guardians.
- At the start of the project, I had an introduction meeting with the girls to provide them with an opportunity to clarify any questions they had about the project.
- At the end of the project a debrief meeting took place, the collaborators were provided with a debrief sheet and were able to raise any questions for clarification.
- I continued to update the SEN Administrator whilst writing up the findings so that the collaborators were kept up to date with the progress of the project.

Collaborators

I decided to use a booklet format (appendix 4) to present the research information to the collaborators, a booklet format allowed me to present information to the collaborators without overwhelming them with large volumes of text. I choose to use different shades of purple throughout the booklet because purple has symbolic meaning linked to creativity which ties in with the project. I used a variety of visuals throughout the booklet ranging from symbols to photographs to break down the text and to help support the engagement of the reader.

I disclosed my autism at the start of the booklet in the hope that the collaborators would feel able to relate on the basis of shared experiences, I opted to reveal three fun facts about myself to breakdown the monotonous information. Empowerment was the thread that ran through the whole booklet, an explanation of why it is important to listen to Autistic people was outlined on page 2, I used a quote from Dr Temple Grandin who has been active in challenging the stigma around autism. On page 3 a summary was provided of the possible activities which might take place during the project. On page 4 I used four bullet points in the form of symbols to convey the following information: -

- Collaborators will be provided with project information and consent forms at the start of the project.
- Information about the collaborators lived experiences relating to education will be collated throughout the project.
- Anonymity- the identity of the school will not be disclosed. The collaborators identities will be hidden, and collaborators can choose their own alias. All information collated will be kept safe.

- Collaborators have the right to check information which is written about them, and they have the right to withdraw at any point up until the data had been included in my thesis.
- My contact details were written clearly and placed at the back of the booklet.

Parent and Guardians

Presenting the research information to the Parent/Guardians I used a slightly different format of two A4 sheets (Appendix 6). The first sheet was broken down into easy-to-read sections not to overwhelm the reader which eased them into the second sheet which had larger sections of text with photographs. I selected shades of yellow because yellow is often associated with happiness, creativity, and intellect which I felt tied well with the project. I used the same symbols and photographs to the ones used in the collaborator's information booklet. My contact details were written clearly and placed in the last paragraph on the second sheet.

Informed consent

Collaborators

The consent forms were very carefully considered, although consent is a continuum and was continually sort throughout the project. For the collaborators I used straight forward language and symbols on the forms to reinforce communication. I choose to use a block of light blue at the top of the consent form, light blue is a calming colour which is associated with trustworthiness and understanding, situated beside the light blue block a picture of colourful threads refers to a rainbow which is associated with diversity and empowerment. I used colourful symbols to reinforce the key areas of written text.

Parent and Guardians

The parent/guardian consent forms were slightly more detailed and largely consisted of written text. Similar to the collaborators information booklet I used different shades of purple reinforcing the creative aspect of the project. The consent forms can be found in the appendices.

Data Analysis

Careful consideration was given in selecting the most suitable analytical framework; thematic analysis was applied as the most appropriate method for analysing the multiple sources of data collected as recommended by (Kiger & Varpio, 2020). Due to the volume and variety of data and the adaptable methodological approach, thematic analysis was used instead of interpretative phenomenological analysis (IPA). IPA is a methodological approach and might not have given the methodological adaptability required. The project was about the girls' voices being heard rather than the researcher trying to make sense of their experiences, on that basis thematic analysis enabled was the best approach. An inductive approach was used throughout data analysis, the project was focused on giving the girls a voice thus themes emerged from the data rather than trying to fit data into themes I had created.

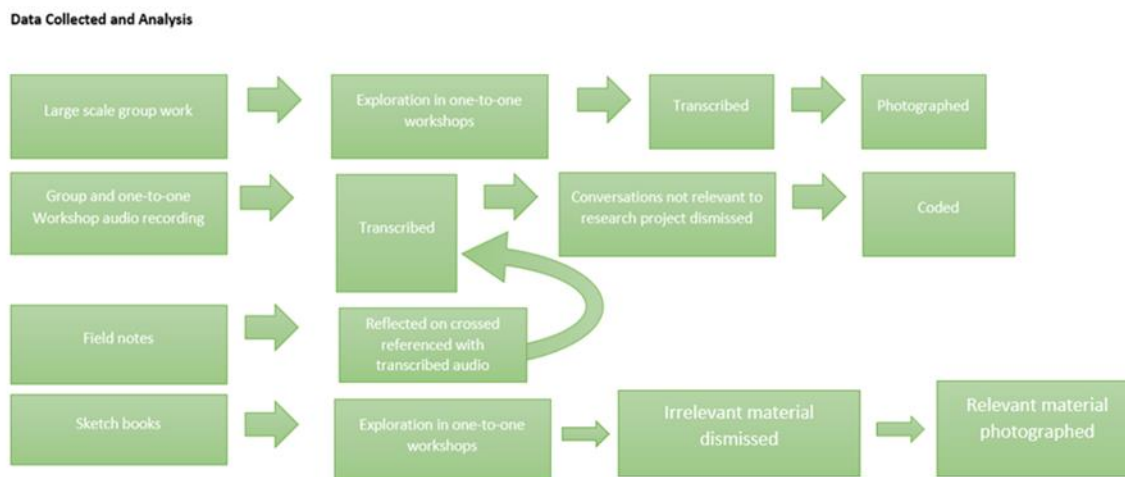


Figure 9 Data Collected and Analysis process.

Figure (9) summarizes the type of data collated and how it was analysed. All group and one-to-one workshops were audio recorded and I took field notes; consent was sort prior to the start of the project. Two collaborators used their sketch books, one contributed material which was not related to the project and subsequently dismissed.

Verbatim transcription

All audio recordings were transcribed verbatim however during the workshops, personal discussions between the collaborators took place which were not related to the project and therefore were not appropriate to transcribe this was noted in the transcripts. I used verbatim transcription because it allowed me to gain a deeper insight into the data as suggested by (Halcomb & Davidson, 2006; MacLean et al., 2004; Hill et al., 2022). The purpose of the project was to give the autistic girls a voice, thus it was imperative that their thoughts, ideas, and views were presented accurately within the research. This was a crucial part of the thematic analysis process, as a researcher it helped familiarise myself with the data and reflect on the autistic girls' experiences (Kiger & Varpio, 2020).

Coding

The next stage was descriptive coding, each transcribed interview was put in a two-column table and descriptive coding was applied which condensed the context of the text. I reflected on the research questions to ensure that the data was relevant, data not related to the research questions was dismissed. During the process I was making note of potential patterns and connections which might develop into themes as the analysis proceeded to the next stage (Braun & Clarke, 2006).

Searching for preliminary themes

I used an inductive approach when searching for themes, the selected themes emerged from the raw data which complemented the data as a whole (Braun & Clarke, 2006). The themes needed to encapsulate the essence of what the autistic girls were conveying.

Reviewing preliminary themes

The preliminary themes were colour coded and the descriptive data was sorted into the relevant colour coded themes. Using colour coding and a two-column table helped keep track of the data and supported refinement of themes and coded data. I kept notes and made detailed diagrams about the development of the themes as recommended in Kiger & Varpio, (2020). Once satisfied I reviewed the themes and data again and modified themes when necessary, referring back to the research questions.

Defining and naming themes

Once I was content with the themes and their relevance to the research questions and data, I started refining the data within the themes. As advocated by Kiger & Varpio, (2020) I focused on the reoccurring themes which were organised, leading to emerging sub-themes and I used colour coded two column tables to organise the data. I created a diagram for each theme which showed the emergence of the sub-themes. Figure (10) is a visual representation of the data analysis.

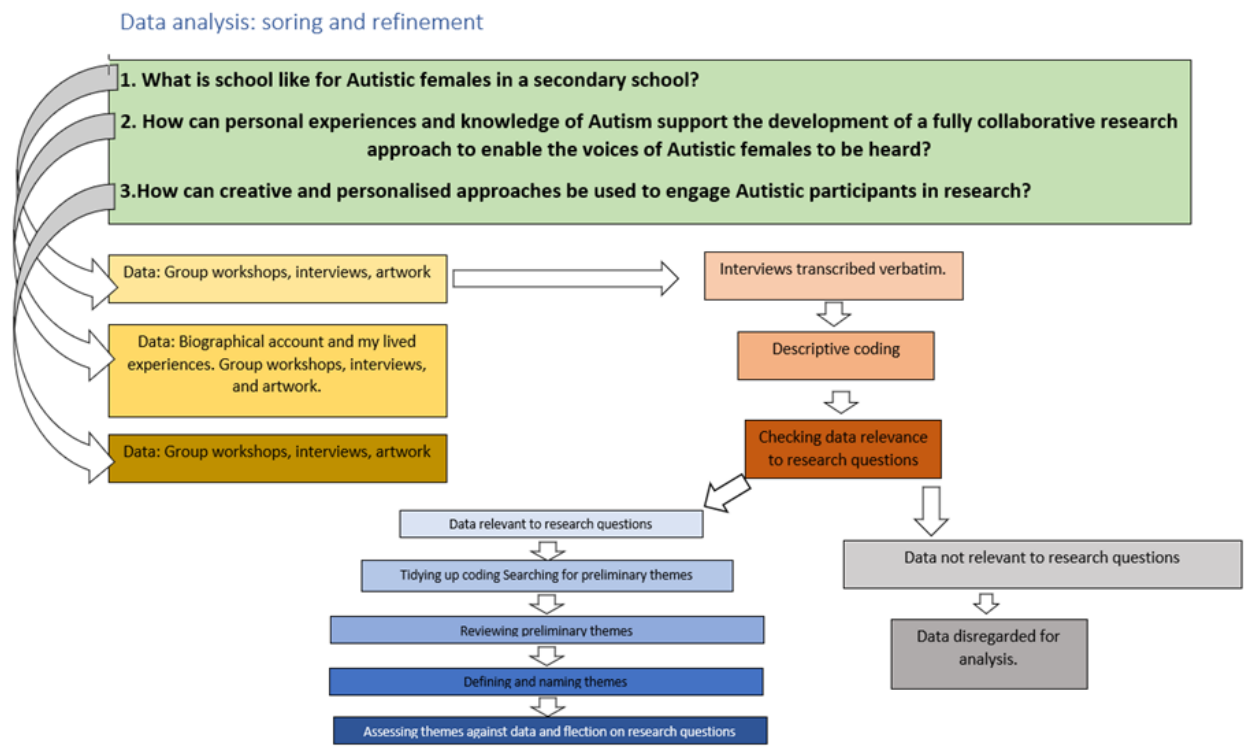


Figure 10 Data analysis: sorting and refinement

Ethics

‘Ethics goes beyond ethics committee approval and consent documents; it addresses broader issues of respect, inclusion, and empowerment in the everyday context of research’ (Cascio et al., 2020:1676). Participatory autism research raises bespoke ethical considerations for researchers, every autistic individual has their own unique experience of autism. Attentiveness was given to Cascio et al., (2020:1676) five person-oriented research ethics guideposts:

- ‘Tailor the research process for the unique needs of each person.
- Think about the world in which people who take part in research live.
- Make it easier for people to make their own choices.
- Value what people who take part in research have to share and consider their needs and strengths.
- Think about how researchers and people who take part in research work together’ (Cascio et al., 2020:1676).

Ethical approval was sought in line with the University’s Ethical guidelines. Careful considerations went into applying for Ethical approval, as an autistic individual who personally participates in autism research, I was able to use my familiarity of being ‘the researched’ along with personal experience of being ‘autistic’ throughout the Ethical process this gave me a unique insight, which enabled adaptations to be made so that the collaborators could fully engage.

Ethical Principles

Milton & Bracher, (2013) highlighted the lack of participatory autism research projects which are fully accessible and listen to the voices of the autistic community, is an area of much needed improvement within the autism research field. As highlighted by Cascio et al., (2020)

researchers within the field of autism, need to ensure that autism research is inclusive and adaptable to meet the needs of autistic participants. This project was created to highlight the importance of participatory autism research. The building blocks of the project were based on five ethics principles agreed by the Academy of Social Sciences endorsed by (BERA, 2018:4). The structure of the project was developed in line with BERA, (2018:16) key principles; minimising the risk of harm, informed consent, right to withdraw, confidentiality/ anonymity, and dissemination of research.

Minimising the risk of harm

This project was designed as participatory research to empower the collaborators to ensure that they feel valued, respected, and listened to, something that hasn't always been forthcoming from the autism research field, adding further distrust between the autistic community and the autism research field. (Nicolaidis et al., 2011). Acknowledgment of the ethical concern relating to potential power imbalance between researcher and participants, this was addressed by: -

- Structuring the project as a collaboration rather than a 'study'
- Being guided by the collaborators in ensuring that their voices were understood and heard.
- Being open about my autism diagnosis; common ground of shared experience
- Factoring in time to build a rapport with the collaborators.

Their wellbeing was paramount, activities, discussions, information, and dissemination were all developed to be fully adaptable to meet the needs of the collaborators. Some autistic people experience sensory sensitivities which can cause discomfort, this could be an ethical issue, if the researcher is not aware of sensory sensitivities, participants may be inadvertently subjected to harm. Prior to the workshops, discussions around each collaborator's sensory

experiences were sought, and adaptations were made accordingly. Workshops took place within the school environment during the collaborators breaktimes to avoid causing anxiety about missing lessons and prevented attention being drawn to the collaborators from other pupils and teachers.

Group workshops were flexible and could be adapted into a one-to-one workshop; this was the case for one collaborator Zakia, I had noticed struggling to engage with the group activities. During our one-to-one sessions I offered her the activity as a one-to-one workshop; Zakia was able to fully engage in the activity on a one-to-one basis.

During the group workshops collaborators were free to engage with as much or a little as they wanted to, they could leave when they had had enough (Robic et al., 2014., Cascio et al., 2020). One-to-one workshops were tailored to each collaborators needs, some needed shorter sessions, others required short breaks, some needed to move around or use fiddle toys.

There is a possibility that the collaborators may have co-occurring alexithymia which could mean that they may have difficulty in expressing emotional aspects of their lived experiences during the project, as highlighted by Cascio et al., (2020). Therefore, being able to adapt verbal activities into creative non-verbal activities can be supportive for alexithymics (Van der Kolk et al., 1996). During a one-to-one workshop with Zakia I was aware that she was struggling to engage verbally with some of the questions during the semi-structured interview particularly questions around feelings, because of my awareness interviews were fully adaptable and I offered Zakia the opportunity to draw how she feels and her experiences. Zakia was able to fully engage, she produced several drawings which provided great insight into her experiences. Had the activity not been adapted or had I been unaware of potential differences in verbally expressing emotions, Zakia would not have been able to express her feelings and experiences, demonstrating the importance

of autistic intuition, autistic autism researchers are able to offer when collaborating with other autistic people in autism research.

Informed consent

The collaborators were provided with the information about the project a few weeks in advance, so that they could read independently or with their parents/guardians, this gave time to process the information at their own pace without social, environmental or time pressures. The information was presented in a suitable format tailored to the needs of the collaborators, detailed descriptions about how these resources were developed have been outlined within the methodology section. Presenting the information to ensure that the collaborators were fully informed was an ethical issue. An awareness relating to autistic related barriers such as information processing differences as well as co-occurring conditions such as dyslexia, attention deficit disorder, alexithymia for example, therefore having large amounts of text using abstract language is not beneficial. Presenting the information using straightforward language, next to visual icons offered the collaborators clear information without hidden meanings. Cascio et al., (2020) highlights pairing text with visual supports can be helpful as many autistic people have strong visual skills. Verbal discussions around the project information and regular recaps took place throughout the project.

Right to withdraw

As stated in point 31 in the BERA, (2018:18) guidelines: - *‘Researchers should recognise the right of all participants to withdraw from the research for any or no reason, and at any time, and participants should be informed of this right’.*

This right was explicitly stated within the project information sheet, booklet and the consent forms, the right to withdraw was also stated within the introduction and debrief

meetings. All the resources stated that they had the right to withdraw their data up until it had been included within my thesis and a date was given. This was also reiterated during the introduction and debrief meetings to ensure that all the collaborators consented to the information provided. Two contact methods were provided, directly via my email address or indirectly via the SEN Administrator who was well known and trusted by the collaborators. The girls were given the opportunity to review their one-to-one transcripts and withdraw or amend any information.

Confidentiality/ Anonymity

Each collaborator was given the opportunity to create their own pseudonym that would be unidentifiable to anyone reading the research paper. Identifiable information including the school was dismissed or changed in order to maintain the confidentiality and anonymity of the collaborators. The verbal and written reassurance of confidentiality and anonymity was a continuum throughout the project.

Debrief

Having participated in numerous research studies I understand the importance of debriefing research participants at the end of a study. From personal experience of taking part in autism research; studies where the debrief has been vague or non-existent can cause anxiety and frustration. As an Autistic researcher I ensured that the debrief was well thought about, I designed a debrief sheet for both collaborators and parent/guardians. However, as the project developed, I reflected on BERA, (2018:4) Ethics principles in particular that all social science should aim to maximise benefit. I felt that the collaborators would benefit from an empowering group debrief workshop as well as a debrief sheet, which supported transparency and provided an opportunity to ask questions about the next stages in the project.

Dissemination of Research

Having participated in numerous Autism studies an area which appears to be overlooked by researchers is disseminating the results of the research in a format accessible to the participants. It is unrealistic to assume that all participants will be able to access a thesis or academic journal. From the studies I have personally participated in, only one study, Moseley et al., (2022) kept participants updated about the progress of the research via email and ensured that the participants had access to the final research paper once it was published, along with two videos discussing the results. The first video was a shortened easy to listen too presentation of the research findings, the second video was a more detailed version of the presentation (Moseley, 2022). It has been documented that some research has been detrimental towards the autism community, generating distrust (Askham and Dattaro, 2021). Participants being able to access research that they have taken part in, is fundamentally important in strengthening positive relationships between researchers and the autism community. Bridging the gap between autism research and the autistic community has been highlighted during a number of research conferences I have attended or presented at, with various organisations such as Autistica and PARC actively building bridges between both communities.

Ethical considerations for participatory autism research

In conclusion when conducting participatory autism research, researchers require a slightly different ethical approach.

- Acknowledging and addressing power imbalance
- Consideration in presenting project information and consent forms in an easy-to-read format with the use of visuals not to overwhelm the reader.

- Provide two methods of contact direct and indirect.
- Introduction meeting, to provide an opportunity to clarify information.
- Ask collaborators about their language preferences.
- Consideration of sensory sensitivities and adaptations
- Activities individualised to the collaborators needs, duration, regular breaks, fiddle toys, movement, reduced eye contact.
- Scope for group activities adapted into one-to-one activities for collaborators who prefer one-to-one.
- Awareness of alexithymia and differences in expressing emotions
- Provide copies of transcripts to ensure collaborators consent to what has been written.
- Provision of debrief sheet.
- Empowering debrief workshop, opportunity for clarification on the next stages of the project and providing the participants with the opportunity to feel empowered after taking part within the project.
- Updates on the progress of the project once field work has been completed.
- Disseminating the results of the research in a format accessible to the participants

Chapter 4

Data Presentation

Four autistic girls took part in the project, the girls were asked at the start of the project to think of an alias to protect their anonymity, all the girls choose their own pseudonym which has been used throughout this thesis. The Oracle took part in all the group and individual workshops; however, The Oracle had left the school by the time the debrief and empowerment workshop took place, her contribution has been included. The project was designed to give the autistic girls a voice about their unique educational experiences, it is important that each collaborator's voice is heard with their creative contributions before the data discussion.

Name: Beth

Age: 14

Diagnosis: Autism spectrum condition, combined-type attention deficit hyperactivity disorder, reactive attachment disorder, dyscalculia, dysgraphia, dyslexia

In the first group activity, the girls explored their thoughts and feelings about school, during our one-to-one workshops Beth spoke about her drawings, "I did this rose because I always doodle this in my schoolbooks and I find them kinda relaxing to do erm and that beaker, science beaker because I like doing experiments in science class." Beth continued to explain her contributions to the first group activity during our one-to-one workshop, she added "I wrote school sucks, cos it does, it is not somewhere I want to be, I would rather be at home with my Mum and brother because my brother is at home, and I feel left out that they are at home, and I am not". Beth wrote 'people are mean', during our one-to-one workshop she unpacked why she felt this way. "People just pick on you for no reason they just, my Mum says it is because they

are jealous but that is what all Mums are supposed to say. I don't know but erm it is just that people are horrible to you about your disability and that is what it was like." During the photo activity Beth pulled out a photograph of the art corridor, Beth explained why this photograph was significant, "I hate it cos people are horrible to me down that corridor all the time, I got a whole bottle of energy drink poured down me. It always happens, stuff like that. This morning when I was walking to school a boy called [name deleted] threw rocks at me. You are the first person I have told about that." Beth hadn't told staff about this incident, "I don't care I am used to it".

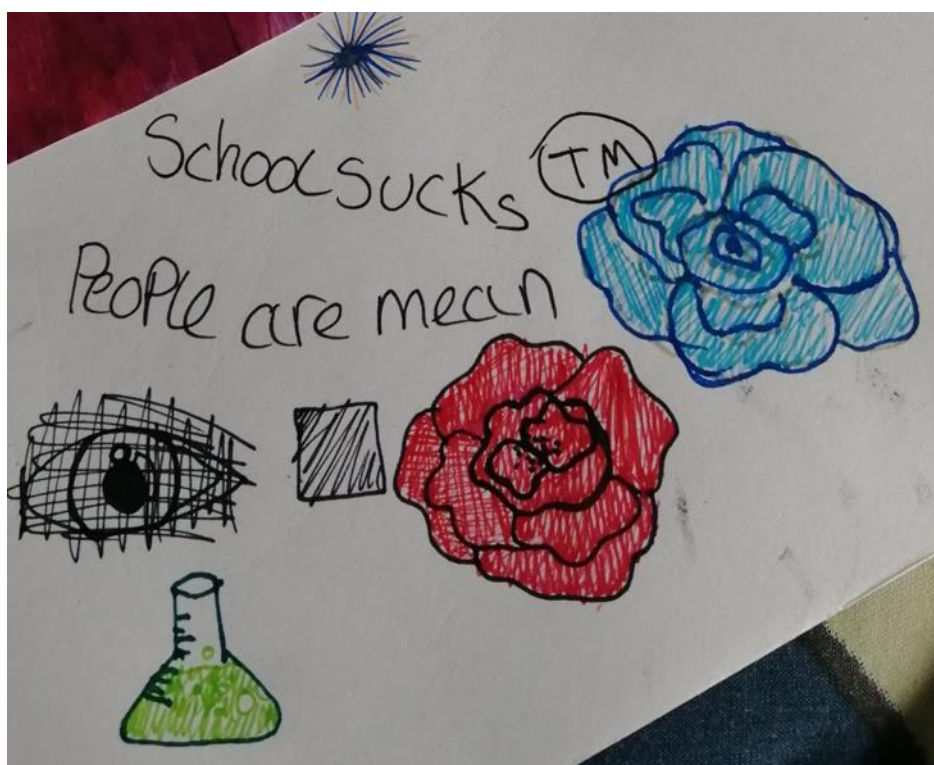


Figure 11 Beth's experiences of school

Beth spoke about having her best friend in the school as a positive aspect of school life. This friendship was important to Beth, describing her friend as, "the first true friend I have ever actually had, we are the opposites of each other, I am more loud, and she is quiet and timid". Beth

explained that they see each other outside of school, they both have different interests, Beth sees this as a positive and why the friendship is so good.

All the Legere Centre staff are of particular importance to Beth, there are three members of staff based within the Legere Centre who Beth will seek out when she needs support. Beth described them as a “second family, they have always been there for me since I started, since day one, since year seven.”

Walking alone or with friends to and from school was Beth’s mode of transport. Beth spoke about her journey home after a school day, “I just sing in my head, I used my brain all day, I just want to have that time when I am not thinking about school”. Beth spoke about how she felt arriving at school in the mornings, “Nothing, I actually don’t feel any emotion, no emotion I guess”. Beth talked what she did to relax after school, “Nothing, just go on my phone I guess, don’t talk to anyone, coz I have had enough of talking to people all day. But my mom calls me anti-social, even though I am constantly telling her that I am always at school talking to people which clearly doesn’t make me anti-social. She [Mom] says that I need to get out of the house more, well I am out of the house every single day of the week and those evenings are for me and my time. I get called lazy”.

Beth spoke about how she felt about exams, “I don’t like doing exams because it is stressful and my brain goes into like a shutdown, where it forgets all the knowledge that I have learnt in lessons so, kind of makes me panic and I end up doing minimum when I really could do more, but I can’t because it is just pressure all the time. Pressure, the quietness, I don’t like quietness, makes me feel all weird, like you can hear my thoughts all together.” Beth described her ideal exam, “for me they would be none”. Beth explained how she would like her achievements to be assessed, “your effort in class, so that all the naughty kids in the class fail.”

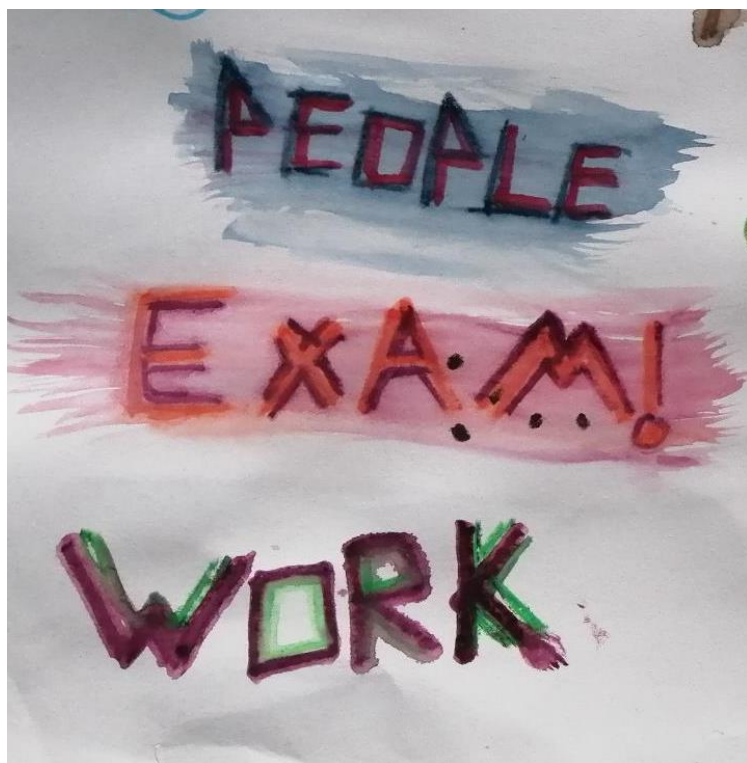


Figure 12 Beth's least favourite part of school life

Beth commented on the solidarity she felt meeting other autistic girls. When looking at some of the photographs taken during the group sessions Beth smiled, “[laughing] I don’t know, just being goofy”. She continued, “It feels relaxing, I feel like I don’t need to put on a front, I don’t need to be someone I am not, just for other people’s eyes, but like [sighs] just myself, just be all myself.” Beth was keen for other autistic people to have positive experiences, “I don’t want them to feel like I felt, I don’t want them to go through that, I want them to have somewhere they can express with other people and not feel judged or classed as weird”. Beth spoke about how would she like to be supported as an autistic female, “I just want people to know that just because I am different doesn’t mean I am stupid or I am weird or stupid, people call me weird and stupid and stuff”.

Beth indicated she had mixed feelings around the pandemic; “At first, I started rough because I was losing focus with everything around my room, but then after a while I started to get used to it and then I started doing more work and then I understood what I was doing.” Beth highlighted some positive aspects of the pandemic, “comfortable, I mean comfortable in my own clothes mostly pyjamas”. Beth continued “there was, there’s no drama, there was just no drama cos no one could really contact you, there is always drama at school, they don’t talk loudly, they don’t be rude or whatever because they don’t get the chance to, I guess, and I like that about the fact that they just keep their mouths quiet”. Beth spoke about experiencing some loneliness during the pandemic and struggling when she return after the pandemic, “No and yes because it felt awkward coming back to school and seeing everyone”. Beth spoke about the people she missed, “yes, teachers yes, students not so much”. Beth spoke about her negative experiences around home-schooling during the pandemic, “not necessarily all the resources you needed for it and support when working to do my work”.

Beth explained her experiences of the post-pandemic restrictions. “Masks make me feel claustrophobic like I couldn’t breathe, and I used to feel that the fact that people were wearing masks that I don’t know what their expressions were like on their faces, and I don’t know if they were pulling faces at me or doing stuff they shouldn’t be behind the mask, and I didn’t like that.”

Name: Zakia

Age: 14

Diagnosis: Autism spectrum condition, attention deficit disorder



Figure 13 Crowds by Zakia

During the first group activity, Zakia drew a picture of a crowded place. In her one-to-one workshop, Zakia spoke about feeling, “stressed and like all over the place really” in crowded spaces in particular corridors. “Erm I am getting a bit better now, but I didn’t really like all the crowded people and all the talking”. Zakia spoke about how the school supported her with transitions between lessons, “I used to go early to go to class, I don’t anymore because I am getting better”. Zakia talked about the noise levels from other students being a challenging aspect of school life, “really hurts my ears quite a lot”.

Listening to music during the journey, to and from school was an important aspect of Zakia’s daily routine. Zakia spoke about why she listened to music on the journey to and from school, “well for some reason it makes to journey from school go quicker and quicker, coz I am

about two or one and a half miles away and it's just, I don't know, I just like listening to it. Sometimes I zone out, but I know where I am going at the same time, and I would be like still walking and there's a certain tree I pass every day. Then I am like at a roundabout, and I am like, how did I get here? [smiling and chuckling] just zone out a little bit". She explained about how she felt walking home from school, "quite tired, and a little bit stressed, because all the popular people walk the same way. They usually stop in a big crowd at a certain point, for some reason it makes me feel stressed".



Figure 14 Journey to school by Zakia

Zakia spoke about her passion for creativity, "I really really like looking at clouds, they are really pretty, when I leave or come to school, I take pictures, a lot of pictures. It inspires me to draw them, coz I really want to paint and draw clouds, like I do it on my works sometimes". Keeping her hands busy by doodling was useful to Zakia during lessons, "I have a little a hello kitty booklet, so I don't start drawing in my [class] books, cos there is no doodling in

workbooks”. Visual stimuli around the school, particularly the display of other student’s creative work was expressed by Zakia as an important feature of her school environment. “I like looking at a lot of art that people have created in the school, and it looks really cool”. Leaving school was one of Zakia’s favourite parts of the school day because, “it means I can get home and do whatever I want”. Zakia talked about her after school routine, “I have a lot of candles at home and every single time when I am walking home because for some reason, I like candles and lighting them, and I just get quite happy because when I get home, I can light the candles and draw something”. Engaging in a variety of creative activities after school is also part of her routine, she prefers to be alone, “coz if I go to my family, they, just I have to do lots of chores and I try to like, go to my room and like hopefully they will forget”.

Another favourite part of the school day is art, “I like it when we have art because I really like art, but I only have it once every fortnight because I have both of the lessons on the same day, so I get excited when we have art because I rarely have it”. Zakia added, “I can improve on different drawing types of art. It makes me feel quite relaxed, like happy”. As well as art Zakia enjoys music lessons, “Whenever we have music, I get excited because like I really like listening to music and trying to make it [pause] and I am starting to play the drums now, I am going drumming lessons on Mondays”.

Zakia spoke about her pandemic experiences, “I actually quite liked it, cos you get to stay at home. It is not very loud; you don’t have to worry about big crowds”. At times she felt overwhelmed, “The homework that you got, cos in the last pandemic I got like 85 homework’s because there were so many classes to do. That homework thing made me quite stressed because I was worried that when we get back to school, I would get a really big detention or something, or they would ask for my work”. Zakia explained how she felt returning to school after the pandemic,

“I don’t know, I just really didn’t like going back to school”. The pandemic restrictions, were, “quite hard”. Zakia spoke about the pandemic social restrictions. “I am not much of a hug person, but no interaction for a long time, I don’t like”.

Zakia indicated that it has been supportive meeting other autistic girls, knowing that others are facing similar situations, “like experience or is experiencing, like not many people wanting to be friends or wanting to talk”. Zakia spoke about finding the creative aspects of the atypical girl’s group enjoyable however, she would have found it easier with autistic girls similar to herself. “It’s just because there are different types of autism, and I am not quite like loud [in audible] it didn’t really help that much.”

Zakia found it easier to draw pictures of her autistic experiences, rather than a verbal interview. She drew a picture of what happens when she has an information overload, depicting information literally falling out of her thoughts. Zakia conveyed through a drawing that she can struggle with her working memory; she recalled an example of this. “Basically, like my stepdad asked me to like er get a lot of things and my mom came in and she was like she won’t remember all that, so I will do it. So, my mom did it and I was like happy”. Zakia drew a picture about her creative experiences, she explained, “well somethings like erm I am not very good at like some creative things but some I am quite good at”.

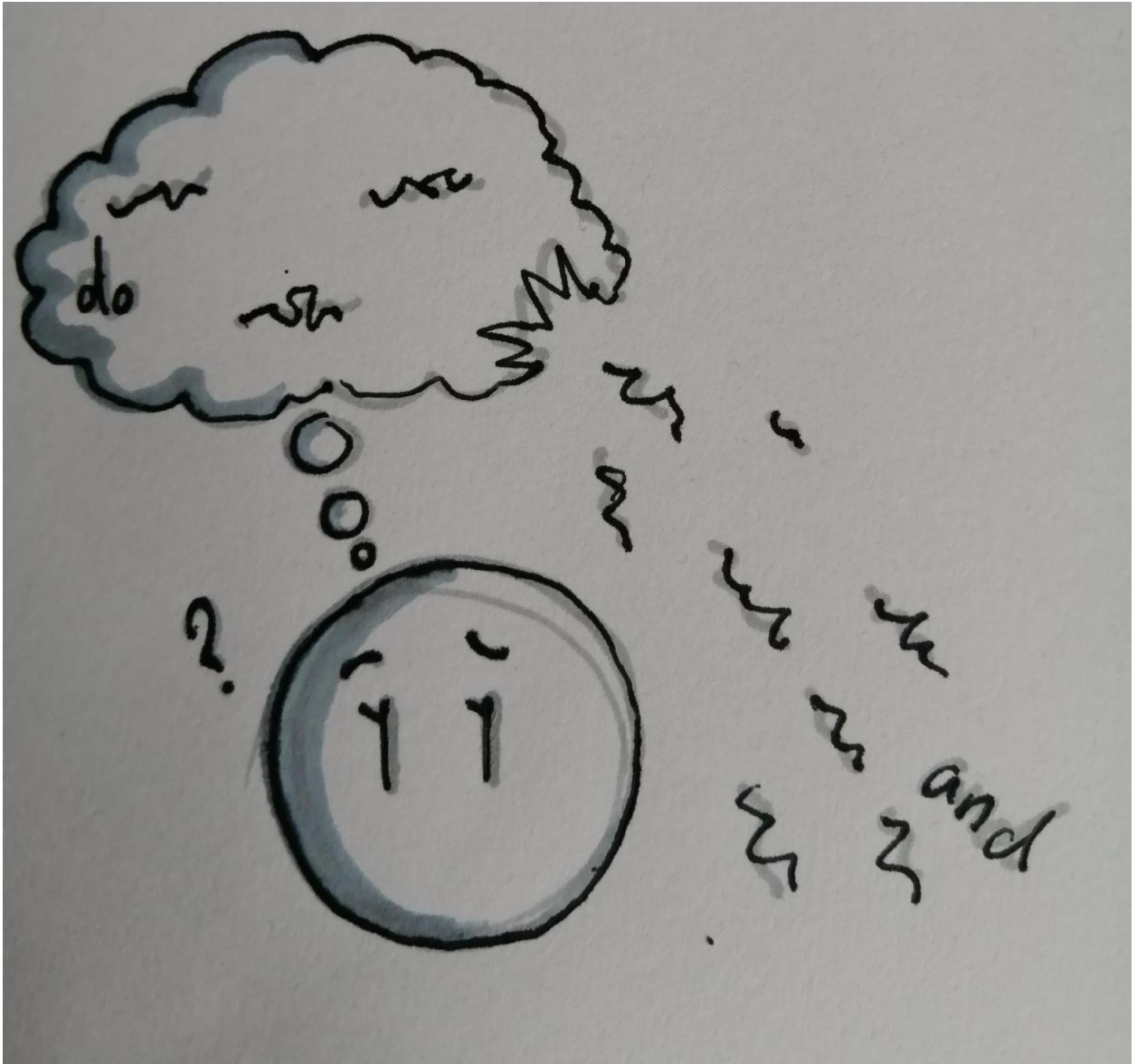


Figure 15 Information Overload by Zakia

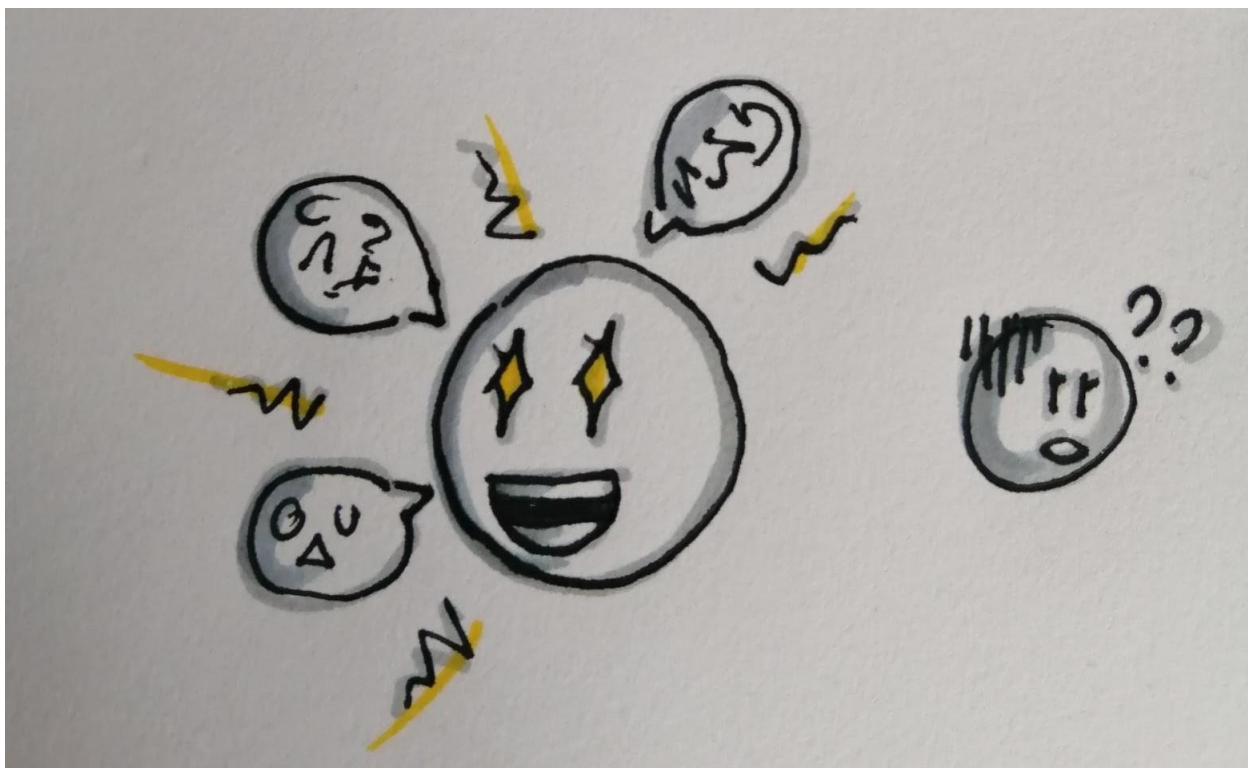


Figure 16 Creativity by Zakia

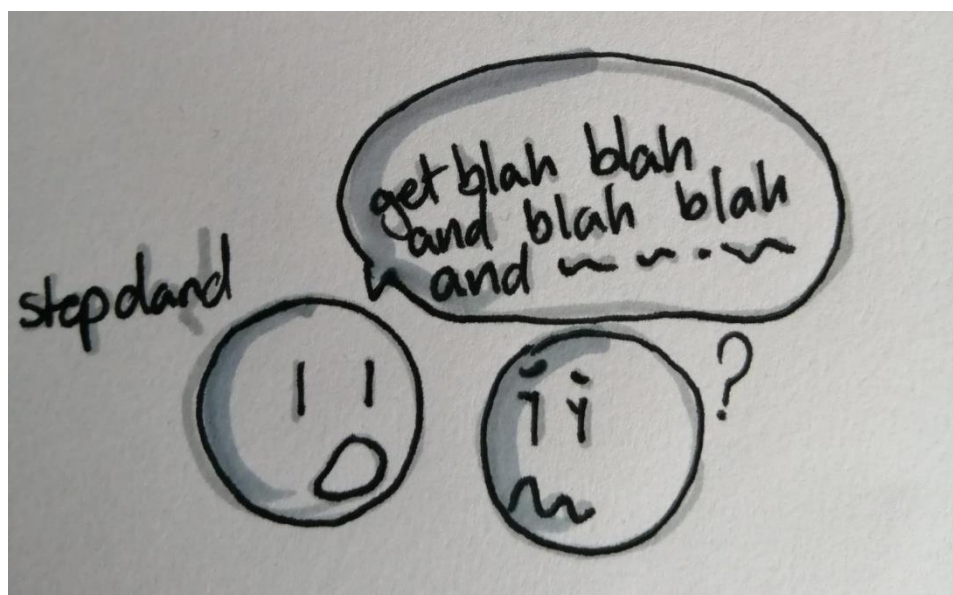


Figure 17 Struggles with my working memory part one by Zakia

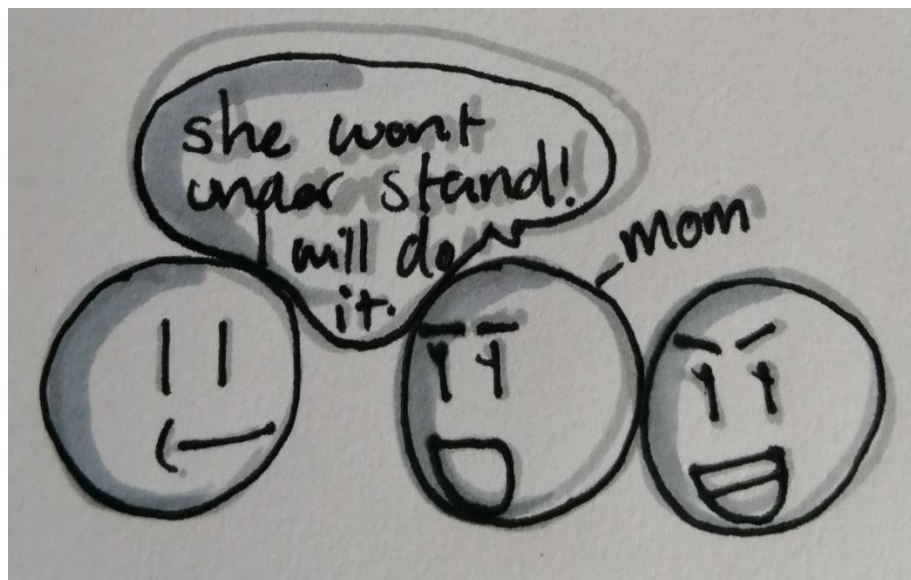


Figure 18 Struggles with my working memory part two by Zakia

Name: Poppy

Age: 12

Diagnosis: Autism spectrum condition, attention deficit hyperactivity disorder, dyscalculia

Poppy spoke about her contributions to the first group activity, “I tried to draw a colourful rose erm because every colour is different, like school every day is different, coz each colour is different so”. During the one-to-one workshops Poppy discussed her passion for music and drama lessons. “I like music because its, you can, when you are in music you can do what you want with it, you can make up the words as you go along and you have a million instruments that you can play, loads of different instruments you can play and erm it is just creative because you can do what you want”. Poppy added, “I love drama because a bit like music you can make up the words as you go along, is if you are doing a script or if you are doing erm acting you can

just think about what you want to say next in your head”. Poppy’s love for drama and music is not confined to school life, Poppy indicated that outside of school she has music and drama lessons. Afterschool on “Thursdays I got piano” and on “Saturdays I do drama. I am a good actress, and I am good at acting and I have managed to get into some really difficult drama camps and clubs.”



Figure 19 Colourful Rose by Poppy

One of Poppy’s favourite parts of the school day is breaktimes. “It is a time to get away from lessons, learning and classrooms and it is just kinda, do what you want and that was fun”.

Poppy explained, “sometimes I go to the library, sometimes I go outside into the playground and speak to people and chat with people and sometimes I may also go to the Support Centre so yeah”. Poppy talked about negative aspects of breaktime, “When I have arguments with people and sometimes breaktime is an opportunity to have arguments with people and that’s the bit I don’t like coz there is like opportunity there. Sometimes I walk away but sometimes there is so much heat in the moment I forget that I should just walk away from that situation, instead I get myself more involved in it”.

Poppy wrote maths as her least favourite part of the school day, “I have dyscalculia, erm I find maths very hard, so I don’t like that”. People with dyscalculia present with a long-standing mathematical impediment (British Dyslexia Association). Poppy continued, “I find math’s very hard. So, I don’t like that, because well I just don’t enjoy math’s, because I don’t understand it, well I will understand it sometimes, not sometimes when I try hard, I don’t understand it. When I try hard, I do understand, but then sometimes it doesn’t matter how hard I try, I just don’t get it! But in the end, I will get it, but it may take a long time for, more than just an hour”.

Poppy spoke about the support she receives in maths lessons, “yeah, I had a teacher [teachers name] and she yeah, I had her through year eight, and she was very kind, and she understood my difficulties. I actually had a one-to-one support anyway, so I have a teacher called [teachers name] who is always in the maths lessons and if she is ill or something, then I may probably go out to the Support Centre to do some maths work in there instead. Cos, I don’t cope very well without her being there or an extra support by my side during maths lessons. So, my teachers are very understanding”.

Poppy spoke about a recent challenge, “a few weeks ago erm one of our maths teachers left and [teachers name] suddenly had to go and leave our lesson with no notice whatsoever! I

did get it explained and she did explain it to me why, but at the same it was a very quick change, and I don't like quick change, I need to know that it is happening ages before it actually happens, usually it can't be on the same day. Usually, I just get stressed there was rumours going around that [teachers name] had left our maths lesson to teach the top set and it was true! And [teachers name] came and spoke to me and she explained to me that she is very upset, but it is true, and it wasn't her fault. But we got put with another maths teacher and it's all just changing at the moment cos I am still getting used to her".

At first the pandemic was a positive for Poppy. "I was quite happy because yay I get to go to school in my pyjamas! Yay I only have to walk about a metre and then I am sitting down at my desk! Erm but and at first, the first week or so I was actually, I was happy! But my parents weren't enjoying it. I started to realise that, and I started to realise that I wanted to go back to school, erm because well first of all my parents didn't let me go to school in my pyjamas anyway".

Poppy spoke about being home-schooled "it was mostly my dad that was home-schooling me, cos my mom was working erm well so was my dad actually". I think lockdown caused quite a lot of arguments for families and stuff, erm but anyway it was difficult because I didn't have professional teachers, it was only my parents that were teaching me and sometimes I just wouldn't get it. Because it doesn't matter how hard I tried I would always get it in the end, but it was just so so difficult because I wouldn't have professionals' teachers who were doing it for a career or getting paid for it. I was used to my parents who were teaching me in-between their work time, which was hard and difficult, and I definitely didn't get anywhere near enough work as I usually did or used to before the lockdown of the school".

Returning to school after the pandemic was mixed for Poppy, “at first, I was a bit upset that I couldn’t walk a centimetre or a metre to my desk even! But then once I was back in school and I saw everyone, I was pretty happy for a while and I was happy back in lessons, but then after a week or so it just went back to normal, normal learning, normal people”. Poppy spoke about struggling with the face masks, “I didn’t like them, I didn’t actually have to wear them anyway. Cos well I tried to wear them for a while, but erm I just didn’t like them and when I was wearing it, I know that this was felt by a lot of people, but I felt like I couldn’t even breathe in them. And I hated them! And I didn’t like them at all! I got a sunflower early on; I got an exemption card for school, and it was all ok, because I didn’t have to wear one. But for the short amount of time, I did have to wear one, I didn’t like it at all! Because erm I just didn’t like the idea of not breathing and even or having a panic attack”. Poppy conveyed her feelings around other people wearing face masks. “Well, I do prefer people being able to see their faces, so that I can see what emotion they are showing. But erm but honestly, I do prefer it like this [no masks] but either way it wouldn’t be the end of the world if we did have to wear a mask because I am exempt. Not to sound mean or anything, but I know I wouldn’t have to wear one because I hate them!”

Social aspects of school life can be, at times challenging for Poppy. Bullying is a particular issue, “there are a few people that aren’t being very nice to me, like constantly, like so in the hall they call me a swear word, or trip me up! Just for fun really and sometimes it is to impress their friends.” “They are just horrible people that aren’t nice to me! Even though sometimes, I don’t understand what I have done to upset them and sometimes I may have not done anything, and it may have just been their personality.” Poppy spoke about the support she receives from the school, “they are supportive but sometimes, they are supportive, and they are

very kind, and they help me a lot, and I am very grateful. Because some people don't get that I think. But at the same time, sometimes I feel like I can't speak to someone about it. Because I will get called a snitch, coz if they find out and even though sometimes teachers may be discreet, they may figure it out for themselves anyway that it was me that told."

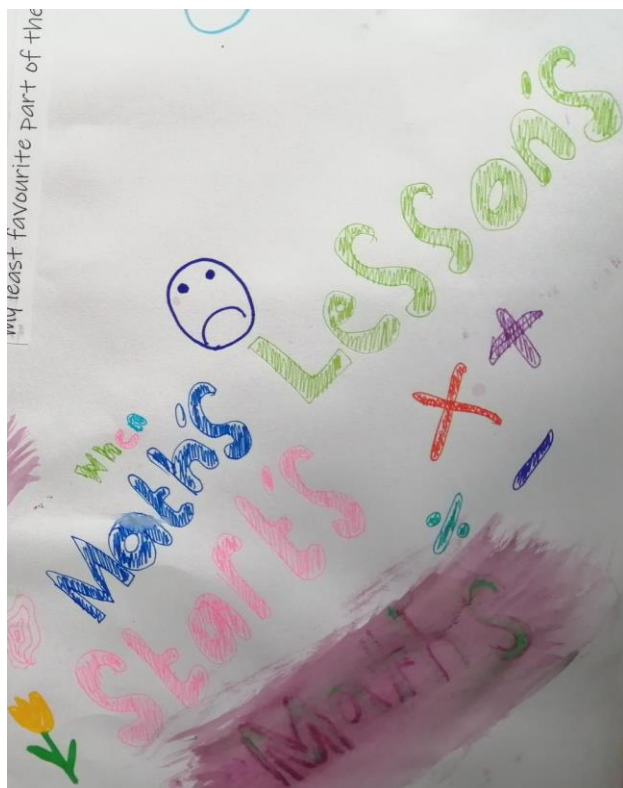


Figure 20 Least favourite part of my school day by Poppy

Poppy spoke about her social experiences outside of school, "I spend time with my family, but erm honestly all my close friends don't go to this school and when I do try to plan things, it can be quite difficult. I have this one friend who probably does a billion clubs a week. She has a million friends; her school is a very competitive school or something. She told me that is she always competing to represent her school and she is very busy. I do try and plan stuff with her, but she is always busy. And I have a few other friends outside of school, again it is just the wrong time, or they are busy, every now or then I will get lucky, and they will say yeah sure let's

hang out. I haven't really got many friends inside of school that could hang out with me." Poppy spoke about her parents encouraging her to interact with other pupils outside of school, "I don't like hanging with people outside of school. I am more, keep myself to myself when it comes to outside of school." That said she indicated that she would like friends who she could regularly meet. "I would prefer to have someone that I can just ring up and play sure let's do that, but in reality, is not like that, people do have plans and people do get busy".

Poppy talked about her journey to school, "like every morning when I get up, most mornings my dad drives me. Coz even though I can walk, it takes quite a while and honestly, if I am completely honest, I am a bit lazy. I don't get up until about 7.30am and I need to be out the house, usually 8.15am. And although that sounds like I have got a lot of time, for me it is hardly any because I get distracted very easily, so probably about 15 minutes is taken up by me getting distracted. So, my dad does drive me to school most days."

Poppy described her afterschool routine, "well sometimes I walk, well on Mondays I have to get picked up because I need to go to my maths tutors. So, after school today, I am probably going to have to walk to the car park by the church or something. So that we can drive to my tutors because she's about 20 minutes away so erm in the car. It takes about 40 minutes walking probably even longer. And then on Tuesdays, again I have erm my counselling session/therapy session or whatever you call it, erm and erm so my mum has to take me again as well. Because I need to go to her and erm but not straight away, but it is at 4 or 4.30pm, I think but I only have like half an hour when I get home to get ready. And my mum knows that if I walk, it will take longer than 30 minutes, and I wouldn't be able to get ready in 10 minutes, so erm that again I have to get picked up. Wednesdays I have erm, I used to have piano now I have it on Thursdays. So sometimes I will walk home and sometimes I will just be like I can't, don't want

to, so I will call my parents and ask if they can come and pick me up. If they can't and too busy with work, I will walk so. Thursdays I walk, because I have my piano lessons on the way home, I go past my piano teacher's house, I literally stop off there and have my piano lesson and then continue walking."

Poppy spoke about her ideal travel preference "Well, it depends if I had someone to talk to as I am walking, I would be happy to walk. If I have no one to walk with or anything I just wanna get picked up and get the walk done and over with or the journey home done and over with. But no one in my year group really walks that way. And kind of, I wish someone walked that way but no one. There is this one [pupil name] you know [pupil name], so she walks the same way I do, but she is usually walks with her other friend and I don't really wanna be around her when she is with her other friend, or she has already gone out of school, and she is too fast for me, and then sometimes she is too slow for me. But yeah, I have walked with her a few times, but erm no one in my year group that I am super close to, or I know that well walks that way so. If someone walked that way, I think I would want to walk almost every day."

Poppy talked about how exams made her feel, "they are boring, they are hard, and I hate silence, I absolutely hate it, erm I need to move around, I can't just sit still in one place for so long!" I asked Poppy how she felt preparing for exams, Poppy said that she feels, "pressured, feeling stressed, angry, upset, erm it makes me feel like the school only wants me to fail, even though they want me to pass." I asked Poppy what would her ideal exam look like, "colourful, bright, happy and they are only for 2 minutes, no 20 seconds!"

Poppy spoke about her experience of the atypical girl's group, "yeah, I mean I didn't even know that some of those people were autistic, yes so that was interesting." I asked Poppy if she was aware of other autistic pupils in the school prior to the project, "I mean I knew a few people

were autistic erm, erm a boy in my side of the year and he is not very nice at all but he is autistic and I know a few people but not many, I think I kind of knew [group member] was autistic coz I see her in the Legere and Support Centre a lot but she says she prefers the Legere Centre to the Support Centre.” Poppy added, “It has been nice to see that there are other autistic pupils, and that I am not the only one with autism in the school”.

Poppy spoke about how she felt being part of a group with other autistic girls, “it has been nice to see that there are other people and that I am not just the only one with autism in the school. I mean I don’t really know in my year group who has autism, which is a bit annoying. Because obviously erm knowing who else has autism in my year group so I can maybe even speak to them or talk to them. But it still has been very nice, it’s just nice to know, coz obviously I know there’s a lot of kids who are autistic in this school. I can’t remember, [teachers name] told me how many kids are autistic in this school, but I can’t remember how many she said now. But erm I know that it is a lot, but then sometimes when you are around people who do have autism in this school, it kind of makes you realise that she was right, and it is true.”

Poppy described what she would like support for autistic girls to look like, “So, it is nice to know that you have someone to talk too, erm so that’s quite important actually, and to just know that someone will, erm be there when it comes to arguments or something, erm to someone with autism.”

Poppy spoke about what her autism means to her, “the best thing about my autism is that it’s unique, different and it not in like a bad kind of way like the special treatment kind of way, but it just makes me feel special. But not as like I want special treatment, or extra attention, or anything, coz well I do kind of. Because I want people to know I have autism, but only people who would understand.” She expressed some of her challenges, “sometimes I don’t like it,

because I just think, why did I get so mad at that? I hate this! because sometimes when I've had arguments with my mum, or dad, or friends, and I look back and think why did I do that? why did I say that? erm and I think, I can't blame my autism on all of it. But I think that obviously, my autism does have something to do with it, obviously and I do not like the fact that sometimes I just feel like it is controlling me."

Name: The Oracle

Age: 14

Diagnosis: Autism spectrum condition

In the first activity The Oracle wrote an abbreviation of the book title she had been writing, "Me and my friend, but she ran away from me, so I don't think she is my friend anymore. But erm we have done one book that has 15000 words, and we have a second book that we are just making at the moment that has got about 8000 words, and they are both coming along quite well". In our one-to-one workshop The Oracle spoke in depth about the book she had been co-writing, "I have no idea what to do in this part of the story because what happened is, so if I write a certain bit of it, there will be another section underneath it, the other chapter which she [friend] is doing and I have got to work with such things. Like the following day, so she [friend] does one that say the following day they do blah blah blah, I would have to end it with like and they went to sleep. It has to work for each other, so we have to work as a team to do it, now she hasn't done it for quite a while since like the 3rd of march or the 4th of march or something erm but yeah but I always, sometimes you don't know what you are going to do, and you just think we'll look at their chapter something interesting is going to happen." The Oracle continued, "I

don't really know because she has decided to run away from me and she heard this thing about me, apparently being a racist and then she just left me. But it is not true."

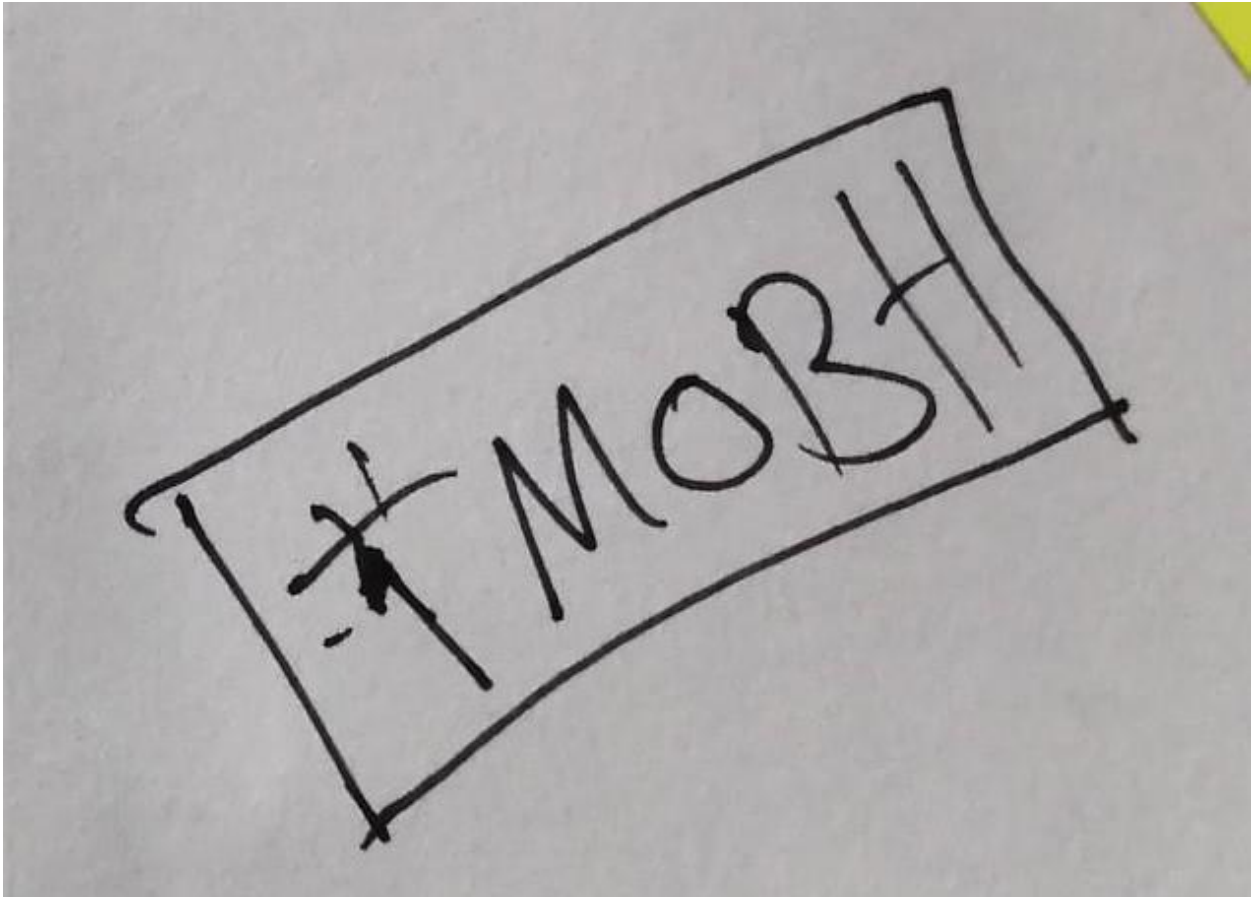


Figure 21 Abbreviation of the book The Oracle is writing.

The Oracle spoke about her passion for drama, "I dunno, I just really like it coz I think, I am not sure what it is about, I just find it is like really interesting and fun and it is just like something I want to continue doing for like all my life, I really enjoy it. Erm, I think the reason I enjoy it, is because just like pretending to be something that I am not and then just being able to act out things just being able to be like get this act done, oh that is perfect acting, I just love it all I can relate to that". She added, "I can express the emotions that I actually feel for other students, like their emotions, and when the teacher says you should not be saying that; I am just like no miss, it is an act, I am acting".

In the activity titled My least favourite part of the school day, The Oracle wrote ‘bullies’, she spoke about how bullying made her feel “sad and annoyed and kind of like I want to smack them around their face but no I can’t coz then like I will get in trouble so.” The Oracle expanded “I don’t like the maths, coz I sit opposite most of the people that happen to be the bullies and happen to be the people who are the problem.” The Oracle spoke about how the bullying impacts her school life, “I like break and lunch time usually, but where we go because of the bullies again, they are just always there. Sometimes just go and hide next to drama, or erm where no one can see me.” The Oracle continued, “I do not know, really mostly just the constant fear of people saying things, or spotting me, and they are like, oh look there she is being attacked for like the fourth time.”

The Oracle spoke about how she felt about exams, “well, if I am honest, I would rather do an entire day of exams than an entire day of schoolwork. I genuinely find exams, if it means that you get to miss a lesson that it’s fine.” The Oracle explained her exam condition preference, “not with a bunch of other people, if it was just like me in the Support Centre sitting a test.” The Oracle spoke about her experience of sitting an exam in a room alone, “Yeah, it was much better, like if I was in this room without you no offence, if I was just in here to do the test, I would probably be fine. I don’t know, because there is not so many people, that I feel like I need to be quick because I might be holding them up. Or I don’t feel like erm, when I am on my own I kind of want to do it by myself. Coz, I don’t know I just prefer doing it by myself, because then I can just fidget, and do whatever I need to do, and there is no one there to say oh you can’t do that. Erm or can you be quite please you are being too loud; I can probably talk to myself and say ok what I need to do here is three times ninety-four thousand.” The Oracle added, “I just prefer doing tests because it is more quiet and we don’t have to do loads of work, you are writing at

your own pace and stuff. You don't have to copy things down from the board, you can just look at it and answer it. Then you can skip and go back, and it is not as stressful, got to do it in the moment, I can always go back and take my time."

The Oracle unpacked why she preferred doing tests, "I just do not like being in the mainstream version of this school. I am not in mainstream part of this school at the moment, I am based in the Support Centre all day." The Oracle spoke about her feelings towards school, "this is my non ideal school [referring to the school she is currently at]". The Oracle explained that she wanted to be supported by the school by, "not go back into the mainstream part of this school, thinking about it, having me put back into the mainstream part of this school, I really don't want to do that."

The Oracle described finding the atypical girl's group supportive. "I feel like I have actually found some people who are like me, and I have found it like exciting almost, like guess what I get to do next". The Oracle had become friends outside of the group with a group member, "I think it is good, because it is like someone else who has also got like autism, someone that I can literally just go to with stuff. And like its coz I find like with the fake friends, you know if they are fake or real. Well, I can't actually say that, because the person I was talking about earlier, erm they gave me hugs and stuff, but then they ended up being completely fake and horrible! erm but like this person [group member] I can always go up to them and hug, or they will surprise me from behind, and quickly give me a hug, and be like 'hi'! We see each other and stuff, like we are really good friends."

The Oracle spoke about The Support Centre, "really quiet and loads of people down here, that might not necessarily have autism, but maybe anxiety, or OCD, or whatever, or genuinely just want to come down here. So, I just sit there at the computer around all of them, and the

teachers down here are quite soft most of the time. They are not like, right you have two minutes until you have to go back to your lesson. They are like, stay for as long as you need”.

The Oracle described how she felt being home-schooled during the pandemic, “that was brilliant that was! So much better than being at school.” Although it was a positive experience The Oracle reported some frustrations with online lessons, “Wi-Fi, the network problems just the fact that you couldn’t actually see anyone. I mean there was no one for me to really see online. There was one person from my old form who pretended that she had been hacked. She kept playing this loud weird music erm out loud to everyone. And she joined on another account, and she said sorry someone has hacked into my account, but it was obviously her. Then there were times when the register would be taken and their names was being called, they are logged into the zoom call, but they are not actually there it was like, what is really the point of being here? But I really liked doing the home school thing.”

The Oracle spoke about a peer being rude to her during an online lesson, “my dad coz he is a police officer, and he was right there, and he heard what people said [referring to online lessons] and he came into my room at that exact moment, when someone from my old form decided to say let’s kick me, erm let’s get rid of her, she is really annoying and stuff. My Dad literally said, ‘if you have a problem with my daughter, you can come and say it to our face because you are just a rude young man.’ And whatever this guy went silent, and everyone worked silent for like a solid two minutes. Then a teacher said, coz it was like this thing at the end of the school day, we just played among us, games online. Teacher was like is your dad, ok? are you ok? This guy was speechless, and he didn’t say anything for quite a long time, and then he was mean the next lesson obviously, but he didn’t dare properly speak out after that. And everyone was laughing about it, saying oh you just got told off by her dad.”

The Oracle Explained, “I can’t lie, I never actually got much work done, like I got some of it. But then it comes to lunchtime, and I would genuinely just wait for my Mum to bring me up a big snack plate, with like all of these different foods on. I would just sit there watching TV, then at the end of lunchtime, go back on and I would do like a quarter of my work. When I knew that my Mum wasn’t coming up and checking on me, I would just play games and then I would go back on to the work, and kind of do a little bit, like two out of five lessons, well three out of five really”.

The Oracle reported not wanting to return to school after the pandemic. “I really just couldn’t be bothered, you know. It was just like why do we have to come back? Can’t we just like never go back to school again? and like never do home school or just never do anything?”. The Oracle expressed her views on face masks, “I didn’t feel it was fair in some ways, coz people were like oh yeah, I have a broken ankle, I can’t wear a mask if you know what I mean. Unless you have something like asthma, but I don’t really see why people with asthma, don’t have to wear masks, it is ok, coz I kind of understand, coz it might make it harder to breathe, but like it just kind of really annoys me. I feel like it should be like, everyone has to wear a mask, or no one wears a mask. Or there is certain days of the week that one side of the year has to wear a mask, and the other days the other side has to wear a mask, or something like that. Just make it a bit more fair for everyone”.

The Oracle conveyed her feelings about being autistic, “I feel quite important being able to use it, I feel quite entitled having autism. I dunno, not entitled sorry, quite special”. The Oracle spoke about having an official diagnosis was helpful, “I like being able to say, like have that thought, where I know that I might be safe in different places, because there is more people looking out for me, because of my autism. And I know that there are actually people thinking, ok

erm we have got to keep a closer eye on her, and make sure that there is nothing going on like, bullying wise and stuff?.

Chapter 5

Findings and Discussion

Due to the number of themes and subthemes, it was felt that the best and most effective way to present the findings and discussion, without confusing the reader was to present them combined in one chapter.

As outlined in the methodology section the audio recordings from the workshops were transcribed verbatim, descriptive coding was applied and preliminary themes started to emerge. The preliminary themes were reflected on, alongside the research question which supported refinement of the themes. Four overarching themes were identified, from each theme subthemes emerged, this was reflected within a colour coded diagram.

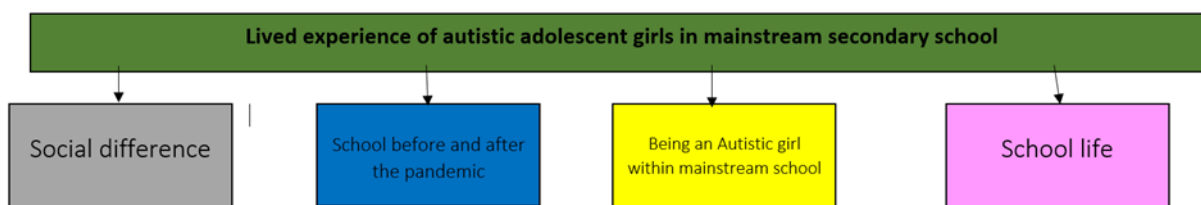


Figure 22 Overarching themes.

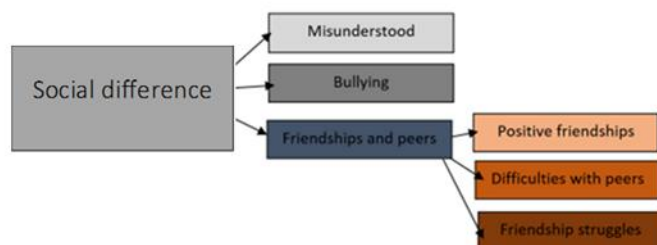
Social difference

Figure 23 Social difference; subthemes

All the girls spoke about the importance of friendships; Zakia spoke about feeling supported by her friendships which enabled her to get through the school day, when she struggles because of crowds or noise, she is able to cope because she has her friends. The Oracle said, “The most important thing is to have friends”. This is consistent with previous research (Calder et al., 2012; Cook et al., 2017; Daniel & Billingsley, 2010; Sedgewick et al., 2015; O’Connor et al., 2022) in addition these findings continue to challenge the conjecture that autistic people are uninterested in friendships (Cresswell et al., 2019). However, the collaborators spoke about the social difficulties they have within the mainstream part of the school, they described struggling to read other students intentions, stressors around conflicts with peers, feeling rejected and not knowing who to trust.

Research has demonstrated that an autistic person’s approach to social interaction is different to a neurotypical person’s approach, the importance being on the word ‘different’ not wrong or in need of intervention, however due to damaging past research which suggested that autistic people have deficient social skills. (Milton, 2012; Mendelson et al., 2016; Mitchell et al., 2021). Beth reported feeling misunderstood by her peers leading to her believing that she is hated by, “most people in the school”. This has been reflected in previous research (O’Connor et al., 2022; Goodall & MacKenzie, 2019). The Oracle reported that she knows her peers within the mainstream part of the school dislike her, she starts school later and finishes earlier so she can avoid them. Avoidance, masking, and imitation have been highlighted in previous research as coping strategies used by autistic females (Tierney et al., 2016; Goodall & MacKenzie; 2019).

During, the group workshops all of the girls agreed that their peers needed more awareness around autism, the girls were keen for their peers to understand them. However, the

girls were also cautious with how autism awareness could be implemented, due to fear of judgement and further ramifications.

Discussions around navigating friendships took place within the group sessions and in the one-to-one workshops. Two of the girls disclosed that they preferred to socialise outside of school with other friends who did not go to the school. Poppy explained “I keep myself to myself outside of school.” However due to her non-school friends’ other commitments she was often left alone, “I would prefer to have someone to hang out with outside of school, but it is not like that in reality.” Poppy reported her dad encourages her to go out and socialise with her friends, but she said there is “no point my friends are too busy.” Some studies suggest that loneliness can be the result of being misunderstood and negatively judged (Jobe & Williams White, 2007; Tierney et al., 2016).

The Oracle spoke about hanging out after school or at weekends with her two best friends who go to different schools. These friendships are very important to her, perhaps the absence of the social complexities attending the same school, enables the friendships to flourish. This was presented and as an important part of her school ethos, within the ideal school exercise. This is consistent with other research, reporting that autistic girls consider friendships as important, positive, and rewarding (Vine Foggo & Webster, 2017; O’Connor et al., 2022). The Oracle described that she had developed a good friendship with group member Beth. Both of the girls spend a lot of time in The Support centre, since becoming group members and being aware of each other’s autism diagnosis’ they get on really well. The Oracle explained that having a mutual understanding of autistic related experiences has nurtured a positive and supportive friendship between them.

Beth reported that she has one really good friend at the school and this friendship means a lot to her. Beth spoke about how her friend is a “true friend” and although they don’t have the same interests, they have plenty to talk about because they learn from each other’s different interests. This has been reflected in previous research, which suggests that some autistic people seek friendships not necessarily based on having the same interests (Vine Foggo & Webster, 2017; Seifert et al., 2000).

Zakia took a photograph of an area of the school which was important to her during the activity. In the follow up one-to-one session, Zakia explained that the area was where she hangs out with her friends. Zakia spoke about how she has good memories with her friends in this area and it was very significant to her.

Meeting other autistic girls appeared to provide positive social experiences and friendships. Beth spoke about her experiences of the group, “I feel like I don’t need to put on a front, I don’t need to be someone I am not, just for other people’s eyes, but like [sighs] just myself, just be all myself”. Zakia spoke about it being helpful meeting other autistic girls who are experiencing similar situations. Poppy reported meeting other autistic girls was a positive experience, “It has been nice to see that there are other autistic pupils, and that I am not the only one with autism in the school”. The Oracle spoke about her experiences of taking part in the autistic girl’s group and becoming friends with one of the group members, “I feel like I have actually found some people who are like me”. Quality friendships have been reported to support healthy mental health for autistic and neurotypical children (O’Connor et al., 2022).

Throughout the workshops with the girls, bullying was raised by three of the collaborators. Beth gave an account of how she hated the art corridor, she said, “students are horrible to me down that corridor all the time”. Beth recalled other students poured a drink over

her in the art corridor, she also disclosed that another pupil had ‘thrown rocks at her on the way to school’. During our interviews Beth tried to brush off the hurt caused by such incidents, “it always happens, stuff like that”. When I asked if she would like to tell someone Beth replied “no, I don’t care I am used to it”. This has been reflected in previous research whereby some autistic pupils report that they do not report bullying due to lack of intervention (Humphrey & Symes, 2010, Humphrey & Hebron, 2014). Beth described, “students being mean is mostly the case all the time”. She reported that students were, “horrible about your disability”. Within the workshops the girls raised that some students use ‘autism’ as a curse or insult towards others. Negative judgements from peers in relation to autism, resulting in social isolation has been highlighted in previous research (Goodall & MacKenzie, 2018; Sproston et al., 2017).

Poppy reported that there were, “a few people who are constantly not nice”. She gave accounts of being sworn at and tripped up. Poppy didn’t understand why these particular students were always mean to her. Poppy disclosed that, “I can’t speak to someone because I will be called a snitch. Teachers try to be discreet, but the bullies figure out who told”. Fear of being labelled a ‘snitch’ was spoken about by other collaborators.

A ‘snitch’ is a word used to describe someone who has informed on someone else (Cambridge Dictionary). During the one-to-one sessions the girls reported feeling unable to disclose friendship difficulties or even bullying because of fear of being labelled a snitch, which would inevitably cause more conflict. Poppy gave an account when peers were hostile towards her labelling her as a snitch when she had not informed on them. This led to crippling anxiety and distress, Poppy did not want to attend school, her parents were very supportive in assisting Poppy to speak with a teacher to resolve the matter and Poppy reported it was dealt with and she felt much better.

The Oracle spoke about bullying being the biggest issue with school. She reported being in constant fear of other students saying things about her, spreading rumours or being spotted and attacked. The Oracle conveyed how much she liked break and lunch times; however, this was often overshadowed by her not wanting to go outside because of fear of being called names. She spent most of her time hiding from the bullies in various different parts of the school. The Oracle expressed that The Support Centre was a safe place away from the bullies. Throughout the project Beth and The Oracle talked about how The Support Centre was a place of comfort and safety, almost a sanctuary for the girls to retreat to if, mainstream school got too much. The Oracle described that bullying made her feel sad and annoyed and she wanted to lash out but can't. She recounted that the school used to be supportive, but recently she hasn't felt very supported. Research highlights pupils within secondary education feel that schools are not tackling bullying. (Holden et al., 2020). However, it was unclear as to whether the school were aware of what was actually happening as The Oracle spoke about her fear of being labelled a 'snitch'. The Oracle reported that she struggled with some of her lessons because she, "sits opposite to the bullies and being in the same room as the bullies is hard".

Beth, Poppy, and The Oracle all reported bullying as an ongoing issue within school life. These findings are supported by wider research which reports, autistic pupils within secondary education are particularly vulnerable to bullying, than other groups (Humphrey & Hebron, 2014, Kloosterman et al., 2013). The wider research paradigm highlights the negative impact bullying has on autistic children as well as the significant impact on their mental health, including a higher risk of suicidal ideation and attempts (Barnhill and Myles, 2001; Humphrey and Lewis, 2008; Humphrey & Hebron, 2014; Hebron, 2012; Mayes et al., 2013; Holden et al., 2020). In addition, autistic females are more likely to die by suicide than autistic men. (Hirvikoski et al.,

2016; Kirby et al., 2019, Holden et al., 2020). These findings are concerning, and certainly raises questions about whether mainstream schools are doing enough to address these issues. Further exploration is required into addressing autistic children and young people’s vulnerability to bullying within mainstream education.

School before and after the Pandemic

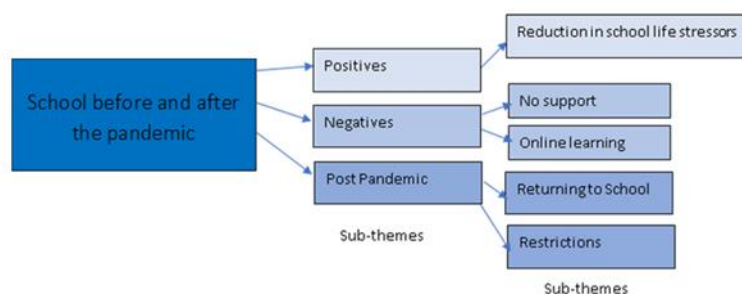


Figure 24 School before and after the Pandemic; subthemes

Initially the girls reported that the pandemic was brilliant, they all enjoyed being home-schooled. This is a slightly different finding compared to Heyworth et al., (2021) where it was reported that initially autistic children and young people found the abrupt transition to schooling at home challenging. However, what is consistent is that a number of parents of autistic children and young people reported once they had adjusted to schooling at home this became a positive experience for them (Heyworth et al., 2021). Beth and Zakia spoke about how home-schooling reduced the sensory bombardment they encounter at school. Beth enjoyed wearing comfortable clothes, such as her pyjamas during home-schooling. Zakia didn’t worry about crowds and the noisy school environment. It has been well reported that mainstream educational settings, particularly secondary school can be a traumatic for autistic children and young people, due to the sensory impact of the educational environment as well as the social demands (Symes and Humphrey 2011; Humphrey & Lewis 2008; Moore 2007; Heyworth et al., 2021; Anderson,

2020; Ashburner et al., 2008). Findings made by Heyworth et al., (2021) are consistent with findings presented here, home-schooling minimised sensory and social overload. What is interesting is that a growing number of parents are deciding to home-school their autistic children, due to the absence of understanding from teaching staff in relation to the negative sensory impact the educational environment has on autistic pupils, as well as neurotypical demands and expectations placed on autistic pupils, resulting in negative repercussions if they do not conform. (O'Hagan et al., 2021).

Beth reported needing to adjust to online learning resulting in losing focus, once she understood the process and adjusted, she regained focus and was able to complete more schoolwork. However, the collaborators spoke about feeling lonely at times during the pandemic and that they missed their friends or teachers, although Beth reported not having contact with peers was beneficial because it meant no conflict. Zakia talked about enjoying the pandemic however after a while it became challenging, "I am not much of a hug person, but no interaction for a long time, I don't like". Some autistic children and young people struggled with the isolation of the pandemic which has been reflected other research (Oliver et al., 2021).

Not having to get ready for school was reported to be a positive aspect of home-schooling, along with the elimination of traveling to and from school, it appears that this reduced stress levels and executive functioning demands for the girls. In a study by Heyworth et al., (2021) it was reported by autistic children, young people, and their parents that home-schooling brought flexibility as well as being able to tailor learning to their needs. The girls reported enjoying break and lunchtimes better during home-schooling, perhaps this was because of the absence of the social stressors of school life. The girls reported engaging in a variety of activities during break and lunchtime, such as watching TV, playing computer games, sitting in the garden

and some would do additional work during their breaks. Consistent with Heyworth et al., (2021) who reported flexibility within breaktimes during home-schooling was a benefit.

The Oracle described home-schooling as better than actual school, although she did very little schoolwork. The Oracle reported struggling with online learning, other students being disruptive during lessons, problems with WIFI and some students only attending registration and not the rest of the lesson was frustrating; Heyworth et al., (2021) echoed some of these findings. The Oracle spoke about despite lessons being online she was still treated badly by her peers which resulted in her father having to intervene.

Poppy reported enjoying the pandemic at first; however, the stressors of her parents juggling work commitments and home-schooling caused tension within family life, resulting in Poppy wanting to return to school. Emerging research has highlighted that the pandemic disproportionately impacted autistic children and young people (Organisation for Economic Co-operation & Development [OECD], 2020; Pellicano & Stears, 2020; Heyworth et al., 2021). Poppy, Zakia and Beth described how not having the professional support and resources they would normally get when at school, to help them learn was very challenging. Zakia and Poppy experienced anxiety because they struggled to understand some of their schoolwork despite the support from their parents, resulting in being unable to complete. Similar reports have been echoed within a number of studies (Heyworth et al., 2021; Oliver et al., 2021; Genova et al., 2021). Zakia spoke about fearing getting in trouble or been given a detention when she returned to school for not completing the work.

All the collaborators spoke about the positives and negatives of returning to school post-pandemic. Beth said it was awkward, but she felt refreshed and that there was less fighting and bickering. Poppy describe being happy to return to school but upset she had to travel. The Oracle

said she couldn't be bothered and Zakia reported returning to school was ok but struggled not being able to have physical contact with her friends due to the post-pandemic restrictions. This is consistent with other studies which have highlighted that autistic children, young people and parents reported a mixture of positive and negative experiences returning to school post-pandemic (Oliver et al., 2021; Genova et al., 2021; Code et al., 2022).

All of the girls reported struggling with the post-pandemic restrictions, Beth found wearing masks weird as it made her feel uncomfortable. She struggled with other's wearing masks as she couldn't see their facial expressions. Three of the girls had to wear a mask during the post-pandemic restrictions, one of the girls was face mask exempt. Poppy spoke about how distressing masks were, she had attempted to wear one however this resulted in a panic attack, she applied for a Sunflower lanyard which meant she was exempt from having to wear a mask at school. Some autistic people experience sensory alterations (Kohn, 2007; Puts et al., 2014), this could impact their ability to wear a face mask. The Oracle didn't mind wearing a mask however the warm weather made it difficult, she found it unfair that some people were exempt. She felt that some people took advantage of the exemption and that there should be one rule for everyone. The Oracle felt it was unfair that teachers were allowed to remove their masks during lessons. Pupils were only allowed to remove their masks when they were outside during break and lunchtimes, however this was problematic for The Oracle because she struggled to go outside due to fear of being bullied, she disliked the one-way systems as they were boring. Zakia didn't mind the masks although sometimes it was hard to breathe, and she did struggle with the one-way system. The girls reported an assortment of feelings towards the pandemic and after the pandemic, this is consistent with the current research which paints a mixed picture of positive

and negative experiences, some autistic children benefited while others struggled (Oliver et al., 2021; Genova et al., 2021; Heyworth et al., 2021).

Being an Autistic girl within mainstream school

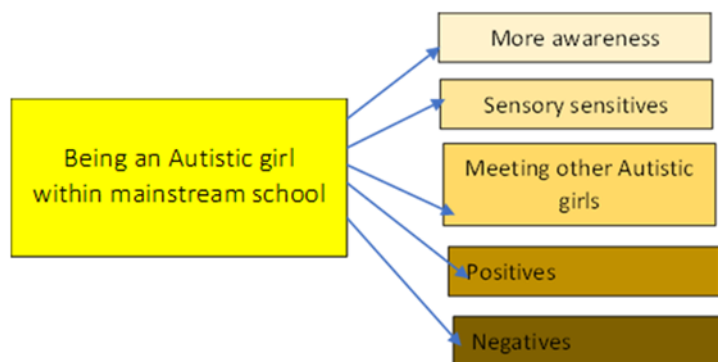


Figure 25 Being and Autistic girl within mainstream school; subthemes.

The girls reported their experiences of school life as autistic pupils. All the girls advocated for more autism awareness for students and staff. Beth spoke about challenging the stigma and stereotypes and for autistic people, “Not feel judged or classed as weird, I want others to understand autism is different not weird or stupid, want people to know words hurt.” Some of the girls applied negative words when describing themselves such as “weird” or “hated”, it appears that some of the girls were internalising the negative stigma associated with autism, this has been reported in previous research (Botha et al., 2020, p. 10). Beth spoke about her experience of stigma; she was keen to advocate a change in narrative, “Don’t want other autistic people to feel the way I felt”, at times Beth spoke positively about her autism, in contrast it was clear that the negative stereotypes and stigmas had an impact on her. Research has highlighted that the stereotypes, and stigmas associated with autism may impact on autistic people’s ability to feel good (den Houting et al., 2021).

During the one-to-one sessions I asked each girl how she would like to be supported as an autistic female in school. Beth, Poppy, and The Oracle advocated more awareness around autism in the form of an assembly for students and teachers. Each girl reported feeling that their autism was not always understood by others. For The Oracle and Beth, this led them to believe that they were not liked by their peers, Beth cited that ‘people are mean’. They were all keen for others to understand what autism actually is, challenging the stereotypes and stigma. This is in line with previous research which suggests autistic people are conscious of societal intolerance in relation to their authentic autistic selves (Han et al., 2021). There was suggestions around celebrating autistic difference and empowerment. Some of the girls were happy for others to know of their autism diagnosis, “but not everyone” or “only people who will understand”. Research has highlighted disclosure and self-advocacy could be beneficial, but it could also result in further stigmatisation (Sasson et al., 2017).

The girls gave multiple accounts of ‘autism’ being used by their peers as an insult or a curse word provoking feelings of rejection, shame, and disempowerment. The girls felt very strongly about this, “Autism shouldn’t be used as an insult”. The detrimental impact of stigmatisation on autistic people has been recognised within previous research (Botha et al., 2020; Drummond, 2013; Humphrey & Lewis, 2008; Leedham et al., 2020; Punshon et al., 2009). It became apparent that the girls wanted to fully embrace their autism but, at the same time they were in conflict with it as an identity, because of not feeling understood or liked. Research suggests some autistic adolescents struggle to align their autistic identity as positive (Sasson et al., 2017). From previous research we know that stigma and negative stereotypes can impact autistic people’s mental health (Bagatell, 2007; Leedham et al., 2020; Punshon et al., 2009), how

to address the stigma associated with autism within educational settings requires further exploration.

The girls reported prior to the research project they were not really aware of other autistic girls within the school. “I actually didn’t know that any of them did”- The Oracle. “I didn’t even know that some of those people were autistic, yes so that was interesting”- Poppy. She continued to explain, “[teacher] told me how many kids are autistic in this school, but I can’t remember how many she said now, but erm I know that it is a lot, but then sometimes when you are around people who do have autism in this school, it kind of makes you realise that she was right, and it is true.”- Poppy.

During the project it became apparent that the girls were benefiting from the group workshops, as well as engaging with the activities the girls were interacting with each other. This was an unexpected find; in the one-to-one workshops I asked each girl about how they found being a part of a group of other autistic girls. The girls reported that the group had given them a sense of belonging, they enjoyed meeting other autistic girls and spending time together. The girls reported that they found the collaboration exciting, supportive, and enjoyable, being part of the group meant a lot to the girls because they, “found people who are like me”- The Oracle. “It has made me feel included in something about autism”- Poppy. “It feels relaxing, I feel like I don’t need to put on a front”- Beth. Although Zakia enjoyed being part of the group and taking part in the creative activities, she conveyed, “it’s just because there are different types of autism, and I am not quite like loud [in audible] it didn’t really help that much.” She added that meeting others who are going through similar struggles was helpful.

Beth summed up her feelings about the group in a collage done within a group workshop, “This collage is us messing around. It’s us being us, no filter, just being ourselves. We were

being goofy in this one, autistic people can be fun.” From the feedback given it appears that autistic girls interacting with one another was a benefit. This is consistent with emerging research which reports autistic people are able to effectively interact and socialise with other autistic people, promoting their wellbeing (Crompton et al., 2020; Sinclair, J., 2010). We know that autistic girls tend to ‘mask’ as a way to blend into societies social demands (Halsall et al., 2021), it could be suggested that the group provided a safe place for the girls to, ‘take off the mask’ because they felt understood, the desire for autistic people to be their authentic selves was highlighted in a previous study (Han et al., 2021). All the girls expressed an interest in the group continuing after the project, Zakia spoke about having a creative group with autistic girls similar to herself would be helpful. This is also an important point; all autistic people are unique thus not all autistic people will get along.

As highlighted above this was an unexpected find however, it supports previous research, Macmillan et al., (2018) found that autistic adults reported that they felt valued by autistic pupils within their school. Humphrey & Lewis, (2008) highlighted in their study autistic pupils within mainstream secondary school struggled to identify positively with their autism diagnosis, adding further weight to the importance of autistic pupils having opportunities to socialise with other autistic pupils. Crompton et al., (2020) acknowledge that increasing evidence is emerging, relating to the benefit of autistic people being part of the autistic community, being able to be their true autistic selves without fear a judgment and developing positive friendships with other autistic people. Adding further weight to challenge past research which defines autism as a bunch of deficits (Crompton et al., 2020).

Goodall, (2018) characterised inclusion as a sense of belonging. This requires further exploration as highlighted in Macmillan et al., (2018) being understood by others is a non-trivial

component of academic achievement, social relationships, and wellbeing. Autistic peer-to-autistic peer support was highlighted as another area for further consideration by the girls. “I don’t know who has autism in my year group which is annoying. Knowing other people in your year have autism would be nice because I can talk with them”- Poppy. Schools providing autistic pupils opportunities to socialise with other autistic pupils, could provide feelings of validation and improve well-being (Crompton et al., 2020).

The girls spoke about their sensory experiences, corridors and crowds were highlighted as a stressor. “I don’t like crowds, I don’t like people near me, but I don’t mind people near me, it’s just when your squashed up.”- Beth. “I didn’t really like all the crowded people” – Zakia. The school offer reasonable adjustments for pupils who struggled with lesson transition, Zakia spoke about how she utilised this support, “I used to go early to go to class, I don’t anymore because I am getting better”.

Some of the girls struggled with noise, Zakia described noise of other students, “really hurted my ears quite a lot”. The Oracle spoke about how she, hates when teachers writes hard on the whiteboard. Beth expressed how the sandwich all made her feel, “there is loads of people shouting and it just arghagh!”. In contrast Beth and Poppy reported that they don’t like silence. “I hate silence”- Poppy. “I don’t like quietness makes me feel all weird, like you can hear my thoughts all together”- Beth.

Sensory differences have been documented within the literature, citing that the majority of autistic people encounter sensory impairments, (Ben-Sasson et al., 2019; Marco et al., 2011; Tomchek & Dunn, 2007). A number of studies suggests that sensory difference in autistic people are lifelong and can occur in some or all the senses, this can be debilitating for some autistic people, making day to day activities and environments traumatic (Baranek et al., 2005; Dawson

& Watling, 2000; Kern et al., 2007; O'Neill & Jones, 1997; Rogers et al., 2003; Schauder & Bennetto, 2016; Watling et al., 2001). For some autistic pupils' sensory differences have been found to negatively impact academic achievements (Butera et al., 2020).

Discussions around the positive aspects about autism and school. All of the girls mentioned that knowing there is an autistic teacher within the school was helpful. Although this area is under researched, it has been cited in a previous study highlighting the benefit of schools employing autistic teaching staff (StEvens, 2022), the value of their input in supporting autistic pupils from a lived experience perspective would be a considerable benefit (Wood et al., 2022). Educational inclusion doesn't start and end with pupils, it extends to school staff, there needs to be more openly autistic representation within the professionals employed by schools.

The Oracle and Poppy spoke about having a 'timeout' card meaning they could leave class if it becomes too much, they found this supportive. The girls described feeling supported by the school, "to know that you always have someone to talk too. But it can be hard at times because they might be busy, in a meeting or supporting someone else."- Poppy.

The girls spoke about change being problematic; sudden changes and planned changes can be difficult for the girls. Poppy gave an account of a particular planned change she found rather distressing, "I am annoyed because the school are changing the uniform. They are changing the blouse, skirt and introducing a tie. Don't mind skirt change but I don't like the tie. I like the blouse we have now, it is different from other schools." Poppy said she had been given plenty of notice about the change in uniform however, she felt that the school did not listen to the views of the students. It could be suggested that the addition of a school tie was a source of anxiety for Poppy and perhaps this could be related to her sensory needs.

Anxiety was highlighted by Zakia and Poppy as an ongoing struggle, both girls reported feeling anxious about being late for school, not completing or forgetting homework, resulting in a detention. It has been cited that autistic girls internalise anxiety (Solomon et al., 2011). Poppy is very focused in maintaining her perfect school behaviour record and at times this could cause Poppy anxiety because of the pressure she put on herself. Some autistic females may present as perfectionists (Ashburner et al., 2010).

All the girls spoke about the different ways their autism can impact their day to day lives. Zakia spoke about her working memory, “I feel with my memory because my long-term memory is fine, but my short-term memory is fine, but my present memory is not that good.” Limited research suggests autistic adolescents may have differences in the working memory system (Barendse et al., 2017). Poppy spoke about executive functioning, “I get really distracted in the mornings; distraction means I lose lots of time.” Executive functioning has been well documented as an area of difficulty within the literature (Hill, 2004; Kenworthy et al., 2008). Beth highlighted that she struggles with the demands placed on her. The Oracle spoke about her experiences within the school, “I don’t know I just do not like being in the mainstream version of this school.” The Oracle added that she felt supported in the in the “Support Centre yeah elsewhere absolutely not.”

Over the project I asked the girls what the best thing was about being autistic, I asked this a few times, over the different one-to-one workshops because at first the girls struggled to find positives. Sasson et al., (2017) found that autistic adolescents were less likely to positively identify with their autism diagnosis. Over time the girls were able to articulate what they thought the positive aspects of being autistic were: Beth spoke about how she has no filter and that ‘autistic people see things others don’t’, Poppy said that “The best thing about my autism is, that

it is unique in a good way. I feel special because I am autistic, sometimes I am proud of being autistic.” The Oracle describe the best thing about being autistic was “privileges erm I don’t know what I mean when I say that I kind of just know that there are”. The Oracle felt reassured by the school being aware of her diagnosis, “so it is so much easier without having to explain a lot of stuff”. Zakia reported the best thing about her autism is, “I can get creative with somethings and that I can get away with somethings.”

For the last group workshop, it was felt that the girls would benefit from an empowering debrief, at times throughout the project the girls expressed internalised stigma in relation to their autism diagnosis. This project was designed to give autistic adolescent females a voice, I really wanted to leave the girls feeling empowered by their autistic identity. Prior to the empowerment debrief I reached out to a number of autistic female professionals and asked the following questions:

1. What does your autism mean to you?
2. What is your Job title and how have your autistic strengths enabled you to become successful?
3. One thing that you would like to tell the next generation of autistic women.

Four successful autistic females answered the above questions (appendix 11), and one autistic girl contributed a poem she had written for autism awareness week. As a group we explored the comments made by the contributors, the girls wrote down their strengths as autistic females and what they wanted society to now about autistic females (appendix 12). The girls provided a really interesting insight into how they perceived their autism in that moment. Beth wrote that her autism means that she is special and happy, Poppy put that her autism means that

she sees things differently. Zakia didn't know how she felt about her autism; however, she did write that she wished society knew that autistic females might get easy things wrong, but not on purpose. Poppy put that she wanted the public to understand why autistic females might get upset. Beth wrote that she wanted others to know that although autistic females might not be overly emotional, they are sensitive to our surroundings. Zakia put that because of her autism she is really good at art and being creative with décor and ideas. Poppy wrote that her autism gave her the ability to be really observant and Beth put that her autism gave her strengths in science and art.

School Life

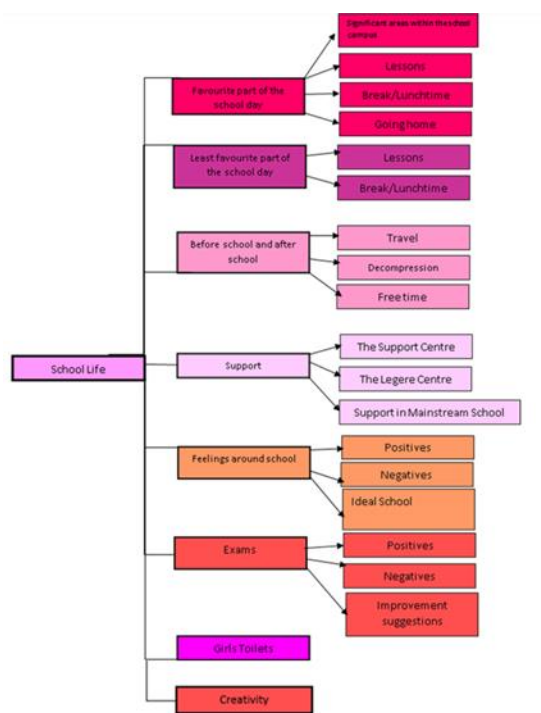


Figure 26 School life; subthemes

During a group workshop, the girls explored their favourite part of the school day. For The Oracle having a zinger burger from the school canteen was her favourite because, “Zinger burgers are delicious”. Drama was The Oracles favourite activity, although it became apparent

that she had mixed feelings due to relationship conflicts with other students who also enjoyed drama, it appeared that this caused some turmoil for The Oracle.

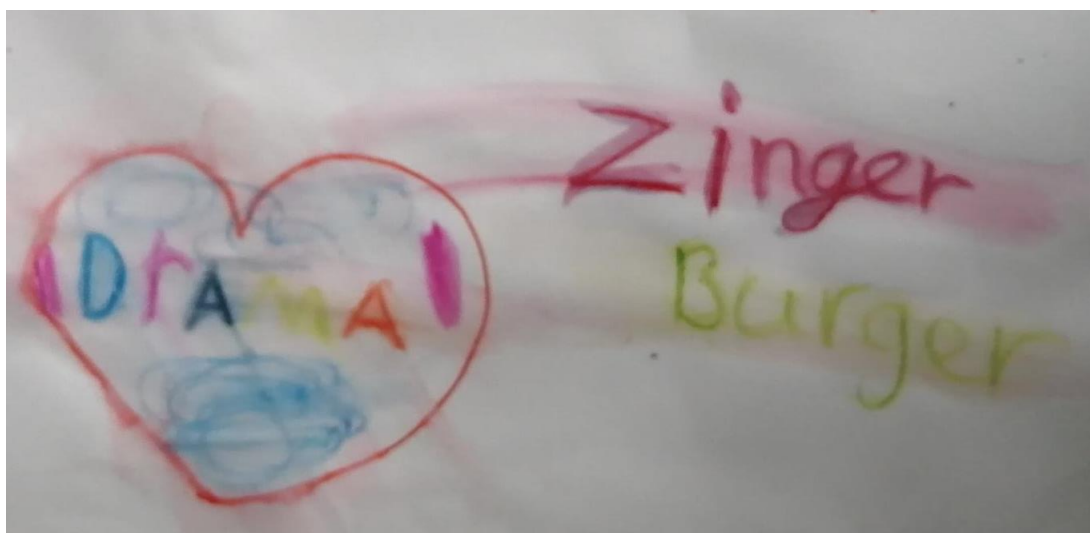


Figure 27 My favourite part of the school day The Oracle

Poppy wrote breaktime, was her favourite part of the school day because she was able to get away from lessons and do what she wanted. Poppy talked about each breaktime being different depending how she felt and where she wanted to go. She explained that sometimes she would go to the library or The Support centre and other times she would chat with her peers in the playground. Drama and music were her favourite lessons, Poppy spoke about her appreciation for music lessons because it allowed her to be as creative as she wanted to be. Poppy passionately described her love for drama lessons, similar to her music lessons she was able to express herself creatively.

Beth drew a science beaker, when asked in her interview she explained that she enjoyed doing science experiments. Zakia spoke about how going home is her favourite part of the day, because she can go home and do what she wants, art was her favourite lesson however because the way her timetable is organised Zakia has art lessons fortnightly.

During our group workshops the girls were given the opportunity to go around the school campus and take photographs of places within the school grounds which were significant to them. During the one-to-one interviews I asked the girls about the photographs they took. Zakia took a photograph of where she goes for lunch, she likes to get there early to avoid queues and have more food choices. The Oracle photographed several areas within the school grounds which were significant to her, she photographed the school office because she felt the staff were supportive and would chat too her. Poppy photographed the drama and music studio; she spoke about how important drama and music were to her in school and out of school. Beth photographed the sandwich hall piano; she recalled singing in there with her music group because the hall has good acoustics. She describes how good she felt when others would listen to them sing and clap.

As a group we explored parts of the school day which were the girls least favourite. All the girls reported that they hated maths. Poppy described her frustration in maths lessons, “Dyscalculia makes maths hard; it doesn’t matter how hard I try I just don’t understand maths.” Zakia spoke about how she struggled to ask for help in her maths lessons, she reported getting bored, and not understanding the tasks during her lessons. The Oracle voiced her dislike for maths lessons, she reported frustrations with her the teacher feeling that she isn’t given enough time for the work and felt pressured to complete the tasks quickly. She had anxieties around feeling unsupported by her maths teacher, worried that the teacher wouldn’t allow her a toilet break or use her timeout card if she needed. Beth spoke about her dislike for maths lessons as well as GCSE art, “it is too stressful; everyone puts pressure on everyone, and everyone is trying to compete with everyone, and it is just too much sometimes, and I feel like I am not good enough because everyone else is actually really good.” It is interesting that all the girls reported

maths being their least favourite lesson, further research in this area would be helpful. In a recent study Bullen et al., (2022) suggest that a considerable number of autistic children without intellectual disability have coexisting difficulties math and reading, highlighting the need to tailored support.

Poppy, Zakia and Beth spoke about their frustrations with the lunch queue and the limited food choices, Poppy felt very strongly about the unhealthy school menu. Nearly every girl reported seeking out a quiet space during break and lunch times, this was balanced with interacting with their peers or chatting with staff. Poppy described breaktime arguments being one of her least favourite parts of the school day and a source of anxiety. Although Beth and The Oracle didn't speak directly about their anxiety around break and lunch times, it appears that both girls struggled to navigate the social complexities, as a way of managing this they preferred chatting with staff at break and lunch times in order to avoid conflict. The experiences of the girls share similarities with previous studies, Sedgewick et al., (2015) found that some autistic pupils were motivated to spend breaktimes with friends to avoid being alone, other autistic pupils preferred to be alone at breaktimes as this brought much needed quiet time. In a study by Moyse & Porter, (2015) they observed autistic girls in mainstream primary experiencing isolation, conflict with peers and distress during breaktimes.

During the one-to-one workshops I asked each girl about how they got to and from school. Zakia drew headphones during one of the first group activities, she explained that she listens to music when she walks alone to and from school. I asked Zakia how she felt on her journey, "quite tired, and a little bit stressed because all the popular people walk the same way, and they usually stop in a big crowd at a certain point." Zakia indicated that listening to music helped her relax during the journey and makes travelling feel quicker. Zakia indicated that she

likes to go to school at a specific time as she does not want to be late. She captured a photo of the school gates; she gets excited in the afternoons when she leaves school through the school gates and in the mornings the gates are very quiet when Zakia arrives because she is so early.

Zakia described her after school routine which consisted of lighting a candle and doing something creative whether that would be art or something crafty. Zakia added that she tends to avoid her family after school so that she doesn't get allocated lots of chores. Lighting a candle appears to be a significant part of Zakia's school routine.

Beth revealed that she walked to and from school, sometimes she would walk alone, other times she would walk with friends. Beth described feeling nothing apart from tiredness when she arrived at school in the mornings. After school is Beth's relaxation time, so she can shut her brain off and give it a rest. Beth's decompression routine after school, is to go on her phone and not speak to anyone because she has been talking all day, this can often be misunderstood as being 'anti-social' or 'lazy'. Beth shared that her family encourage her to socialise outside of her home environment, this can be challenging for Beth as she feels that she needs decompression time, as she is out of the house every single day of the week because of school.

Poppy spoke about getting to school can be a challenge due to time management, being late and receiving a behaviour point is a continuous worry for her. She indicated that being home schooled during the pandemic was far less stressful in the mornings as she did not need to travel to school. It appears that by removing the travel element of school life, was easier for Poppy to manage, and reduced her anxiety around being late. After school was a mixture of walking or being picked up by parents depending on Poppy's after school activities. Poppy conveyed that she likes to do a variety of activities after school such as taking part in drama, music groups,

watching television, reading, or playing with Lego. She added that she tends to go through phases where she is fixated on a type of activity or toy.

The Oracle decompressed after school by spending time with her pets and has a shower to 'clean off the school smell. The Oracle liked to spend her free time either by seeing her friends who go to different schools, or by 'chillaxing' playing computer games such as Roblox, or scrolling through TikTok in her bedroom, most of her time is spent alone although sometimes she plays with her brother.

The demands of school environment can place significant stressors on autistic children and young people, many autistic people report trying to 'keep it together' at school suppressing their traits, this can result in after school shutdown (Nair, 2017). It appears from the girl's accounts, they all have their own unique ways of decompressing after school, albeit this may be misunderstood by family members as the girls being anti-social. In a study by Aubineau & Blicharska, (2020) autistic adolescents report school exhaustion as a reality of school life, emphasizing the need for teaching staff to have more awareness and to promote decompression and recovery breaks.

I asked the girls what they did in their free time at the weekends, Poppy spoke about attending her drama lessons on Saturdays and spending time with her family. Poppy indicated her frustrations as she would like to spend time with her close friends, who go to different schools however, they are always busy. Zakia talked about going on her virtual reality game, at the weekends, she said that most of the time she was alone and that she enjoys being by herself. The Oracle spends her weekends playing games on her computer in her bedroom.

The girls spoke about the support they received from the school, Beth talked about struggling with The Support Centre, she didn't always find staff kind. In contrast Beth spoke

warmly about The Legere Centre, she described The Legere Centre giving her comfort, comparing it to a second home, she feels relaxed and is able to load off her problems to staff. The Legere Centre staff were like a second family, she described having three go-to members of staff who have supported her since she started at school, she felt listened to and understood. During the photo story exercise, Beth had taken a photo of the English room in The Legere Centre. Beth spoke about the positive support received there, she was able to understand and improve her literacy skills.

The Oracle spoke about her experiences at school, during her first one-to-one interview The Oracle was based within the mainstream part of the school and would receive support from The Support Centre. Going to The Support Centre was one of her favourite parts of the school day, she was able to relate to the other pupils and found that the staff understood her. The Oracle conveyed that she felt The Support Centre was a much safer environment. By the second one-to-one interview The Oracle was experiencing some challenges, which meant she was based within The Support Centre full time and by the end of the project she had been transferred to another school. The Oracle spoke about struggling with the mainstream part of the school, she felt supported by staff within The Support Centre but did not feel supported by staff anywhere else in the school.

Zakia reported finding school alright and that she wouldn't want to change anything. She informed me that she didn't like asking for help. After exploring our experiences of being autistic through drawing, Zakia realised it would be helpful if others could understand what an overload was like, as well as what it is like to experience information processing delays.

During the sessions I asked Poppy about her school experiences, Poppy spoke confidently about The Legere Centre, she reported it being a good place to learn, was bright and

colourful, with very nice staff and pupils. Poppy indicated that she felt supported by the school and that she had a named member of staff she could talk to when she needed.

The girls were asked about positive aspects of school life, Beth said that the only positive part of school life were her best friend and some teachers. Zakia spoke about her art lessons, “I get excited when we have art because I rarely have it.” Zakia informed me that she feels inspired by her art lessons as she is able to explore new techniques and improve her skills. Poppy conveyed her passion for drama and music lessons as a positive aspect of school life. Throughout the project The Oracle expressed her passion for drama and performing as a positive, she was delighted to inform me that she got a lead role in a drama production the school were organising however, due to conflicts with peers she had to drop out, this appeared to have an impact on her.

All the girls agreed that school ‘sucked’, and it is boring. Beth made it very clear that school is, “not somewhere I want to be”. She reported feeling left out because her mom and brother were at home. The Oracle was also vocal regarding her feelings around school; “When I arrive at school I feel, please don’t tell me I have another 5 hours of this hell!” although The Oracles frustrations, appeared to be aimed at the mainstream part of the school, “I don’t like this school; I like The Support Centre because there are people like me there, I get on with other students because they are like me”.

Listening to the girls’ perceptions of school life was fascinating, I felt that giving the girls the opportunity to creatively explore ideas of their ideal and non-ideal school would provide a unique insight. This was very loosely based on the Ideal School Drawing Technique developed by Williams and Hanke, (2007). The activity was suggested to all the collaborators, Zakia did not wish to participate, although she did draw her ideal classroom in her sketch book. Poppy and Beth designed their ideal school, The Oracle designed both her ideal and non-ideal school.

The Oracle described her ideal school as a happy environment with nice understanding teachers who would give you a day off if you were distressed. In her ideal school pupils would always have friends, no bullies would be present and if they were, the teachers would stop the bullying. The Oracle designed a 'timeout room', this was a colourful relaxing space with music, books, food, and drinks. The Oracle described the classrooms having big white boards with bigger writing on them, so it is easier to read as she always forgets her spectacles. The outside space would have a field, a seating area and a separate football pitch which would only be allowed to be used at break, not lunchtime because The Oracle does not like people playing football at lunchtime.

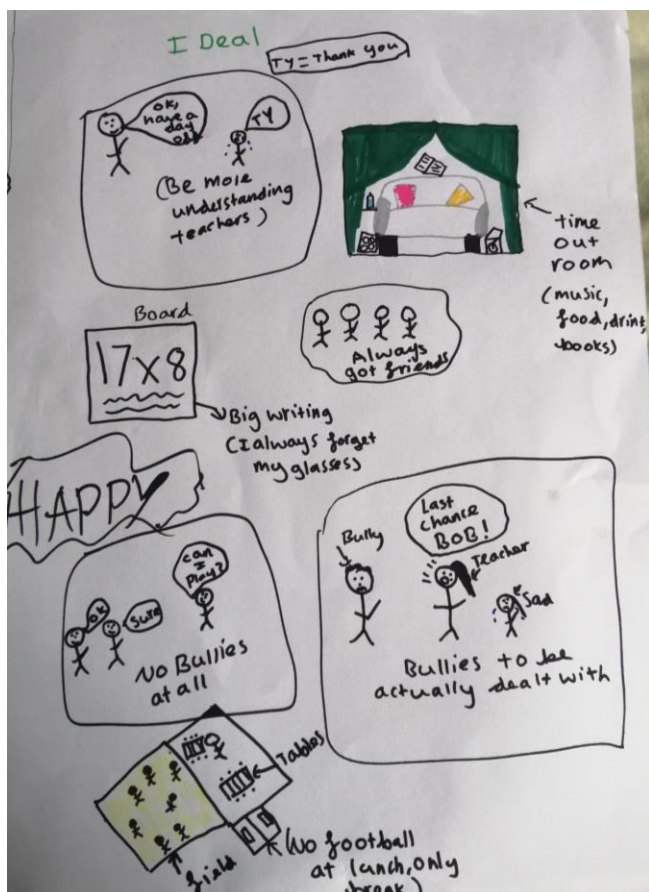


Figure 28 My ideal school by The Oracle

Beth designed a sensory based school environment, she drew stripy hammocks with green bean bag chairs, the school would play relaxing music and there would be a lava lamp pillar. 'Happy' written in large neon lighting and fairy lights throughout the school. There would be a number a food related vending machines, and everything would be free. Within the school Beth designed a 'beach room', for relaxation. No one was required to wear school uniform. Beth's ideal school ethos would be that everyone is kind towards each other, no one should look different because of money, no judgment of others, and no sarcastic teachers. Beth wrote that every pupil has their own laptop and at the start of the school day all pupils had to hand their mobile phone into school and would collect it at the end of the day.

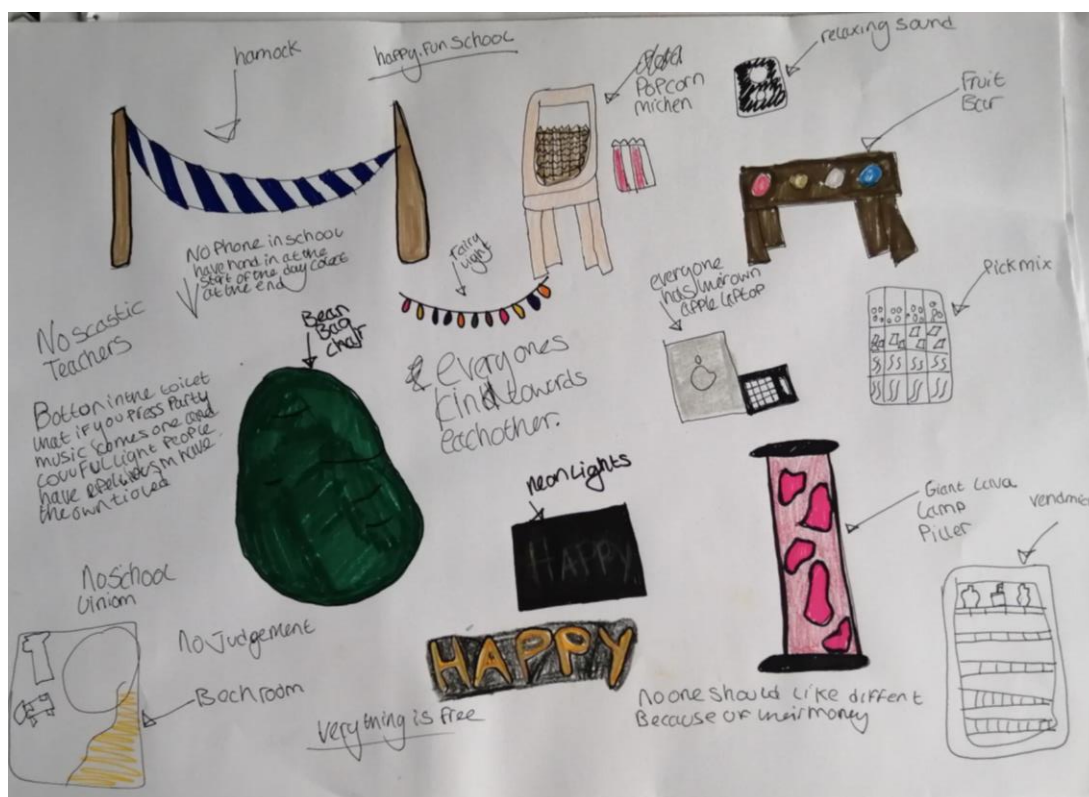


Figure 29 My ideal school by Beth

Poppy created a bright and colourful school using rainbows in her design, because they are 'a happy thing'. The school ethos would be centred around community, happiness, and working hard. Pupils would decide who they wanted to be, and everyone would be treated equally. Poppy described the staff as being like the staff in the participating school because they are fun and fair. Poppy wasn't sure about the uniform however it was clear she wanted it to be on the colourful side, "I wouldn't want anyone to have specific uniform, they would have sort of colours they would have to wear, like rainbow stuff".

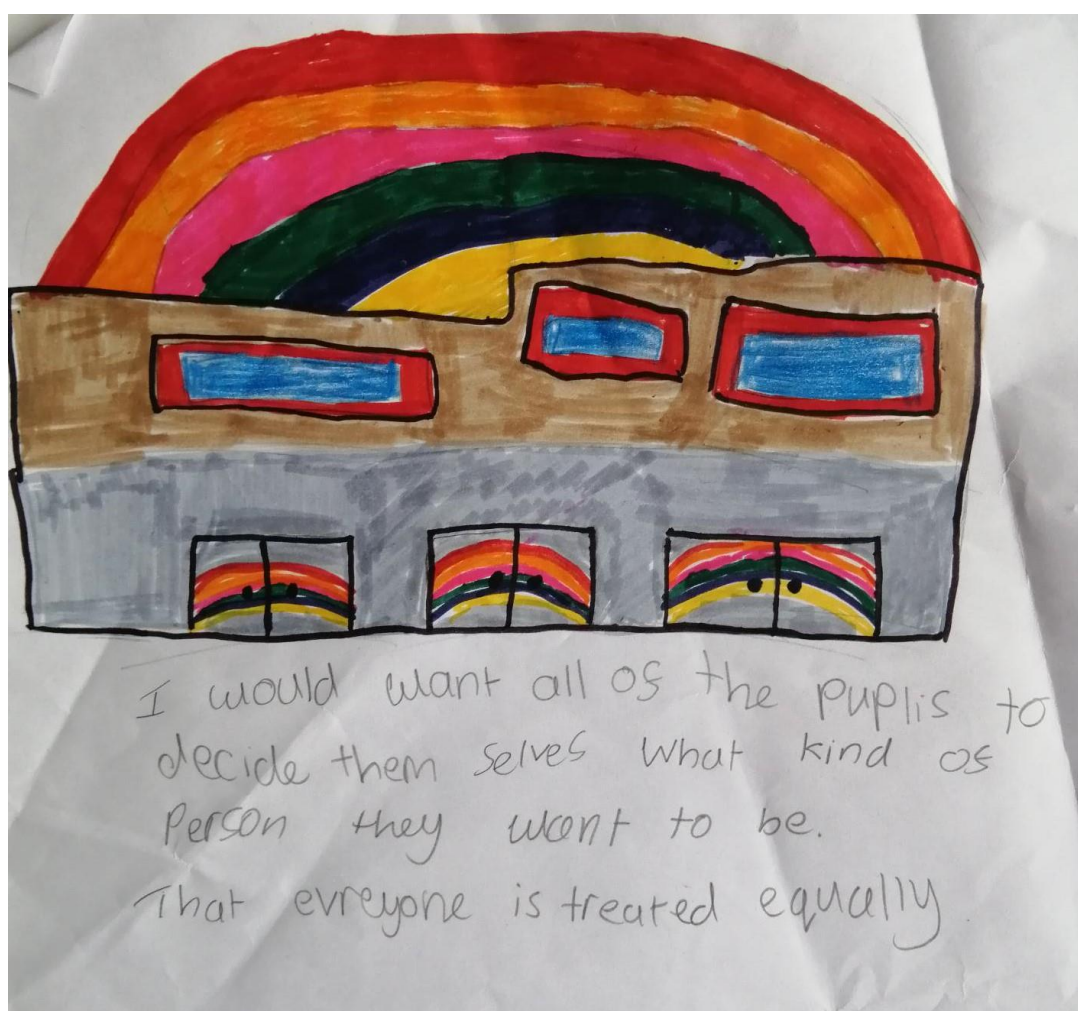


Figure 30 My ideal school by Poppy

Zakia sketched My Little Classroom in her sketch book, the classroom had hanging plants, a small area with soft cushions.



Figure 31 My little classroom by Zakia

Both Beth and The Oracle designed a sensory focused space for relaxation, all of the girls designs had many sensory elements, Poppy's bright rainbows, Zakia's small nature classroom with plants and soft cushions. The designs given by the girls are interesting, particularly how sensory focused their ideal schools were. Previous research has highlighted that sensory overwhelm is experienced by many autistic pupils in mainstream school, as well as the importance of autistic pupils having decompression and relaxation time (Butera et al., 2020; O'Hagan et al., 2021; Aubineau & Blicharska, 2020).

The Oracle explained that the participating school was her non-ideal school. She described the environment as sad and stressed with bullies everywhere. Teachers were not

understanding and prevented 'timeouts' as well as overloading pupils with homework.

Classrooms had small whiteboards with tiny writing which meant The Oracle was unable to read the board. The outside space had 'football everywhere' with pupils telling others to 'move out of the way so they can play football'.

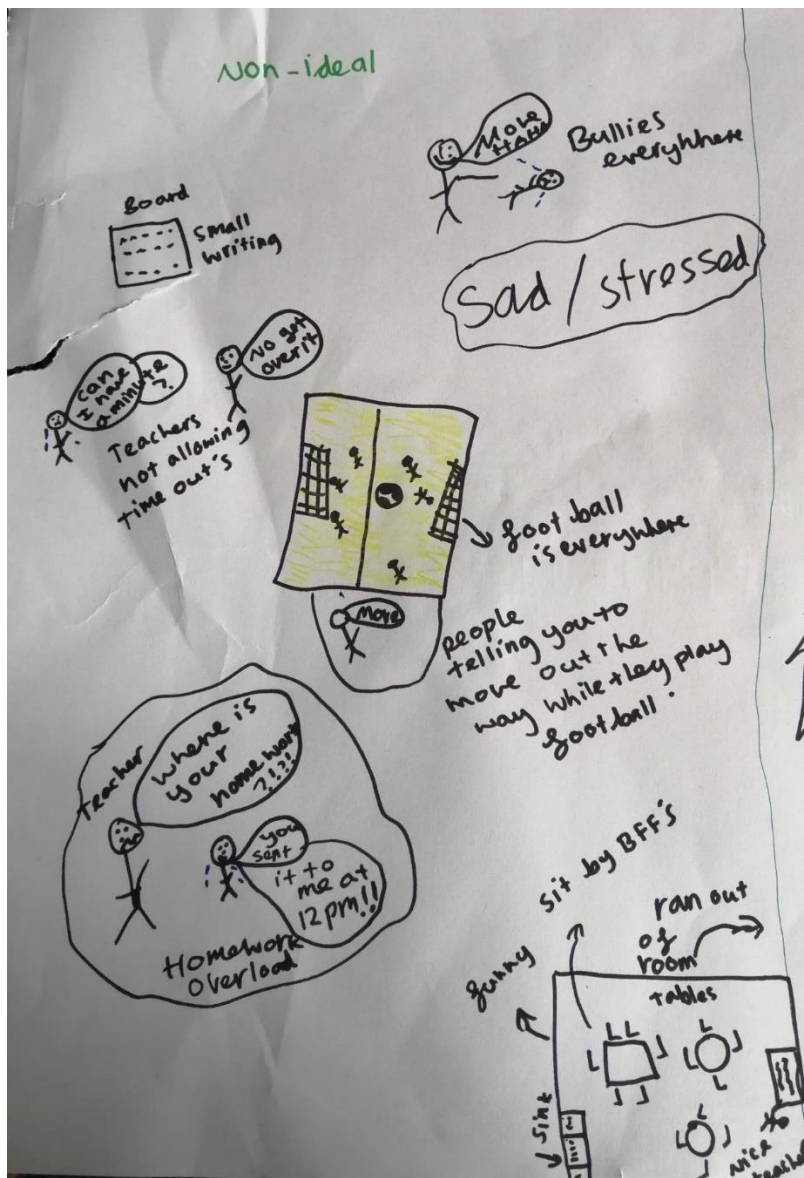


Figure 32 My non-ideal school by The Oracle

In the group activity my least favourite part of the school day, three of the group members wrote exams and assessments were there least favourite part of the school day. In the one-to-one workshops I explored this further with each girl.

The Oracle appeared to prefer exams; she sits all her exams in a separate room alone. The Oracle said that she would, “rather do an entire day of exams than, an entire day of schoolwork.” I ask if she could expand on this, and The Oracle explained that she preferred doing tests because it was quiet, and she was able to work at her own pace. This was reflected by some autistic pupils in a study by Aubineau & Blicharska, (2020) who favoured exams as they provided a much needed brake from the noisy classroom.

In contrast Poppy described exams as boring, she finds them difficult and indicated strong feelings around the physical side of the examination process, “I hate silence, I absolutely hate it, erm I need to move around, I can’t just sit still in one place for so long!”. Poppy explained how exam preparation made her feel, “pressured, feeling stressed, angry, upset, erm it makes me feel like the school only wants me to fail, even though they want me to pass.”

Beth at first did not want to talk about how exams made her feel, until her second one-to-one workshop, although she was keen to advocate for the overhaul of exams and assessments. Beth felt that exams were not a good way to measure achievements. When asked how achievements should be measured Beth said, “your effort in class so that all the naughty kids in the class fail”. Beth explained how exams made her feel, “I don’t like doing exams because it is stressful and my brain goes into like a shutdown, where it forgets all the knowledge that I have learnt in lessons so, kind of makes me panic and I end up doing minimum when I really could do more but I can’t, because it is just pressure all the time, pressure, the quietness, I don’t like quietness, makes me feel all weird, like you can hear my thoughts all together.”

Zakia stated that, “assessments and exams are quite stressful especially history cos I don’t know much about history.” She reported feeling nervous on the run up to her exams although it depended on the subject as some subjects are more stressful than others.

Previous research has highlighted that autistic children appear to be struggling to achieve in national tests (Wood, 2017). Research paints a mixed picture in relation to whether exams are useful in measuring attainment outcomes for autistic pupils; this raises the need for professionals to review whether tests are currently designed in line with the strengths and learning styles of autistic pupils (Wood, 2017; Wood & Happé, 2020).

Each girl was asked what their ideal exam was would look like, their responses have been displayed in a mind map below.

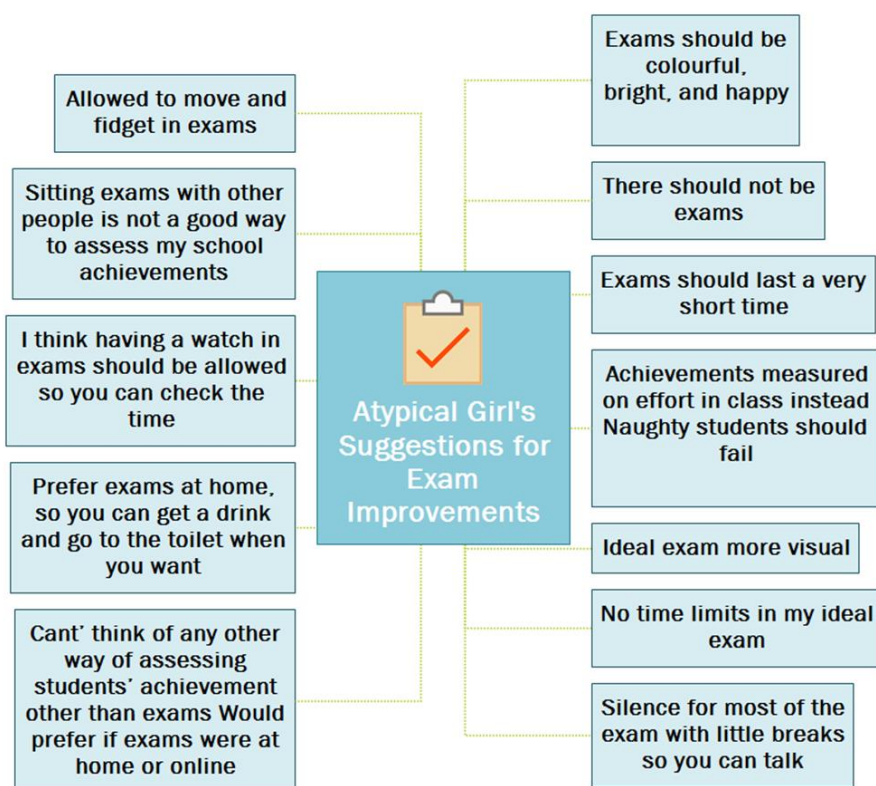


Figure 33 Atypical girls' suggestions for exams

During the group workshops the school toilets were raised as the least favourite part of the school. Zakia wrote girls bathrooms on the least favourite part of the school day activity. During our one-to-one workshop Zakia explained why, “because it is just really disgusting there, girl’s hangout in there eat food”. She felt the girls’ bathrooms were cleaner than the boys’ however, she tries to avoid using the girls’ bathrooms unless she really has to go, although she would use the ‘all gender toilet’ because it is just one room, and no one can walk in or hang out in there.

The Oracle drew a toilet during the least favourite part of the school day to represent the girls’ bathrooms. She said that there is a lot of horrible things written on the walls and that she struggled when there are crowds of girls hanging out in there. The Oracle said generally she found the girls bathrooms ok, and she will use them although, prefers to use the toilets in The Support Centre.

Poppy made similar comments to The Oracle, she is generally ok with the girls’ bathrooms, however, does not like the writing on the walls and finds crowds of girls hanging out in the bathrooms difficult. Poppy indicated that she prefers to use the disabled toilet near the drama studio as it does not smell as bad and because it is a single toilet, girls cannot hangout in there.

Beth had a slightly different perspective on the girls’ bathrooms, “I don’t really go to these toilets, I wait until I get home if I can, if I desperately need to go, I will go to The Legere Centre or The Support Centre coz there quiet”. Beth spoke about the smell, and girls hanging out in the bathrooms made her feel uncomfortable and icky. She said that the writing on the walls was interesting, and she has read the comments hoping that they were not about her.

This is an interesting insight into the girls' experiences of the communal bathrooms within educational settings. There is little literature, exploring the challenges autistic people experience when using communal bathrooms. However, literature does highlight that many autistic people experience sensory impairments and differences (Ben-Sasson et al., 2019; Marco et al., 2011; Tomchek & Dunn, 2007). Furthermore, information on the internet suggests that autistic people may find using public toilets challenging due to sensory differences (Richardson, 2017). Mathews et al., (2021) outlined that using public toilets for people with sensory impairments can be distressing. Thus, further exploration is needed to establish the sensory impact of educational settings.

Creativity

Music

From the first introduction meeting with the girls, it was clear that creativity played an important part of their lives, in and outside of school. All of the girls shared the love of music; the music rooms were chosen as an area of the school, which was significant to them, it was reported that music enabled them to feel creatively free, allowing them to be as creative as they wanted to be at the time. Beth, Poppy, and The Oracle were very passionate about singing and would sing together during the group workshops, Zakia was more interested in the instrumental side of music. Poppy and Zakia explored music inside and outside of school.

Drama

Two of the collaborators spoke about their love for drama, they described how acting meant they could express themselves in ways that they felt unable to in day-to-day life. Poppy talked about how she was able to 'express her emotions' when acting and being able to do 'what she wanted', she felt free in drama, which allowed her creativity to flow. The Oracle articulated

how she used drama in order to express her feelings towards other pupils, in particularly peers that she didn't like or who were unkind to her, as though drama gave her an invisible cloak of protection. The Oracle viewed drama as being in a 'completely different world' where she could, 'pretend to be something I am not'. Perhaps drama provided an opportunity to safely escape reality, of being in an environment that did not always meet their needs and were conscious of not always 'fitting in' or being understood.

Art

Within the group there were mixed feelings around art, Poppy conveyed her dislike for art. Beth and Zakia reported their love for doodling, it helps them to relax. Beth enjoys doodling in lessons and on her workbooks. Zakia carries a doodle book around with her so that, "I don't doodle on my class books". Zakia reported that doodling helped her to feel calm and kept her hands busy during lessons.

Beth spoke about how she used to enjoy art, until she started GCSE art, which subsequently meant she 'lost interest because it is a school thing'. She found it too stressful and felt that there was too much competition, between her art class peers resulting in Beth feeling, "I am not good enough because everyone else is actually really good."

In contrast Zakia is very passionate about her art lessons, she felt that she doesn't have enough art lessons on her school timetable. She described the importance of art lessons, which help her to develop skills and support relaxation as well as feelings of happiness. The lessons inspire her, to experiment with ideas and techniques at home. It appears that Zakia utilises her zeal for creativity perhaps as a coping strategy, she spoke about creativity helping her to relax and unwind as well as a form of escapism.

Creative Writing

The Oracle spoke at length about her passion for creative writing, she had co-written a book with one of her friends, she was proud of this achievement, unfortunately there had been a breakdown in the friendship during the collaboration, this was difficult for The Oracle. The Oracle described her love for writing as it helps her to express herself but also provides her with the opportunity for escapism, explaining that she has an active imagination and that she “just starts writing and the story forms itself”.

All the girls expressed a passion for creativity and experienced unique creative talents. Historical research suggests autistic people experience deficits in creativity and imagination (Scott & Baron-Cohen, 1996; Craig & Baron-Cohen, 1999), in contrast several studies and books challenge such findings, steering towards innovative perceptions of creativity and imagination in autistic people (Shaughnessy, 2013). Loyd, (2013) found that autistic students enjoyed drama and reported it helped them work with peers, they expressed a like for the make-believe elements. Furthermore, art and autism has been well reported, with famous autistic artists such as Stephen Wiltshire, Nadia Chomyn and Peter Howson to name a few, demonstrate a wide range of visual creative skills. Dr Temple Grandin has written a number of books about visual thinking and that many autistic individuals think in pictures (Grandin, 2006; Grandin, 2022). The girl’s creativity strengthens the argument against historical research citing autistic individuals have deficient creativity.

Chapter 6

Conclusion

The project was a small-scale study, one mainstream secondary school in the west midlands took part, during a period of unprecedented, global adjustment after the COVID-19 pandemic. As stated previously the project was not designed to make generalisations, it sought to explore the following questions.

1. What is school like for autistic females in a mainstream secondary school?
2. How can personal experiences and knowledge of autism support the development of a fully collaborative research approach to enable the voices of autistic females to be heard?
3. How can creative and personalised approaches be used to engage autistic participants in research?

What is school like for autistic females in a mainstream secondary school?

The data gathered from the girls provided a unique insight into their school experiences at the time of this study. Interestingly all the girls were talented in various areas of creativity, challenging historical research which suggests autistic people experience deficits in creativity and imagination (Scott & Baron-Cohen, 1996; Craig & Baron-Cohen, 1999). Furthermore, the girls revealed passion and enthusiasm for their creative endeavours, providing them, stress relief, expression of self as well as escapism.

All the girls reported the importance of having friends which is consistent with previous research (Calder et al., 2012; Cook et al., 2017; Daniel & Billingsley, 2010; Sedgewick et al., 2015; Sumiya et al., 2018; O'Connor et al., 2022) however they often felt misunderstood by their peers as identified within other studies (O'Connor et al., 2022; Goodall & MacKenzie, 2018). Worryingly the girls reported bullying and stigmatisation, it was clear that this had a detrimental

impact on the girl's well-being, feeling unable to report incidents to staff because of fear of being labelled a 'snitch'. Bullying has been highlighted as a concern for autistic pupils in previous studies (Humphrey & Hebron, 2014, Kloosterman et al., 2013). The project highlighted the need for more awareness about what autism for all students and staff, the girls were keen for this to take place however were concerned about negative repercussions from others.

All the girls reported a dislike for mathematics, it's important to note two of the girls had an official diagnosis of dyscalculia, although perhaps further exploration into developing maths lessons which are accessible and relatable for autistic pupils maybe beneficial. The study highlighted the anxiety felt by the girls in relation to school exams, previous research has highlighted that it appears autistic pupils achieve low or inconsistent outcomes in standardised assessments and questioned whether current school examinations tease out the strengths of autistic pupils (Wood, 2017; Wood & Happé, 2020).

The girls provided a unique insight to their sensory experiences within the school environment, noise levels, crowded corridors, lunchtime ques and the school toilets were all highlighted as areas of difficulty. In contrast some of the collaborators reported the need for more sensory stimulation such as the need to move around, dislike for silence and the desire for bright colourful surroundings. These findings reiterate the uniqueness of each autistic individuals lived experiences, as well as highlighting the sensory complexities within the school environment.

The girls painted a mixed picture around their experiences of the pandemic however reductions in sensory and social overload were reported as a positive aspect of being home-schooled. The sensory and social overloaded experienced by autistic pupils within the school environment has been acknowledged in previous research (Symes and Humphrey 2011; Humphrey & Lewis 2008, Moore 2007, Wing 2007; Heyworth et al., 2021; Anderson, 2020;

Ashburner et al., 2008). For some of the girls home-schooling provided a reduction in stress levels and executive functioning demands. In contrast not having access to support and resources was a negative aspect of home-schooling and some of the girls were unable to complete their schoolwork resulting in anxiety. Interestingly some of the girls did not enjoy the isolation they experienced during the pandemic. Mixed feelings were reported around returning to school post-pandemic and well as the implementation on COVID 19 restrictions.

The girls reported that significance of the Legere and Support centre, feeling that it was a safer environment than the mainstream part of the school, teachers, staff, and peers within these provisions were thought of as more supportive and understanding to some of the girls.

An unexpected finding was the solidarity found in meeting and interacting with other autistic girls, increasing evidence is emerging, relating to the benefit of autistic people being part of the autistic community (Crompton et al., 2020; Sinclair, J., 2010). Further exploration into providing autistic girls with social opportunities with other autistic girls would be beneficial. The girls reported having an openly autistic teacher within the school was a positive, emerging research has highlighted the importance of schools employing openly neurodivergent staff (StEvens, 2022; Wood et al., 2022) this area requires further research.

How can personal experiences and knowledge of autism support the development of a fully collaborative research approach to enable the voices of autistic females to be heard?

As an autistic researcher I was able to use my experiences and knowledge of autism to adapt the project to each girls' individual strengths, empowering them to share their experiences on their terms, challenging the assumption that communication is only effective through words alone as well as the notion all autistic people are the same. Having taken part in participatory

autism research myself, I was keen to ensure that this project was not ‘another tokenistic’ study. I tried to ensure that the project was designed to listen to the voices of the girls and ensure that they could fully participate throughout, including the provision of an easy read summary of the research findings.

How can creative and personalised approaches be used to engage autistic participants in research?

The project demonstrated the importance of participatory autism research and the value of implementing creative, flexible, and personalised approaches. This was evident with the adapted approach for Zakia, one could have assumed that she did not have much to say, however this was certainly not the case, as her drawings gave an in-depth personal insight into her world and experiences. Had the project lack such flexibility would Zahia’s voice have been heard?

Within educational research there are many debates around whether mainstream education is able to offer full inclusion for autistic pupils, what this study has highlighted is that listening to the experiences of autistic pupils provides a unique insight into what school is like for them, challenging the assumptions and stereotypes around autism. These findings could provide a better understanding into ensuring that each autistic pupil is provided with positive educational experiences, whether that is within a mainstream setting or not.

Implications for the Future

This project did not seek to answer a hypothesis or make generalisations, instead it sought to give autistic adolescent females a voice and demonstrate how creative, flexible, and personalised methodological approaches, can be used to support the engagement of autistic adolescent females in research, as well as giving weight to the autistic researcher advantage.

Autism is a unique experience for each individual, in order for us to understand, it is important for us to listen to the experiences of autistic individuals; therefore, using standardised rigid methodological approaches and research tools won't be suitable for all autistic individuals. Using a flexible personalised approach allowed the collaborator to engage fully on their terms and preferred communication style. Further exploration into flexible and personalised research methodological approaches would support research engagement for autistic people who are non-speaking or non-verbal.

Recommendations for further exploration; Goodall, (2018) characterised inclusion as a sense of belonging, research has highlighted the benefits of autistics socialising with other autistics (Macmillan et al., 2018; Crompton et al., 2020) perhaps this could be explored further within educational settings?

Consideration given to low sensory areas within the school to support autistic pupils with regulation during break and lunch times as highlighted by this and previous studies (Butera et al., 2020; O'Hagan et al., 2021). A recognition of the importance of decompression after school for autistic girls could have a positive impact on wellbeing for autistic individuals this has been highlighted within this and previous studies (Nair, 2017; Aubineau & Blicharska, 2020).

Further exploration into the complexities of bullying and stigmatisation, this is a widely recognised problem for autistic pupils within mainstream education, as well as the identification of the impact this can have on autistic pupils mental health (Barnhill and Myles, 2001; Humphrey and Lewis, 2008; Humphrey & Symes, 2010; Hebron, 2012; Kloosterman et al., 2013; Humphrey & Hebron, 2014; Mendelson et al., 2016; Sproston et al., 2017; Goodall & MacKenzie, 2018; Goodall & MacKenzie, 2019; Holden et al., 2020; Mitchell et al., 2021; O'Connor et al., 2022) however, efforts to address this appear to have been unsuccessful.

In addition, further exploration into the strengths of neurodiverse teaching staff, a small number of studies have recognised the benefits of employing openly autistic staff, inclusion does not start and stop with pupils (StEvens, 2022; Wood et al., 2022).

The insight gained from this project has provided a cornerstone for further future research. Autism research requires a change in perspective, a move away from the deficit lens to one of empowerment, this project is an example of the benefits derived from an alternative approach.

Limitations

This was a small-scale study and is not representative of all autistic adolescent females. However, this research could provide a useful building block for future research.

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Appendix

Appendix (1) Research disclaimer

I would like to highlight that at the time of designing the research information I used person first terminology, I did not fully understand the importance of using identity first terminology, this is something I have taken on board for future research, it is important that the general preference of the autistic community is reflected in research, and I apologise for any offense caused.

Appendix (2) Declaration

Annex 2 - Declaration form PhD by Thesis or Portfolio

Declaration

I declare that:

- The work presented in this thesis is my own and embodies the results of my research during my period of registration.
- I have read and followed the University's Academic Integrity Policy and that the thesis does not breach copyright or other intellectual property rights of a third party. Where necessary I have gained permission to reproduce copyright materials.
- Any material which has been previously presented and accepted for the award of an academic qualification at this University or elsewhere is clearly identified in the thesis.
- Where work is the product of collaboration the extent of the collaboration has been indicated.

Signature:



Date: 07/03/2023

Declaration of material presented previously for an academic award:

State the name and date of the award and the institution.

Appendix (3) Research invitation to schools



Dear Sir or Madam,

My name is Esther Whitney, I am a research student at Canterbury Christ Church University. I am currently undertaking research into the experiences of adolescent girls with a diagnosis of ASC.

As a female with ASC myself, I am keen to engage with female pupils with a diagnosis of ASC in order to understand their experiences in the here and now. I would like to collaborate with a small group of adolescent females who have a post autism diagnosis, to understand their experience of living with autism while attending mainstream secondary school. I believe that females with autism have been overlooked in the context of autism related research and this is not okay. Females with autism can make a very important contribution towards autism research, so that we can understand what life is like for them.

The essence of this small research project is to give adolescent females with autism a voice. I believe that research should be a fun and empowering experience, I intend to utilise my creative skills throughout this project. This research will be conducted in a non-intrusive manner, under the guidance of the school. Consent will be sought at every stage of the process. Data protection will be adhered to throughout the research and post research. I will be working closely with my supervisor Dr. Alison Ekins throughout this project, she can be contacted via email: alison.ekins@canterbury.ac.uk.

Brief outline of the project: -

- Introduction of researcher, discussions around the research project and how best to work together.
- Planned activities such as graffiti wall, diamond 9, individual and small group interviews within school hours at a time and place suitable to the students and staff.
- Debrief

Students will be provided with information sheets and consent forms; they have the right to withdraw from the project at any time without needing to provide an explanation. However, once

the data has been incorporated into my thesis, this would be around December 2021, it cannot be withdrawn.

This is the research criteria: -

- (1) Female
- (2) Post ASC diagnosis without learning disability.
- (3) Aware of diagnosis
- (4) Between the ages of 11-16 years
- (5) Regular attendee of mainstream secondary school
- (6) Able to verbally communicate.

This is a voluntary project; it is really important that none of the pupils feel pressured taking part, the most important part of this project is that the girls feel safe and comfortable.

Timescales

Ideally, I would like to start discussions around the research project in term 6, working collaboratively to identify potential students. I should like to start the activities mid to late September. If you would be interested in undertaking this research in your school, please contact me on 07850194132, I would be delighted to hear from you.

Yours sincerely,

Esther Whitney

Appendix (4) About the researcher information sheet



ESTHER WHITNEY

RESEARCH STUDENT

Hi There,

My name is Esther Whitney, I am a research student at Canterbury Christ Church University. I am interested in researching adolescent girls who have a diagnosis of autism spectrum condition (ASC).

A LITTLE BIT ABOUT ME

I have a diagnosis of ASC which I am proud of because I see and experience the world in a unique way.

- I am very creative and love to paint 
- I have a pet tortoise 
- I used to compete as a female power lifter. 

RESEARCH PROJECT

I would like to collaborate with a small group of adolescent females who have a post autism diagnosis, to understand their experience of living with autism while attending mainstream secondary school. I believe that females with autism have often been overlooked in the context of autism related research and this is not okay. Females with autism can make a very important contribution towards autism research, so that we can understand what life is like for them.

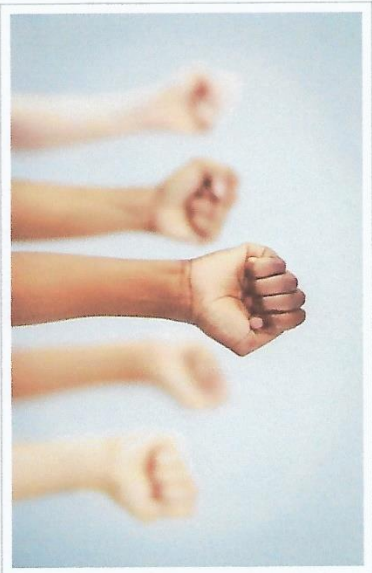
The essence of this small research project is to give adolescent females with autism a voice. I believe that research should be a fun and empowering experience, I intend to utilise my creative skills throughout this project.

Appendix (5) Research project information sheet for the collaborators

**THANK YOU FOR TAKING THE
TIME TO READ THIS
INFORMATION**

If you have any worries, questions, or concerns or you are not happy, please contact me on this email
e.whitney458@canterbury.ac.uk or talk to your teacher.

**Research
Project**



**GIVING FEMALES WITH AUTISM
SPECTRUM CONDITION A VOICE**



Giving females with autism spectrum
condition a voice

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Research Principles

As a female with ASC myself, I am keen to engage female pupils with, a diagnosis of ASC in order to understand their experiences in the here and now. The project will be centered around these principles recommended by Shaping Autism Research UK.



Trust



Mutual respect



Listening



Learning

More Information



At the start of the project, you will be provided with information sheets and consent forms.



During the research project, I will be collating information about your experiences, stories and ideas relating to your educational experiences as an adolescent female with ASC. I hope that you will find this interesting and empowering.



Nobody will be able to recognise you because I will change your name and I won't include any information that would show people who you are. You could even choose a name for yourself in my research! All the information you share will be kept safe.



You can check what I am writing about you as well. I won't include anything unless you say it's OK. It is up to you what you share and what you don't. You can stop at any time by just telling me. You have the right to withdraw at any point during data collection, no explanation needed. However, once the data has been incorporated into my thesis, this would be around December 2021, it cannot be withdrawn.

Introduction

A little bit about me



Hi! My name is Esther Whitney, I am a research student at Canterbury Christ Church University. I have a diagnosis of ASC which I am proud of because I see and experience the world in a unique way.



I am very creative and love to paint



I have a pet tortoise



I used to compete as a female power lifter

Purpose of this booklet



I am interested in working with a small group of girls who have an ASC diagnosis. I want to hear your stories, experiences, and ideas, about what it is like to be a female with ASC in secondary school.

Why is listening to people with ASC important?

In the past society has not always listened to people with ASC, which is not okay. People with ASC experience the world in a unique way, listening to real life experiences will help others understand what life is like.

“The world needs different kinds of minds to work together.”

Dr Temple Grandin

Girls with ASC

I believe that girls with ASC have been overlooked in the context of autism related research and this is not okay. Girls with ASC can make a very important contribution towards autism research, so that we can understand what life is like for them, from their perspective.

What will happen during the project?



Figure 1 Graffiti Wall

We will start off with an introduction, we will talk about the research project and how best to work together, as well as being respectful of each other's privacy during the research activities.

There will be planned group activities such as graffiti wall, diamond 9. I would then like to conduct one to one semi structured interview within school hours at a time and place suitable to you. Activities could last up to 60 minutes. You can stop the activities/interview at any time, you won't be letting anyone down by doing so, the most important part of this research is that you feel okay and safe.

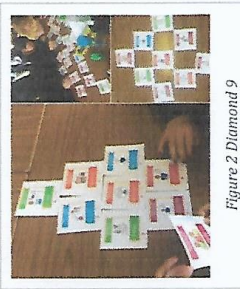


Figure 2 Diamond 9

Figures 1 & 2 show what the group activities might look like, we will have discussions around the activities during the introduction.

If you consent to being voice recorded or having photographs take of your work, you can ask to delete anything that you are not happy with. Throughout the project I will be collating data, such as your views, opinions, and things you might make or draw. All data will be kept safely stored via encrypted USB drive or stored in a locked drawer.

At the end of the project, we will have a debrief, we can discuss what it was like for you taking part in the project. The information you share will be incorporated into my thesis, this is a lengthy piece of writing, during the debrief we can discuss the format you would like the findings of the research presented to you. It is important that the research findings are presented in a way that is easy for you to understand.

You can leave the project at any time, and you don't need to provide an explanation.

Appendix (6) Research project information sheet for the parents/guardians

RESEARCH PROJECT

INFORMATION FOR PARENT/GUARDIAN

I would like to collaborate with a small group of adolescent females who have a post autism diagnosis, to understand their experience of living with autism while attending mainstream secondary school.

WHAT WILL HAPPEN?

- Introduction of researcher, discussions around the research project and how best to work together.
- Planned activities within school hours at a time and place suitable to the students.
- Possible focus group session and semi-structured interviews
- Debrief

All students will be provided with information sheets and consent forms. All students have the right to withdraw from the project at any time without needing to provide an explanation.

WHY IS THIS RESEARCH IMPORTANT?

There is little research from the perspective of adolescent females post ASC diagnosis. It is important for people with autism to have a voice so that, there is a better understanding of their experiences.

SKILLS

As a female with ASC myself, I am keen to engage female pupils with, a diagnosis of ASC in order to understand their experiences in the here and now.

The project will be centered around these principles recommended by Shaping Autism Research UK: -



Trust



Mutual Respect



Listening



Learning

"The role of a creative leader is not to have all the ideas. It is to create a culture where everyone can have ideas and feel that they are valued."

Ken Robinson

MORE INFORMATION



Figure 1 Graffiti Wall

within school hours at a time and place suitable to your daughter. Activities could last up to 60 minutes. Your daughter can stop the activities/interview at any time, this is a voluntary project, it is really important that she doesn't feel pressured taking part, the most important thing in this project is that she feels safe and comfortable. Throughout the project I will be collating data, such as your daughters' views, opinions, and things she might make or draw. All data will be kept safely stored

via encrypted USB drive or stored in a locked drawer.



Figure 2 Diamond 9

Figures 1 & 2 show what the activities might look like, we will have discussions around the activities during the introduction.

At the end of the project, we will have a debrief, we can discuss what it was like for the students taking part in the project.

Information Collated

During the research project, I will be collating information as your daughter shares her experiences, stories and ideas relating to her educational experiences as an adolescent female with ASC. I hope your daughter will find it interesting and empowering.


Nobody will be able to recognise her because I will change her name and I won't include any information that would reveal her identity or the school's name. I will check everything I write about your daughter with her, and you can ask to see this as well if you wish. I won't include anything unless you say it is OK (up to the point where I submit my work). It is up to your daughter what she shares, and she can stop at any time by just telling me, you or her teacher. Interviews maybe recorded if consent is given, and photographs maybe taken during the project if consent is given. Recordings and photograph's can be deleted if you or your daughter are not happy with them.


Your daughter has the right to withdraw at any point during data collection, no explanation needed. However, once the data has been incorporated into my thesis, this would be around December 2021, it cannot be withdrawn. If you have any worries, questions or concerns or you are not happy, please contact me on this email e.whitney458@canterbury.ac.uk or talk to your daughter's teacher.

Appendix (7) Research consent forms for collaborators

CONSENT FORM


Please read the statements and tick the boxes if you agree with them.
Name:
Age:





I HAVE LISTENED TO AND UNDERSTOOD THE INFORMATION ABOUT THE PROJECT.

I agree with the above statement.



I UNDERSTAND THAT I CAN ASK NOT TO TAKE PART IN THE PROJECT AT ANY POINT, WITHOUT GIVING AN EXPLANATION. BUT ONCE THE DATA HAS BEEN INCORPORATED INTO THE RESEARCHER'S THESIS (AROUND DECEMBER 2021) I WOULD NOT BE ABLE TO WITHDRAW DATA COLLECTED.


I agree with this statement.




I AGREE TO TAKE PART IN THE COLLABORATION.

I agree to this statement.

I AGREE TO THE FOLLOWING

I am happy to be audio recorded. 

I am happy for my creative work to be photographed. 

I understand that information given will be used, I will not be identified by name or any other means.



Appendix (8) Research project consent form parents/guardians



Parental Consent Form

This consent form is required for the participation of your daughter in the research project. Please complete the form, sign, and date it. Thank you.

Parent or Guardians
Name

Child's Name

Please read the statements and tick the boxes if you agree with them.

- I have read and understood the information about the research my daughter will be taking part in and I agree to my daughter's participation in this research project.
- I understand that my daughter has the right to withdraw at any point during data collection, no explanation needed. However, once the data has been incorporated into the thesis, this would be around December 2021, it cannot be withdrawn.
- I agree that all data held relating to my daughter will be kept in accordance with UK-GDPR and Data Protection Act 2018 for two years until submission of thesis. All digital files will be destroyed, and hard copies will be returned to my daughter. Any information used will not identify my daughter by any means.
- I am happy for my daughter's creative work to be photographed
- I am happy for my daughter to be audio recorded
- I understand that information given by my daughter will only be used if I and my daughter agree.
-

Giving females with autism spectrum
condition a voice





Parental Consent Form

Sign and date:

**Giving females with autism spectrum
condition a voice**



Appendix (9) Research debrief letter collaborators.



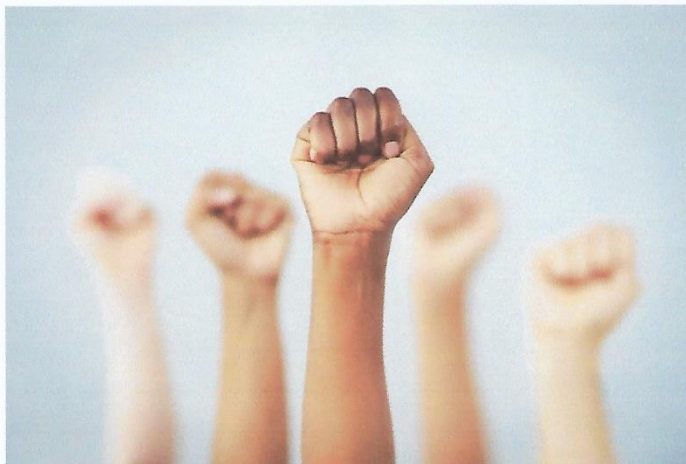
Thank you!

The research activities have now concluded. Just wanted to say a big thank you for taking part in this project. It was a joy working with you and I wish you all the best in the future.

What happens next?

As discussed in the debrief; the results of the project will be put in an accessible format, for you to read should you wish to. If you have any worries, questions or concerns or you are not happy, please contact me on this email e.whitney458@canterbury.ac.uk or talk to your teacher.

Appendix (10) Research debrief letter parents/guardians.



Thank you for your support!

Just wanted to say thank you for supporting your daughter during this research project. The research activities have now concluded. I have enjoyed working together and wish you all the best in the future.

What happens next?

Once the results are ready, your daughter will be provided with a copy in a format accessible to her; we have discussed this in our face to face debrief. If you have any worries, questions or concerns or you are not happy, please contact me on this email e.whitney458@canterbury.ac.uk or talk to your daughter's teacher.



Giving females with autism spectrum condition a voice.

Appendix (11) Empowering debrief workshop.



Cathie Long

Independent Social Worker

What does your autism mean to you?

Being diagnosed has given me insight into the fact I'm different, not faulty. I understand and embrace my stims, rather than trying to stop them. I see my quiriness and difference in a positive light and most of the time I enjoy being me. I am part of a growing community of autistic women, and I am proudly autistic.

How has your autistic strengths enabled you to become successful in social work?

Social work is my passion. I love working with people, I love applying the Law to my practice, I am deeply empathic, I love to do the right thing and am incredibly person-centred. I have the ability to hyperfocus, to zone in when writing a report as an expert witness. I have no concept of hierarchy meaning I'll do whatever it takes to get the right outcome. I love learning. I love teaching people, using personal and professional experiences to make it applicable and relevant. I enjoy the variety of my work; I like being my own boss (I hate being told what to do) and I really enjoy supporting and encouraging others to become the very best of who they are

One thing that you would like to tell the next generation of autistic women.

We are wonderfully different, we are not faulty, and we are not a bunch of deficits. It's really OK to put ourselves first, to make sure we attend to our needs rather than masking and adapting our behaviour to please others. Yes, sometimes we must do this but it's really important to speak up and not let other people impose their neurotypical expectations about how we should be. Learn to love yourself for who you are. Follow your passions. If you have a dream, go for it regardless of what others think. It's not our job to change the world but when we learn to love and accept ourselves, the world changes around us.



CathyJ

IT Trainer and Executive Director of Autistic UK

<https://www.linkedin.com/in/catherine-jackson-c-o-l-f-32635017/>

What does your autism mean to you?

Mostly it explains how my brain works. I'm not diagnosed, but if I'm not autistic, then my life doesn't make sense! Having something I can reference things against helped me a lot and I wish I'd had that when I was at school.

What is your Job title and how have your autistic strengths enabled you to become successful?

I'm a self-employed IT Trainer. I show mostly older people how to use their phone, iPad, laptop or whatever they need to know about. I think it's actually the ADHD that has helped me be able to break things down into small steps and give explanations of things that help people see the bigger picture of what they're trying to do. I also build rapport with people really quickly, and while this doesn't always help with keeping friends, it does help me be a friendly professional. It means people aren't afraid to ask me questions even if they might be "stupid" questions!

One thing that you would like to tell the next generation of autistic women?

Do I have to pick just one?! OK – I would say, figure out what your autism means to you – how it affects you or helps you or hinders you or whatever – and own it!

I've often found that if I can talk about something matter-of-factly, people generally accept it and work with it as I've presented it. For example, I've got a really bad memory for some things, but I can remember lots of details and personal things. I can remember lots of my customers' passwords, but I can't remember what I'm supposed to do on any given day unless I put it in my diary. I have to write things down. If I say so to someone else, though, I think it helps them too. Think of the difference between saying "I'm autistic/adhd" versus actually explaining it, with "My working memory is terrible, I have to write everything down. It's an ADHD thing". It not only shows what the problem is, but the fact that you've taken that and done something with it. You're not just "saying it" like we sometimes get accused of 😊



Abbie

Dental hygiene and therapist

Botox and filler Aesthetic practitioner

What does your autism mean to you?

My autism means to me that my brain is wired differently, so I think and feel differently. I often find loud and social situations overwhelming. I'm quite happy with my own company and have a small number of friends who I feel comfortable around. I tend to be a creature of habit and routine. When my routine is disturbed, I find it difficult to relax and my anxiety will quite often spike and rear its ugly head. Because my brain is wired differently, I am able to think outside the box and see different perspectives and views that others would not see.

Growing up I often felt uncomfortable in my own skin, this was because I tended to compare myself to others. As time has gone on, I have found a greater sense of inner peace and have learned to accept my own feelings and thoughts. I found this has gotten a whole lot easier as I have gotten older. It's really important to me that I am independent, I like my own space and often enjoy silence, so I'm able to process my thoughts and feelings and recharge.

Home is very important to me, it's my safe space and for many years I struggled with letting people into my own home. As I often thought they would overstay they're welcome, socialising was too much, and I'd often run out of things to say or talk about.

I prefer animals too people I have two cats which I adore, they both have helped me through difficult times and understand my routines. Both cats enjoy our feeding and cuddling routines and often softly meow when it's feeding time, or they want to go outside. I find I'm much better in one-to-one situations rather than crowds and large groups of people. Crowds and large groups of people often make me anxious and overload my brain.

Being creative is part of my personality and luckily my career enables me to be creative every day. Which I adore, but also it requires me to be sociable but on a one-to-one basis which I can cope with.

After work I quite often find I need to decompress which sometimes results in a rant or an outburst but this is how I process the day and get it out of my mind and out of my system so I can then unwind and enjoy my evening. Often others have found this difficult to experience and over time I have naturally drifted away from these people.

Being autistic has helped me relate to others who perhaps have anxiety OCD learning disabilities and also autism. Where is Neurotypical people would struggle, I find I thrive as I have a much greater understanding.

How has your autistic strengths enabled you to become successful in the Dental industry?

I currently work in Special Care Dentistry. So, the types of patients I see quite often have autism, learning disabilities, mental health issues and severe anxiety. I find I can relate because I am autistic. It helps me think outside of the box and try different approaches to treatment which a neurotypical clinician wouldn't think of. I am much more patient and understanding. I am very creative, and my career enables me to use my hands every day. I think of my job as an art and science, it has a huge practical side which I love and thrive in. I struggle with the academic side but excel with the practical side which luckily is 99% of the job.

My career means a lot to me, it enables me to utilise my practical strengths, I am able to help with special Care Dental patients and I get great satisfaction from my role. We quite often spend more time at work than we do in our home environment so being happy and comfortable at work is a must for me.

One thing that you would like to tell the next generation of autistic women.

One thing I'd like to tell the next generation of autistic women. Except yourself for who you are, get to know your mind, nervous system, and body so you have a greater understanding. Please don't compare yourself to others. Each one of us has been made in a unique and special way. As time goes on and you get older you develop a greater understanding and care less about how others may perceive you. Think of autism as your superpower, your strength, something that set you apart. Embrace your outburst, love your senses, spend more time trying to make something of yourself and less time worrying about others.

Maria

Teacher

What does your autism mean to you?

I feel being autistic means that I view and experience the world in a way that is slightly different to that of neurotypical people. It does mean my senses are often heightened and I can find social situations difficult however it also means that I can get really, I really love some sensory experiences, probably a lot more than most people! I crave dark low-level lighting and certain scents / spaces / textures. I also love the down time after socialising and now see that as a positive bit of 'me' time rather than 'recovery'.

What is your Job title and how has your autistic strengths empowered you within your job role?

I have been a teacher for 20 years. I feel being autistic has enabled me to relate to some of the challenges my pupils experience and I have always been able to work with them and alongside them to meet their sensory and communication needs, it has often felt like a mutual shared experience working with those with additional needs. As a teacher my hyper focus for detail has meant my lesson plans have always been very detailed and precise and my assessment analysis very thorough. This means I have always had to be really wary of work / life balance issues, but it has also meant my class has always been managed well with lessons that are well organised and highly personalised and differentiated to children's needs. I basically treated everyday like an OFSTED inspection, which long term is probably not recommended for good mental health as I tended to 'crash and burn out ' of an evening. Working part time worked best for me and my family as it gave me more of a balance which is really important.

One thing that you would like to tell the next generation of autistic women.

Be yourself and be proud of yourself - enjoy the journey

Autism Awareness Week

I'm glad I'm Autistic

I want you to know that autism isn't all that bad,

It's actually a superpower that I was born to have.

Although the sensory issues are a pain,

Each day there are super-powers that I gain.

Did you know so many artists, scientists and writers are autistic too?

Have you ever thought about your friends or you?

I was diagnosed Autistic when I was eight years old,

I was confused and scared wondering what was wrong,

What were all these weird feelings I'd been having for so long?

But then I was told;

It means you're

Amazing

Unique

Tremendous

Inspiring

Super

Magnificent

I felt a sense of relief,

Finally, I felt complete.

Everything was starting to make sense,

All my little things that I thought weren't normal had a reason.

I'm glad I'm autistic, I wouldn't change it for the world!

Emily Edgar, age 12 year

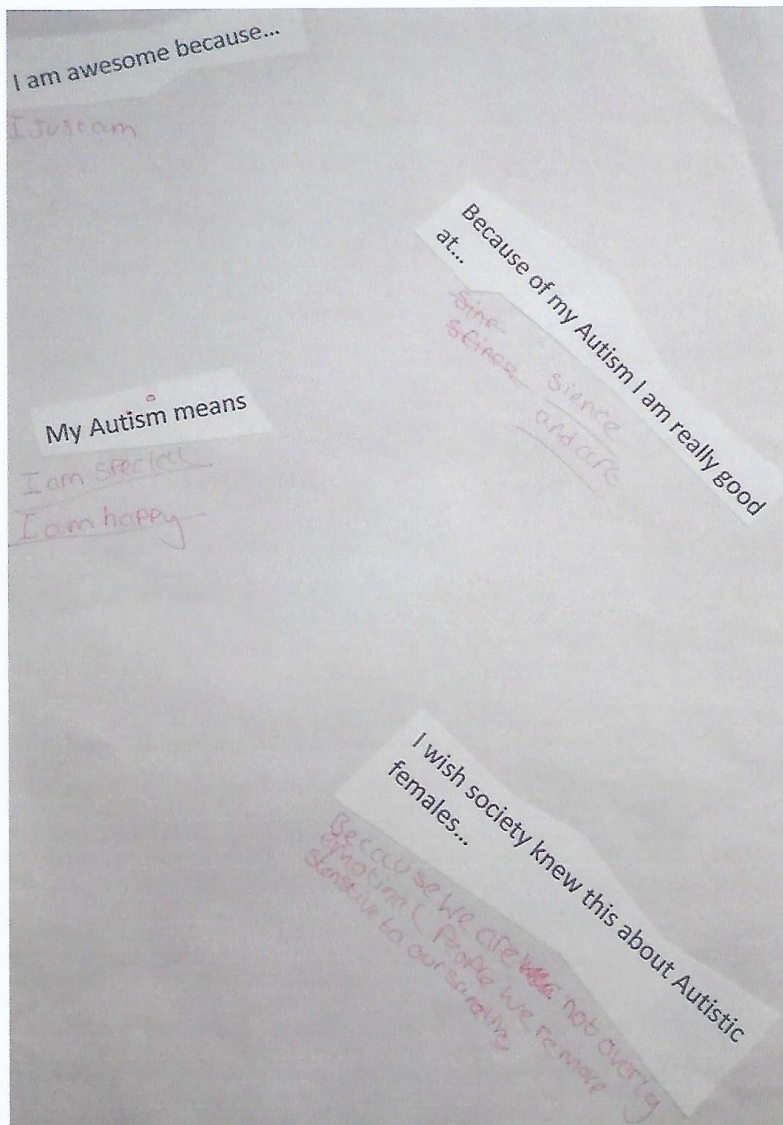
Appendix (12) Outcome of empowering debrief workshop.

Empowering the next generation of autistic females

Prior to the debrief workshop I asked a number of professional autistic women to write about their autistic strengths and what would they like to say to the next generation of autistic women. Two of the professional autistic women asked to be anonymised, the others waived their right to anonymity.

The booklet can be found on page in the appendences. During the workshop three of the four girls attended, The Oracle had moved to a different school, I asked the SEN Administrator to send her a debrief sheet. Discussions around autistic strengths took place and we read through the information provided by the professional autistic women, Zakia spoke about being able to relate to Abbie who preferred the company of her cats than humans. Beth indicated how impressed she was with the autism poem by Emily. The girls answered the following questions and spoke about their strengths as autistic females.

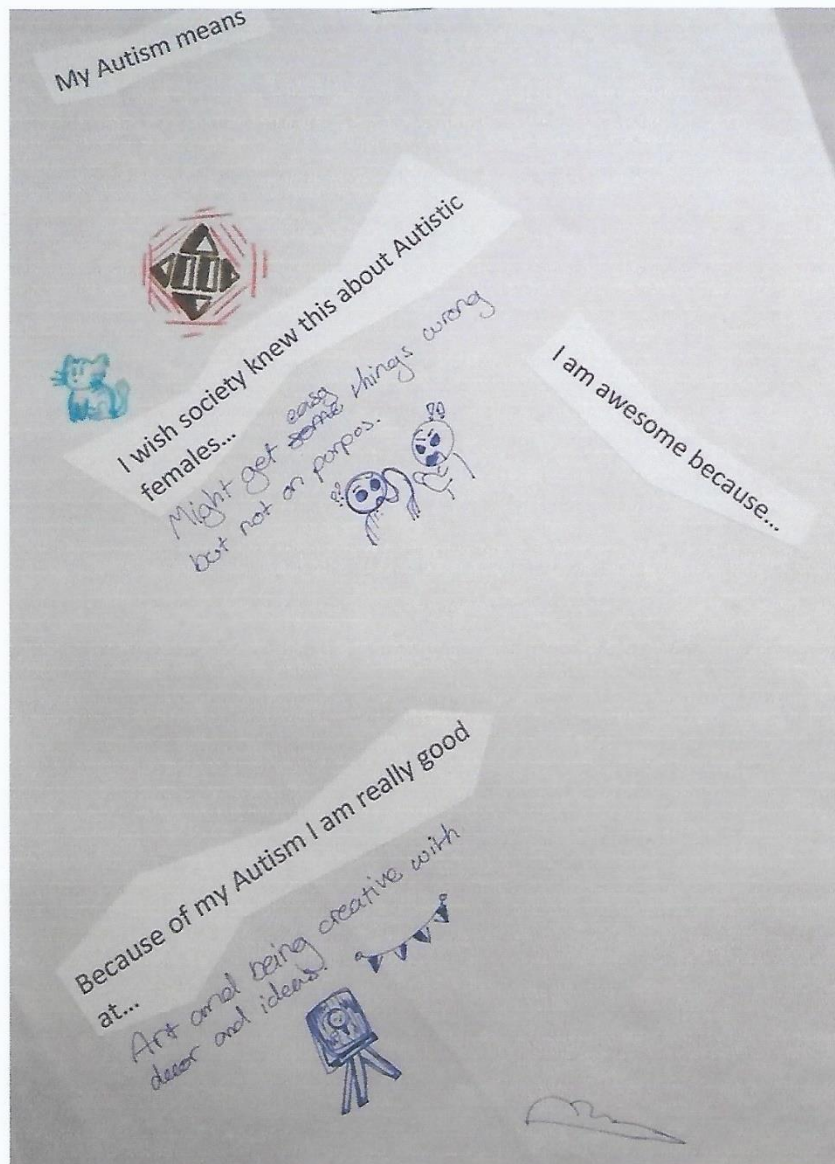
1. I am awesome because...
2. My autism means...
3. Because of my autism I am really good at...
4. I wish society knew this about autistic females...



Beth Celebrating our autistic strengths activity.

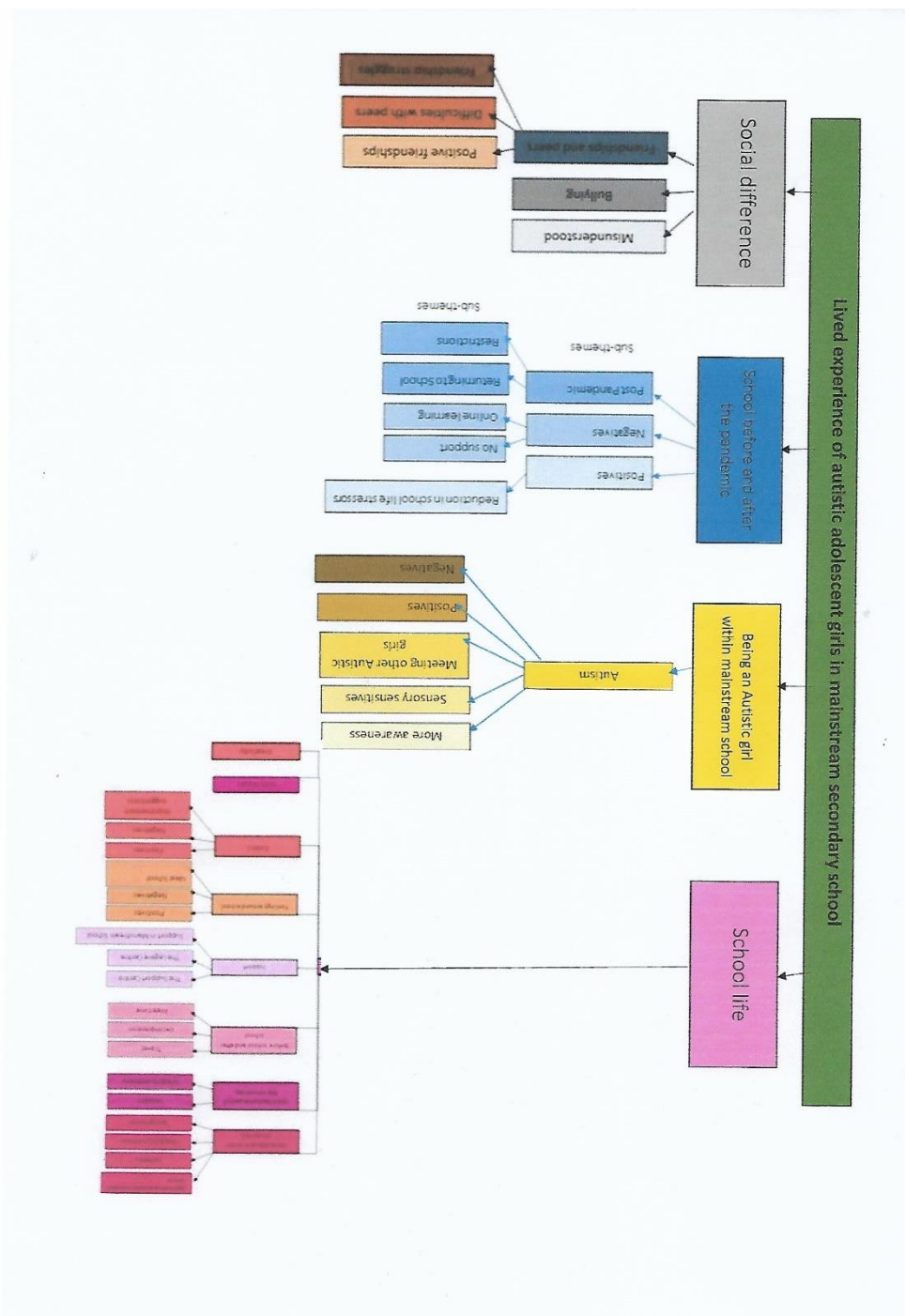


Poppy Celebrating our autistic strengths activity.

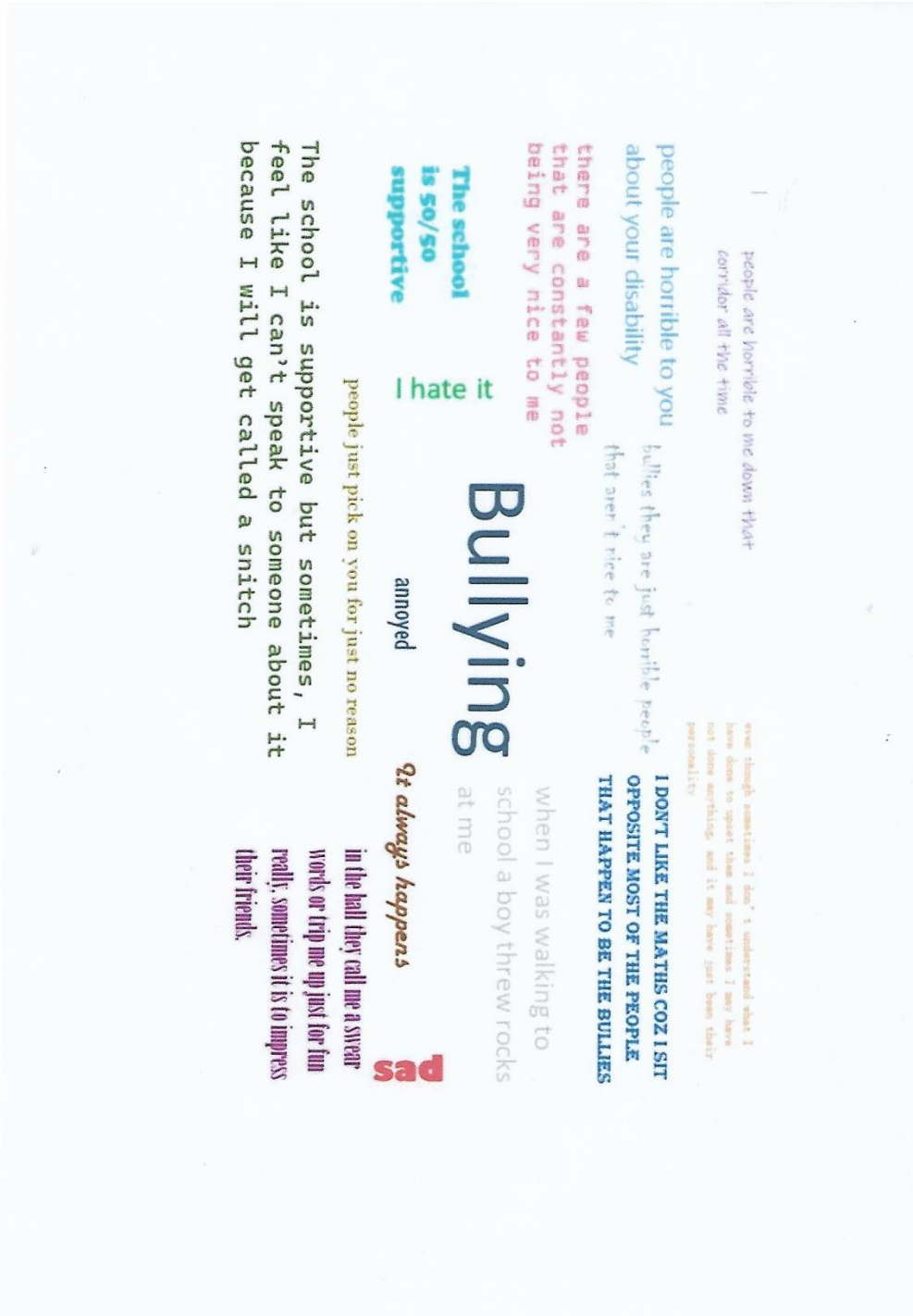


Zakia Celebrating our autistic strengths activity.

Appendix (13) Thesis themes



Appendix (14) WordArt from data



Arguments during break and lunchtime causes me anxiety

Sometimes I go to the library, sometimes I go outside into the playground and speak to people and chat with people and sometimes I may also go to the Support Centre

At break and lunchtime, we get to go outside and take the masks off for a little while which I liked; but the problem is I never actually got to because the horrible people were there, so I had to stay inside and keep my mask on the whole time except for when I was eating but you have to sit down for that.

Break and Lunchtime

The part of break and lunchtime I don't like is when I have arguments with people and sometimes breakfast is an opportunity to have arguments with people and that's the bit I don't like because there is like opportunity there

I like break and lunch time usually but where we go because of the bullies again they are just always there

IT IS KIND OF A BIT OF A MIX. SOMETIMES JUST GO AND HIDE NEXT TO DRAMA OR RRM WHERE NO ONE CAN SEE ME

Where I go is different each break and lunchtime

I would just see like loads of teachers like I will go to my old farm teacher because that is a bit of a nicer environment than the new farm I am in

they are hard

Upset

I hate science, I absolutely hate it

pressured

EXAMS

feeling stressed

nervous

angry

quite stressful

they are boring

Exams, if it means that you get to miss a lesson that is fine

makes me feel like the school only wants me to fail, even though they want me to pass



I would genuinely just wait for my Mum to bring me up a big snack plate with like all of these different foods on and I would just sit there watching TV

yay I only have to walk about a metre and then I am sitting down at my desk

I didn't have professional teachers, not necessarily all the resources you needed for it support when working to do my work at home

don't have to worry about big crowds

I think lockdown caused quite a lot of arguments for families

there's no drama

they don't be rude

I started doing more work and then I understood what I was doing

last pandemic I got like 85 homeworks because there were so many classes to do made me quite stressed

SO MUCH BETTER THAN BEING AT SCHOOL

it is not

I definitely didn't get anywhere near enough work as I usually did or used to before the lockdown of the school

Lockdown/home-schooling

very loud

when I knew that my Mum wasn't coming up and checking on me, I would just play games

I can't lie, I never actually got much work done

they don't talk loudly

started rough because I was losing focus with everything around my room

comfortable in my own clothes mostly pyjamas

NO ONE COULD REALLY CONTACT YOU

if felt awkward coming back to school and seeing everyone

I was happy but my parents weren't enjoying it and I started to realise that I wanted to go back to school

Home schooling, that was brilliant

I missed the teachers, yes, students not so much

I did some of the work, some of them I didn't understand I was worried that when we get back to school, I would get a really big detention

I actually quite liked it was quite to have to go to school

I was quite happy because yay I get to go to school in my pyjamas

I did enjoy the fact that I could just watch TV a breacktime

I REALLY JUST COULDN'T BE BOTHERED. IT WAS JUST LIKE WE HAD TO COME BACK, CAN'T WE JUST LIVE. JUST NEVER GO BACK TO SCHOOL AGAIN.

I didn't feel it was fair in some ways coz people were like oh yeah, I have a broken ankle, I can't wear a mask if you know what I mean.

At first, I was a bit upset that I couldn't walk a cart, trolley or a trolley to my desk.

social distancing that was hard

I didn't like the masks; I didn't actually have to wear them. I got an exemption card.

I just got used to people around me wearing masks.

I feel like it should be like everyone has to wear a mask or no one wears a mask.

I just really didn't like going back to school.

I AM NOT MUCH OF A HUGE PERSON, BUT NO INTERACTION FOR A LONG TIME. I DON'T LIKE

Mixed teachers vs. students not so much.

I didn't like the restrictions; I didn't really like the fact that I could touch anyone or hug anyone or even high five someone.

I just really didn't like going back to school.

once I was back in school and I saw everyone I was pretty happy for a while.

I hate having to walk around the one-way system, I found the one-way systems boring.

with nobody coming back to school and seeing everyone.

RETURNING TO SCHOOL AFTER LOCKDOWN

masks were genuinely okay.

I don't know what their expressions were like on their faces, and I don't know if they were pulling faces at me or doing stuff they shouldn't be behind the mask, and I didn't like that.

It was quite hard to get over the one-way system.

a lot of work to catch up on.

masks make me feel claustrophobic like I couldn't breathe.

the masks were ok, but sometimes, if you wear them for a whole day or a long time, it is hard to breathe with them on.

I didn't like wearing a mask it made me feel uncomfortable.

teachers got to take their masks off when the lesson started because they were in their boxes. found it unfair I guess coz we weren't allowed to take ours off because we were sitting down.

they are just awful, if you ever wanna go, then you will know Girl's bathrooms are the worst

I don't go to the school toilets when I am at school

The all-gender toilets are better because well just it's just one room and no one can just walk in

it is just really disgusting there, girl's hangout in the girls' toilets are disgusting there eat food

The Girls toilets

there is a lot of horrible things written on the walls, but I genuinely find the toilets okay

they are much cleaner than the boys' toilets

I don't like when you go in and there is a big crowd of people sitting in there with vapes in their hands.

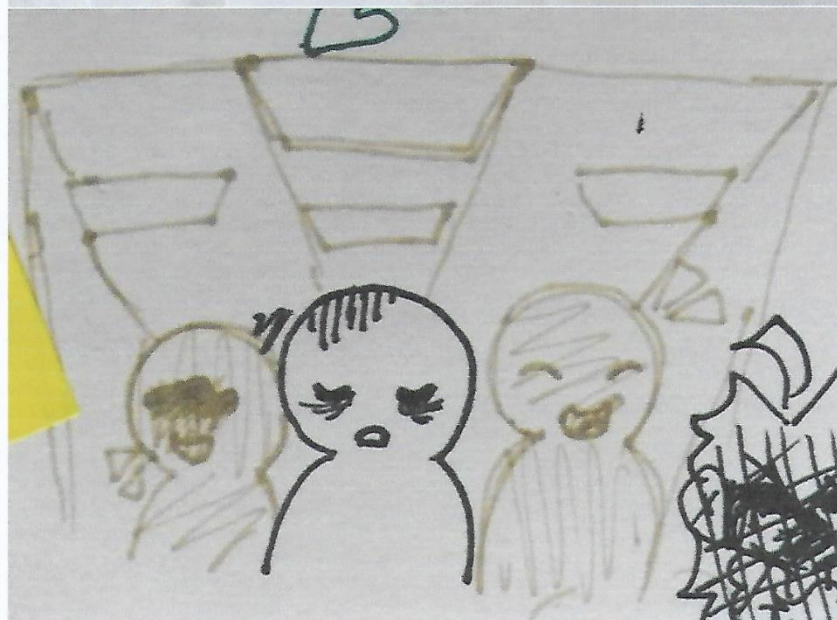
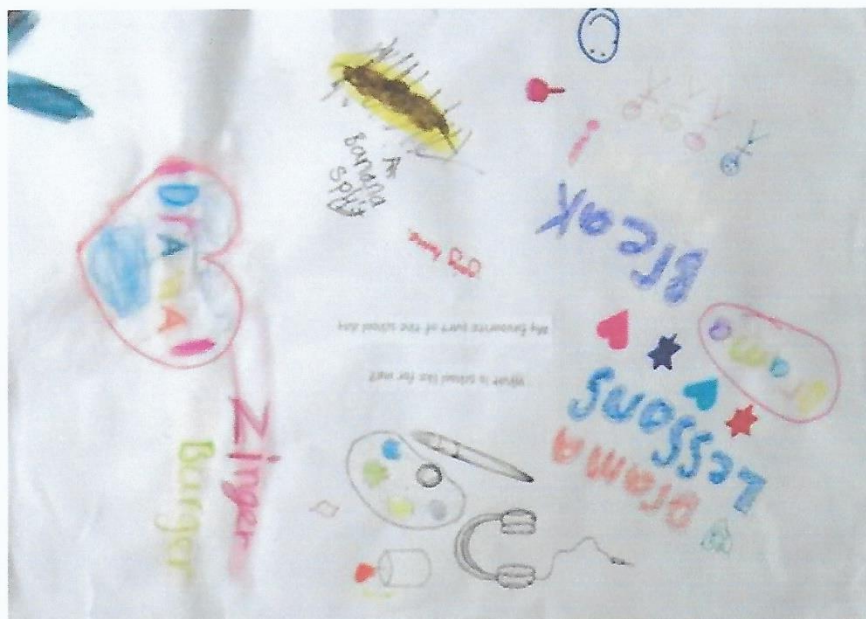
I don't like the fact that erm you go in and there is literally half used toilet roll still on the actual thing, you are just like erm I don't want to use that.

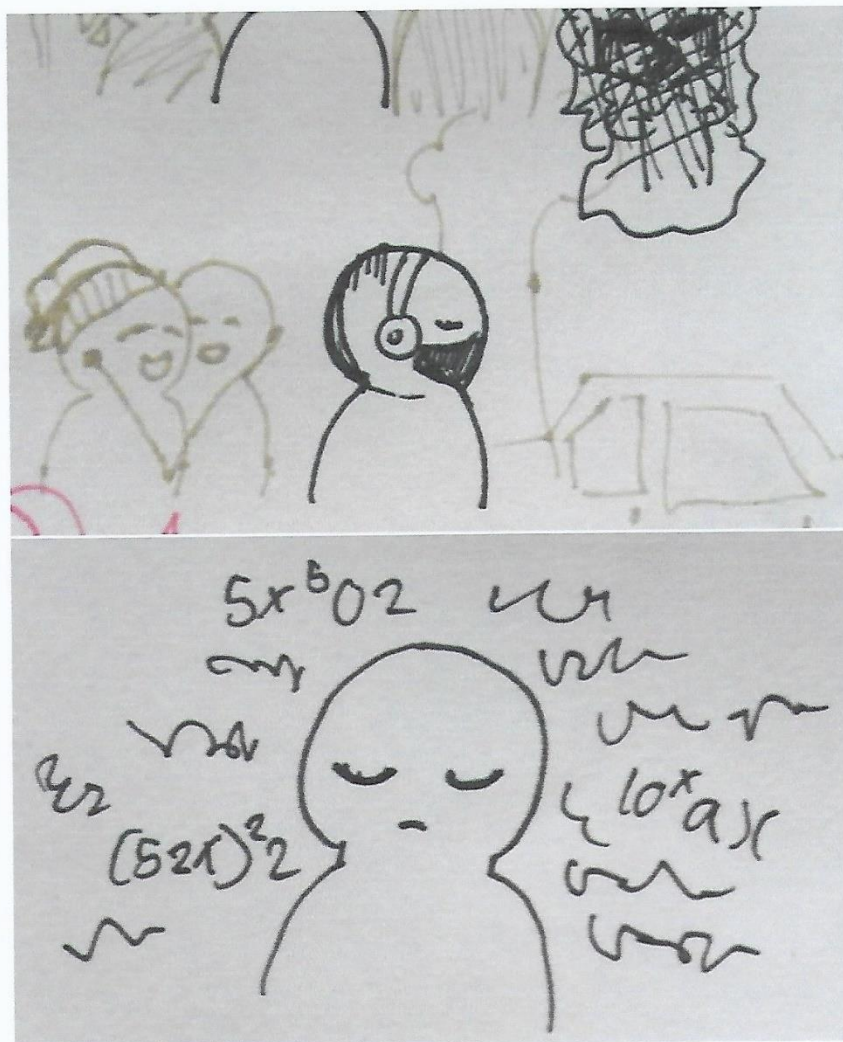
NO BODY REALLY HANGS OUT IN THE ALL-GENDER TOILETS WHICH I FIND EASIER *try and avoid, if I do need the toilet I just try to go to the all-gender toilet*

I like the toilets down in the Support Centre, though I have a constant fear that I might get locked in because the toilets are locked, and you must ask for the key

Appendix (15) Artwork from the project



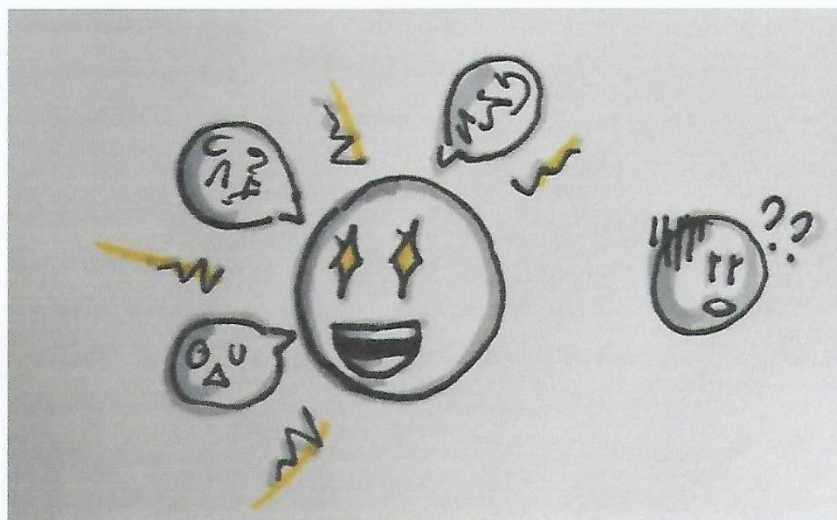


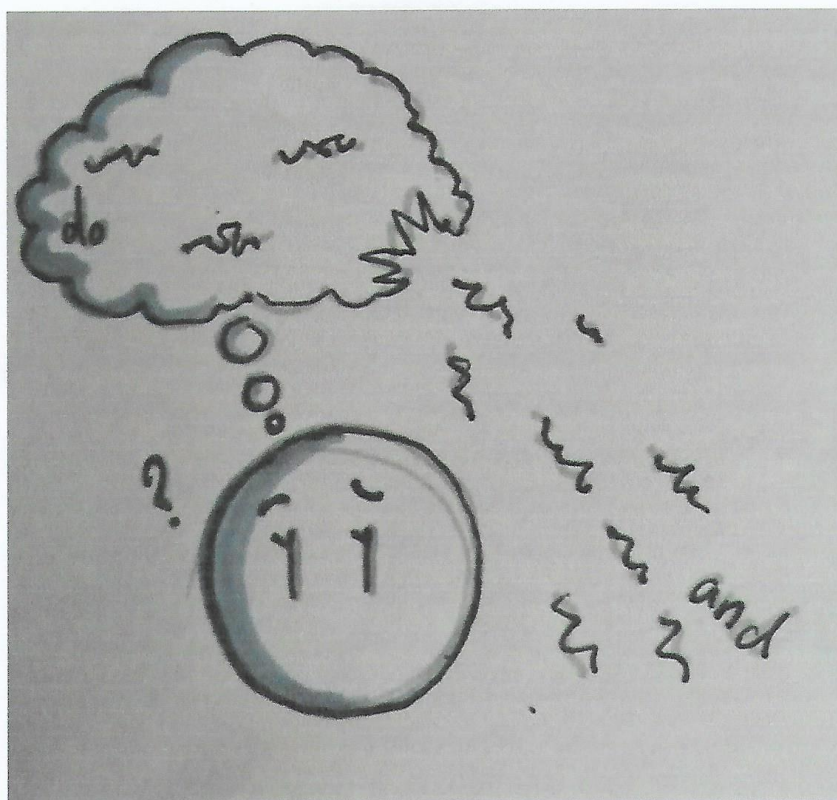


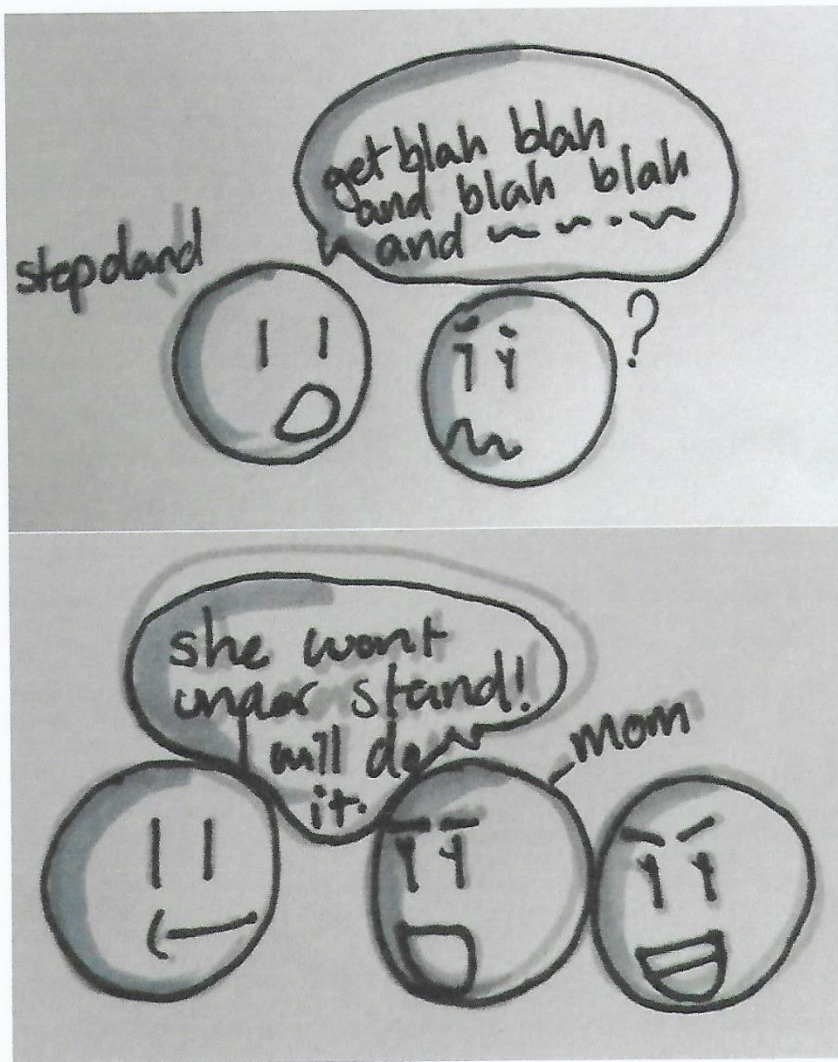
School is
boring.











I Deal

TY = Thank you

ok, have a day off

TY

(Be more understanding teachers)



time out room
(music, food, drink, books)

Board
17x8

Big writing
(I always forget my glasses)

Always got friends

HAPPY

can play?

No Bullies at all

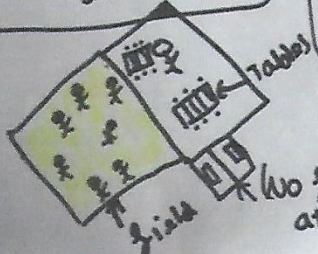
Bully

Last chance BOB!

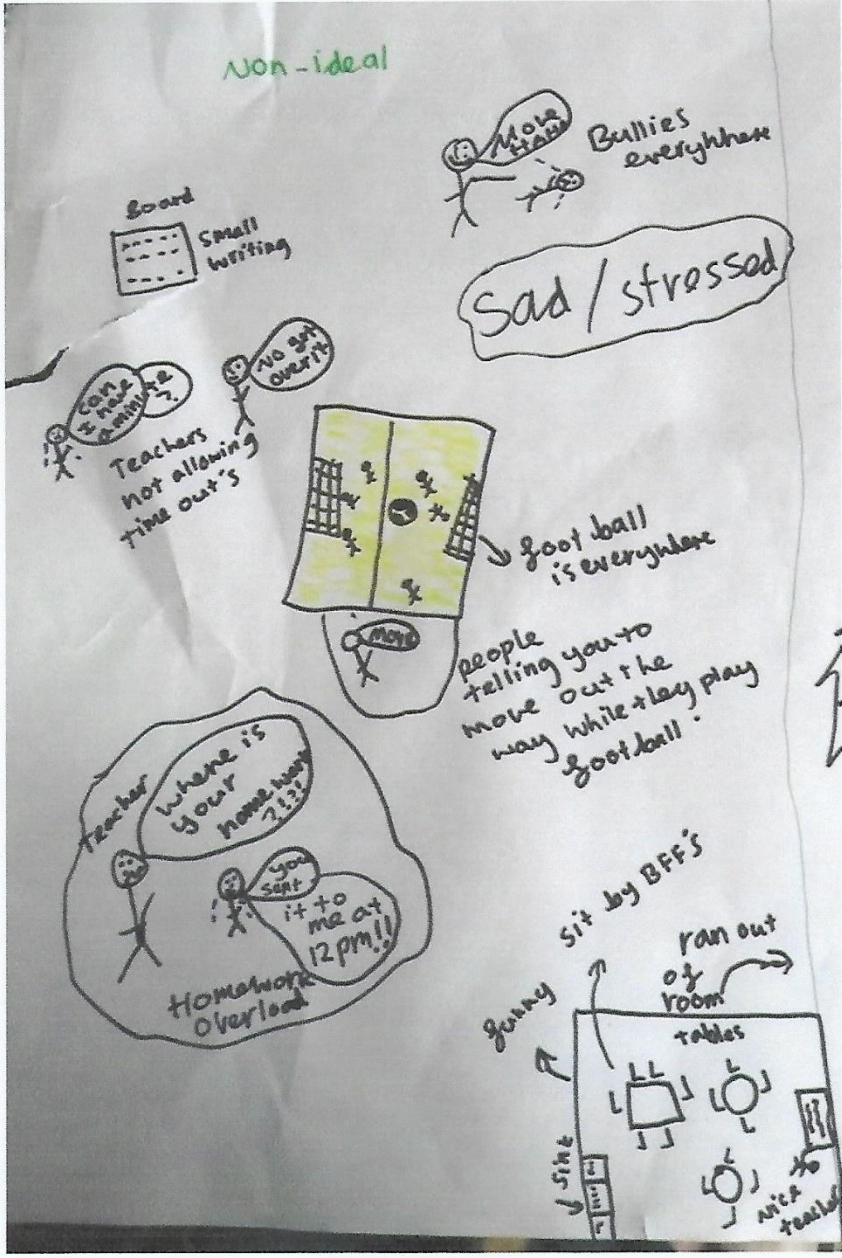
Teacher

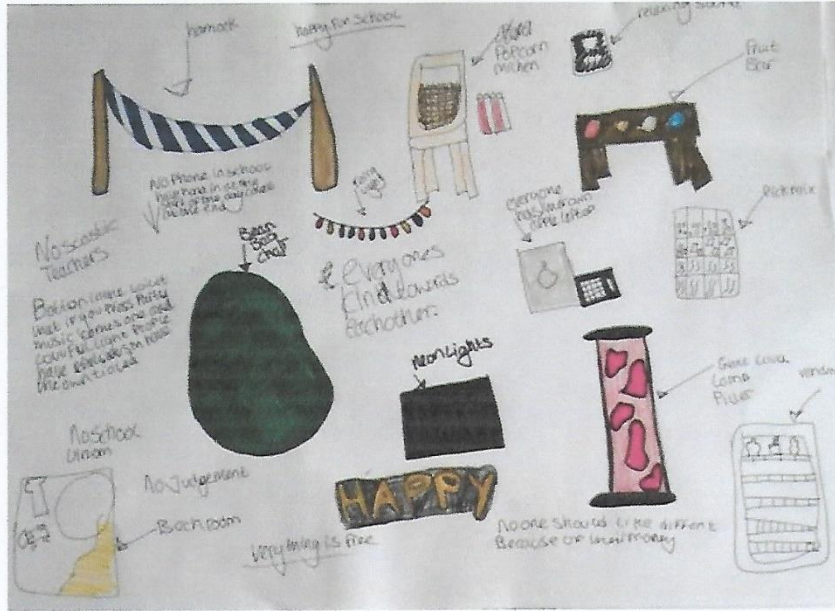
Sad

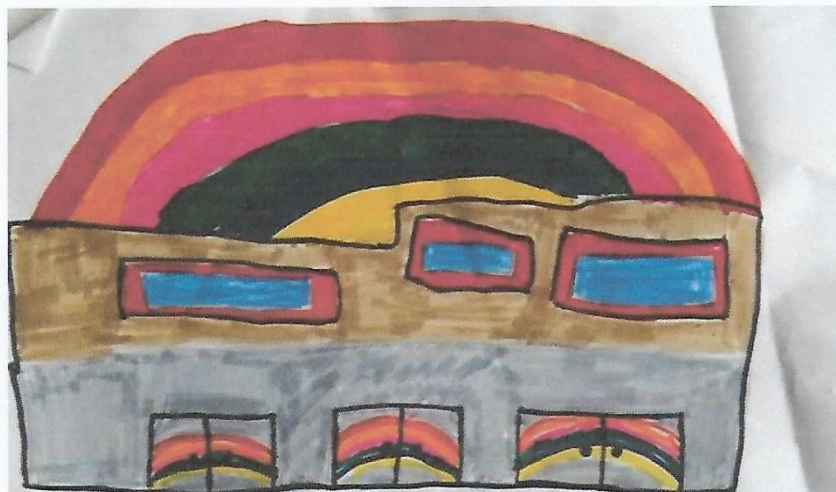
Bullies to be actually dealt with



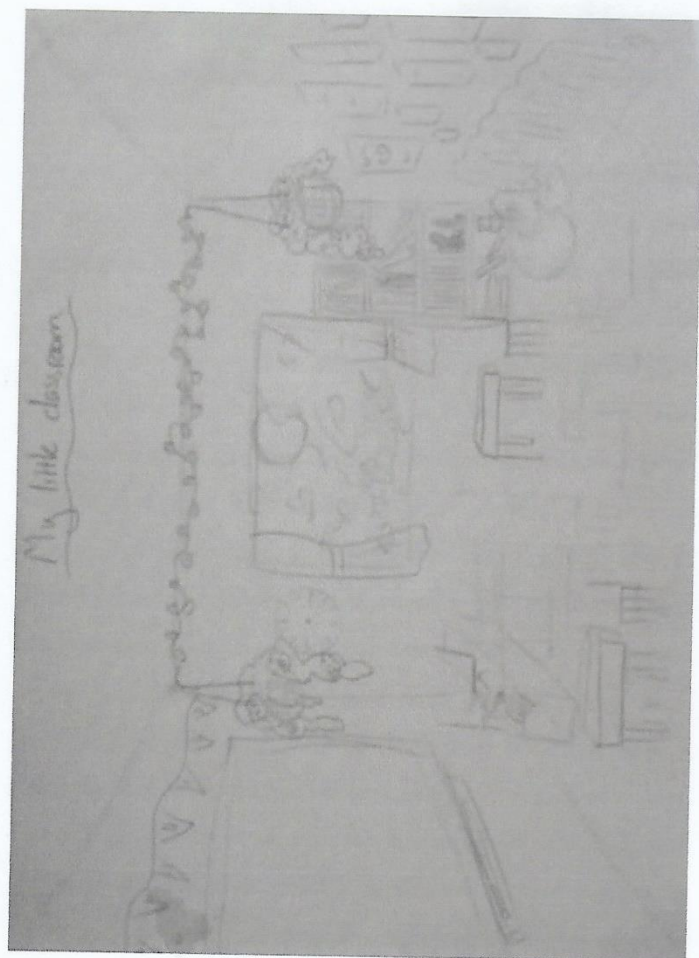
(No football at lunch, only break)







I would want all of the pupils to
decide them selves what kind of
person they want to be.
That evreypne is treated equally



Appendix (16) Prompts used in one-to-one workshops.

This research project is about listening to your experiences of School. It's not appropriate for me to hear or talk about things that are outside this research area.



*Listening to your experiences of
school*