DOCTOR OF PHILOSOPHY

Missing voices
The educational experiences of girls with autism

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Missing Voices:
The Educational Experiences of Girls with Autism.

by

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A dissertation submitted as part of the requirements for the Degree of Doctor of Education in the School of Social Sciences, Education and Social Work, Queen’s University, Belfast

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Abstract: Missing Voices - The Educational Experiences of Girls with Autism.

The presentation of girls with autism varies considerably from boys’ presentation upon whom most of the diagnostic and support literature is based. It would appear that this historic and androcentric approach continues to inadvertently reflect inaccurate statistics for girls with autism. In some instances, girls are primarily identified with a learning need or mental health difficulty that is ultimately masking autism. The female presentation of autism remains largely unexplored and in particular, the adolescent female perspective of autism has had limited voice.

Photovoice, a participatory arts-based method, lends itself to the widespread adolescent use of smart phone technology including the use of cameras to document daily lives on social media. This research harnesses the use of this type of informal documentary photography to provide insights to the underrepresented world of adolescent girls with autism and aims to enlighten those stakeholders with either a vested interest or an outright obligation to support them.

This research engages collaboratively with nine girls with autism (11-18) in four post-primary schools across Belfast. Photovoice is used to expose both the challenges and coping strategies adopted by these girls. Using Interpretative Phenomenological Analysis (IPA), the research uncovers six main themes in portraying the lives of the participants: School as a safe place; Obstacles to learning; Importance of idiographic curriculum; Sensory overload; Coping strategies; and Identity and Challenging the Assumptions of autism. To increase the wider understanding of girls with autism and to fulfil the goal of Photovoice, the research also culminates in three photographic exhibitions at: Queen’s University Belfast; the Northern Ireland Assembly at Stormont; and the University of Atypical for the Belfast International Arts Festival 2019.

The findings of both the IPA and Photovoice exhibitions are critical in subsequently informing those stakeholders involved in curating transition support services and in-school interventions for girls with autism. This pioneering use of Photovoice by girls with autism demonstrates that the voices of these girls have been previously overlooked and need urgent, idiographic acknowledgement across support and education services.
while simultaneously cultivating civic responsiveness in terms of neurodiversity, specifically girls with autism.
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Finally, this thesis is dedicated to my two daughters Lucy and Janey. You are the future empowered young women of this world, many determined young women have gone before you, fighting for your voice to be heard, fighting for your place in society, make sure you take your place and carry on the fight.
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Chapter 1: Introduction

Autism in children is characterised by challenges relating to social communication and emotional intelligence as they interact with wider structural and cultural barriers in a neurotypical society (Cleary and Hayes, 2012; Attwood, 2007). A key consequence of these challenges at an individual level is elevated levels of anxiety for which children with autism have limited coping strategies (Fritschie, 2010). School and all its written and hidden curricula can be a potential trigger for this anxiety and more importantly, these triggers are often unacknowledged or unanticipated by neurotypical educators (Tsai and Ghaziuddin, 2014). Yet school is where a student with autism will spend five days a week, for upwards of twelve years of their childhood.

There exists a plethora of resources and support available for addressing anxiety, developing neurotypical social skills while enhancing the lay educator’s understanding of autism. However, it could be argued that these interventions, while worthwhile, are more suited to, and reflective of, the male presentation of autism. There are two possible reasons for this proposed androcentrism. Firstly, research indicates that more boys than girls are identified with autism suggesting that criteria for identification is more attuned to the male behaviours associated with autism than the female behaviours (Gould, 2017). Secondly, girls and women with autism may be more adept at masking autism than their male counterparts, often receiving alternative primary diagnoses before autism is identified (Tierney et al, 2016). Either way, while acknowledgement of the gender gap in autism is emerging in literature, there remains limited advancement in our understanding of how this translates to the actual lives of girls with autism, especially those in adolescence in the transitional years of post-primary school. Their struggles and challenges in schools, their coping strategies for social anxiety and social interactions in the context of a neurotypical environment remain largely undocumented. Furthermore, the camouflaged female presentation of autism, by virtue of its subtlety, is dominated by its male counterpart and so the female voices of autism remain unheard (Dean et al, 2017).
This research aims to give voices to girls who are marginalised not only by their individual learning experiences but also by the imposed etic of the male perspective of autism. This assertion comes from my position as a Special Educational Needs Coordinator (SENCO) in a co-educational post-primary school in Belfast, Northern Ireland. Having worked in the field of autism for over twenty years, I have observed this gender marginalisation first-hand in mainstream education and remain frustrated by the lack of regard given to the finer differences in autism between girls and boys. Furthermore, I am crucially aware of how the absence of bespoke educational interventions and supports for girls with autism can negatively impact on their mental health wellbeing and future quality life outcomes as adult-women.

Research into the behavioural and emotional differences between boys and girls with autism and in particular, those with what is understood as high functioning autism (discussed in Chapter 2.2), is beginning to emerge in literature. Pisula et al, (2017) quantitatively suggest there exists different phenotypes for male and female autism but their research also concludes that, while some gender differences exist in the internalising of emotions in girls and the externalising of behaviours in boys, the extent of these differences remains statistically insignificant. However, this study subsequently acknowledges that their sample was not representative of the population with autism in Poland.

Pathologising autism in a positivist fashion does not give the full picture of the neurodiversity that is autism. This is supported Dean et al’s, (2017) argument that the subtle differences between male and female autism profiles are undetectable in positivist research due to the variation and unpredictability of autism itself and the undeniable ability of girls to mask the associated challenges of autism. Tierney et al’s (2016) interpretive phenomenological analysis acknowledges the subtlety of these gender differences, in particular in the management of social relationships by girls with autism. In support of this research’s proposed gender differences, the girls with autism interviewed in Tierney et al’s (2016) research highlighted their own perceived differences from boys with autism especially in terms of their autism identity as opposed to any autism deficits. Furthermore, Tierney et al (2016) elicit themes regarding the normative misconception that girls with autism have an inability to show empathy on the basis that boys with autism have difficulty demonstrating the
neurotypical version of empathy. This suggests that adopting a qualitative approach, in particular one that recognises the value of the phenomena of experience, has the potential to glean a deeper understanding of the experiences of girls with autism. Gould (2017) directly addresses the under-recognition that girls with autism are experiencing. She warns of the quantitative discrepancies that can be made when investigating sex differences in autism and highlights the importance of gaining insights from individuals with autism rather than enforcing cut-off statistical parameters. Vine-Foggo and Webster (2016) further demonstrate the benefit of seeking first-hand knowledge in their phenomenological inquiry of seven girls with autism. The lived experiences of these girls is insightful and actually pedestals the female perspective of autism by omitting any comparison of the sexes.

However, both girls and boys with autism can face communication barriers when articulating their feelings and therefore the use of language-based research could be an erroneous method to employ when seeking direct insight (Mesibov and Howley, 2003). In the case of narrative inquiry, Gillam et al (2015) clearly link the perceived core features of autism: theory of mind, executive functioning and central coherence with barriers to normative conventions of narrative proficiency. Baixuali et al (2016) conducted a meta-analysis of twenty-three different studies which considered the oral narrative abilities and performance of children with autism in both storytelling and autobiographical accounts. Children with autism consistently faced more obstacles in demonstrating performance when compared to their neurotypical peers in all aspects and so this may therefore limit the appropriateness of narrative inquiry as a sole method for engaging children with autism in research. Contrastingly, Bottema-Beutel and White (2016, p.362) argue that children with autism do “display some sensitivity to discourse contexts when formulating narratives” and while they may experience barriers when expressing the emotions behind their stories, facilitating the use of photos or images to aid discussion can facilitate the child with autism’s participation in the research process (Teti et al, 2016).
The careful selection of arts-based methods in educational research has the potential to elicit deeper insights into all students’ worlds (Leavy, 2009). Arts-based methods remove the necessity for language proficiency against normative standards and enable participants “to be open to what is not yet known” (Walsh, Bickel and Leggo 2015, p.1). One such technique is the participatory research method of Photovoice (Wang and Burris, 1997) which is considered by Jurkowski and Paul-Ward (2007, p. 363) to be “a useful method for engaging people with limited social and communication abilities.” The benefits of the use of Photovoice in public health research are outlined in the extensive literature review conducted by Catalani and Minkler (2010) with Obrusnikova and Cavalier (2011) demonstrating the first use of Photovoice with participants with autism. The combination of this unique and under-researched group: girls with autism; with the bespoke and creative arts-based method of Photovoice could potentially address the current dearth of research in this area by illuminating and platforming the experiences of girls with autism.

1.1 Research Aim and questions of “Missing Voices”:

The research aim and questions of this research study are set out as follows:

Aim: To present the educational experiences of girls with autism through Photovoice.

Research questions:

1. What are the challenges faced by girls with autism in the transitional years of post-primary school?
2. What are the coping strategies used by girls with autism in the transitional years of post-primary school?
3. How can the personal experiences of girls with autism be used to increase educational awareness and inform educational practice in supporting other girls with autism during their post-primary education?
1.2 Organisation of further chapters

Chapter 2 considers the research literature informing current understanding and practice relating to autism. Chapter 3 interrogates the methodologies used to conceptualise autism subsequently proposing the use of creative participatory arts-based methods as an appropriate means of uncovering the voices of girls with autism. Chapter 4 outlines how Photovoice was employed in this study with Chapters 5 and 6 respectively depicting the findings of the Photovoice through an Interpretative Phenomenological Analysis of the photographs and a discussion of the impact of the Photovoice exhibitions. Chapter 7 concludes with a summary of the overall findings of the research in relation to the aforementioned questions and outlines further recommendations for future research including implications for my own professional practice.

This literature review aims to consider how autism has been normatively defined and redefined through diagnostic revision and practice. The chapter also considers gender differences in autism and the corresponding co-existence of other conditions alongside autism. The educational context of autism is discussed with a focus on inclusion concluding by locating the research within autism provision in mainstream education in Northern Ireland.

2.1 Defining and contextualising autism.

Definitions and understandings of autism continue to evolve over time. The International Classification of Diseases, 11th revision (ICD-11)(WHO, 2019), categorises ‘Autism Spectrum Disorder’ as a neurodevelopmental disorder. The term ‘autism’ is commonly used by health professionals in a medicalised way to refer to a suite of pervasive developmental disorders sharing a commonality of difficulties in relatedness, social interaction and social communication and characterised by special interests with restricted/repetitive behaviour patterns (American Psychiatric Association, 2013; Dudova et al, 2015). ICD-11, which will come into practice in January 2022, refers to variations of ‘autism spectrum disorder’ with or without a disorder of intellectual development and with or without absence of impaired functional language. These variations replace previously known sub-types of autism where the term ‘spectrum’ was umbrella-like in accounting for those diagnosed with severe forms of autism right through to milder but no less significant manifestations such as high functioning autism or Asperger syndrome (Ritvo, 2006). Use of the term ‘disorder’ throughout such classifications pathologises autism and detracts from the strengths and capabilities of people with autism, these medical connotations and associated use of deficit language continue to reinforce the cultural and structural factors that exclude and marginalise people with autism. In this study and in recognition of the neurodiversity that is autism as opposed to the medically classified synopsis of it by neurotypical health professionals, the term ‘autism’ is used rather than ‘autism spectrum disorder’ henceforth.
It is estimated that 1 in 100 people in the United Kingdom (UK) are identified with autism, reflecting a population of 700,000 (Baird et al, 2006; Brugha et al, 2012). Of this 700,000, Fombonne et al (2011) specify the UK school-aged population with autism as 137,607. In the United States (US), the number of school aged children (6-17) identified with autism has increased over a five-year period (2007-2012) from 1% to 2% (Blumberg et al, 2013). In 2011, the number of adults with autism in the United Kingdom increased to between 1.1-1.2% (Brugha et al, 2012) and statistics reflecting the population with autism continue to increase. Furthermore, a searing gender gap in autism also exists: in 2010, the male to female ratio for autism was predicted as 4:1 in the United Kingdom. Taylor et al (2013) later reinforce evidence for this gender gap with ratios of 3.9: 0.81 for eight-year old boys and girls in the United States.

The numbers reflecting those with autism could be deemed inconclusive as they do not accurately account for the population of unidentified people with autism. Historically, Ritvo (2006) considers that at the higher end of what was called the ‘autism spectrum’, Asperger syndrome was relatively new in its addition to the classification of autism and it is conceivable that prior to this addition, many adults and children with what has been labelled high functioning autism/Asperger syndrome were under-identified. The current increase in the number of adults seeking health professional investigations for autism (Abbot et al, 2018) and Isaksen et al’s (2013) interrogation of what they perceived as the possible epidemic status of autism is further evidence of the inadvertent inaccuracy of rates of autism. However, this inaccuracy is increasingly acknowledged and significant work is ongoing to more holistically present these statistics (McConkey, 2020). Tierney et al (2016) demonstrate that the gender disparity in population rates of autism has been a feature of autism since its conception by Kanner in 1943 and that the current biased gender statistics are testament to the ability of females to avoid identification through their coping strategies or camouflage skills (Dean et al, 2017).

In the 1940s, both Kanner and Asperger simultaneously charted what they called ‘deficits’ in theory of mind and executive function pronouncing weak central coherence and autistic psychopathy, reclassified by Wing (1981) as the triad of impairments. Autism remains synonymous with barriers to social communication, highly specific interests and repetitive behaviours (Attwood, 2007), the variations of which are cited in
ICD-11 (WHO, 2019). Specific classification of autism remains inextricably linked with intellectual development and language ability ultimately shaping both the presentation and ‘prognosis’ for each individual hence the umbrella classification of a ‘spectrum’. Those individuals without “disorder of intellectual development and with mild or no impairment of functional language” (WHO, 2019, p.6.2) are deemed to have the greatest potential for surmounting any difficulties. However, the continuing use of reductionist classification systems on the basis of intellectual functioning and attempts to measure ‘impairment’ once again ignore neurodiversity (Rosqvist et al, 2020). Creating hierarchies within the population of people with autism on the basis of language and intellectual development further imposes structural and cultural boundaries and contributes to the exclusion of individuals on the basis of normatively adopted neurotypical markers of functioning.

2.2. The difference between autism and Asperger syndrome/high functioning autism

Prior to the publication of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) (American Psychiatric Association, 2013) the distinction between autism and Asperger syndrome (hereafter AS) was understood as definitive (Dudova et al, 2015). At least average intelligence, age appropriate language acquisition and cognitive functioning differentiated AS and autism and consequently individuals with AS were ‘permitted’ to attend mainstream schooling as opposed to the exclusionary special schooling traditionally afforded to those with autism (Volkmar & Klin, 2000; Edwards, 2012; Jarman and Rayner, 2015; Kauschke et al, 2016). Those with AS could expect more independent futures in terms of independent living, adult relationships and the potential to hold down professional jobs unlike those with autism whose adult lives were deemed to require supported living arrangements and limited independence (Ritvo, 2006). This is indicative of the ways in which different forms of categorisation can manifest as positive or negative in practice. AS is perceived to be characterised by challenges with higher order executive functioning namely obstacles to understanding abstract and complex ideas and inferential thinking (Attwood, 2007). It is through the comparison of individuals with AS and their non-AS peers that the nuances of AS become increasingly distinct, among them, the challenges presented by multiple
instructions (Jarman and Rayner 2015), socially incongruous expressions of the normative understanding of empathy and relatedness, (Milton, 2012), and both heightened and diminished sensory sensitivities (Wing et al, 2011). Deviation from ‘normalised’ and socially acceptable behaviours and experiences are thus presented as problematic and an inherent individual shortcoming for which they bear the burden, rather than bearing any relation to the world in which we live.

The aforementioned gender gap with regard to identification of autism is understood to be more pronounced in AS with ratios between males and females reaching between 8:1 and 10:1 (Fombonne et al, 2011; Tierney et al, 2016; Pisula et al, 2017). The disparity among identification rates for AS could reflect the indistinguishable aspects of AS versus high-functioning autism (Jarman and Rayner, 2015). This is further compromised by the lack of precise and objective indicators for developmental milestones in social competence, a marker which contributes to the classification of both AS and high-functioning autism (Wilkinson, 2008). AS tends to be identified later than autism (Pisula et al, 2017), marrying with Ozonoff et al’s (2000) assertion that AS and high-functioning autism are one and the same but have different developmental pathways merging by adolescence.

2.3. The removal of Asperger Syndrome as a discrete term from DSM-5

Controversially, this disparity of conclusive research led to Asperger syndrome, along with other subtypes of autism, being removed as a discrete term in the reviewed DSM-5 (American Psychiatric Association, 2013). The current DSM-5 now identifies autism in relation to the significance of characteristics associated with autism as opposed to the distinguishing features of previous subtypes (Jarman and Rayner, 2015). Outside of the US, the DSM-5’s equivalent, the International Statistical Classification of Diseases and Related Health Problems, 11th Revision (ICD-11) (WHO, 2019), has according to Hong et al, (2020) retreated in its willingness to identify sub-types of autism due to a lack of sufficient biological evidence and more broadly classifies autism spectrum disorder citing variations in behaviours and their impact across different levels of functioning. Recent research suggests that the removal of AS as a distinct term from the DSM-5 is premature and not supported by those working in the field (Tsai and Ghaziuddin, 2014). More importantly, the removal of the term is criticised by those individuals who have
been identified with and identify as having Asperger’s or ‘Aspies’, a term affectionately adopted by those on the higher end of the spectrum (O’Reilly & Wicks, 2013). Considering that two thirds of those identified with autism were classified as high-functioning or Asperger syndrome, this new subsuming adversely affects the greater population of individuals with autism (Jarman and Rayner, 2015) and perpetuates the continuous marginalisation of this neurodiverse population by restricting its identity in diagnostic and medicalised charters.

2.4 Gender differences within autism and discussion of possible androcentric diagnostic criteria

Originally both Kanner (1943) and Asperger (Wing, 1981) focussed on the presentation of autism in boys. While later revised, Asperger considered that girls were not affected by autism (in Wing, 1981) and similarly Kanner’s original study concluded that autism was four times more likely in boys than in girls (Kanner 1943). In Wing’s (1981) review of both Asperger’s and Kanner’s research, she establishes lower instances of gender disparity in autism at 2:1 male to female however at the higher end of the spectrum this rose to 16:1. Gould (2017) later reviewed Wing’s research and cautioned that Wing’s ‘autism sex ratio differences’ did not account for girls with autism in mainstream education and merely represented those girls with more severe presentations of autism. Considering that early populations of autism are now among the adult population within the UK, it is unsurprising that Brugha et al's (2012) survey (N=290) confirms this gender disproportion with 1.8% of adult males surveyed disclosing an identification of autism, compared to 0.2% of adult females. In the UK in 2015, the male to female ratio using National Autistic Society (NAS) adult services was estimated at 3:1, and for those using NAS schools the ratio was 5:1 (NAS, 2016).

The possible explanations for such gender discordance are two-fold. It is conceivable that autism is a predominantly male condition which would suggest a genetic or biological indicator as investigated aetio logically by Rimland (1964) and genetically by both Lord and Schopler (1987) and Skuse (2000). Baron Cohen et al (2002, p.248) interrogated ‘extreme male brain’ theory suggesting that autism is the result of a brain more competent at systemising than empathising. While these findings have been useful
in furthering the understanding of the male presentation of autism, it still does not account for the possible gender discrepancy within identification rates with Kauschke et al (2016) concluding that gender differences in the phenotypes of males and females with autism require further research.

The second possible explanation considers the methods used to classify autism. With early research concentrating on male presentations of autism, it is entirely plausible that the screening criteria emerging from such research is based on this male presentation and is therefore androcentric (Wilkinson, 2008; Lai et al, 2011; Kauschke et al, 2016). Evidence to support this supposition comes from Gould and Ashton-Smith (2011) who attribute the steady increase of adult women seeking autism screening to the historic male bias of diagnostic criteria and this is further supported by Pisula et al’s (2017) finding that girls are typically identified with autism significantly later than boys.

Tierney et al (2016) suggest that there is a mismatch between female presentation of autism and the criteria for autism and with the new ICD-11 (2019) omitting acknowledgement of gender differences in autism, this continues to be a fair assumption. Wilkinson (2008) suggests that the clinical criteria used to identify autism overlooks female nuances and behaviours such as levels of perfectionism and internalised anxiety and Tierney et al (2016) claim that this unintended inattention to gender differences has perpetuated inaccurate autism population rates.

Gould (2017) notes the mounting evidence that professionals using these clinical instruments are less likely to confirm autism in girls but acknowledges a shift in improved understanding of how autism may appear differently in girls and therefore may need to be identified in a different way to boys. This is supported by both Duvekot (2017) and Goodall and MacKenzie (2019) who attest that girls fulfil some of the criteria for autism but their absence from the compulsory criteria of restricted specific interests and repetitive behaviours can result in under-identification. Kauschke et al (2016) describe this as the male stereotype of autism and the small, androcentric samples used to validate the clinical instruments used for identification maintain the evidence for gender bias (Bloss & Courchesne, 2007). Revisions to the criteria to include both male and female nuances of the presentations of autism are heralded and
considered to have the potential to address this gender imbalance (Gould and Ashton Smith, 2011; Lai et al, 2011). For example Vine-Foggo and Webster (2016) demonstrate that girls with autism will score higher than their male counterparts in normative measures of empathy but will score significantly lower on this criterion than their neuro-typical female peers. Gould (2017) also suggests that while girls with autism are more skilled at masking the challenges they face with social interaction and communication, this does not however negate the presence of autism but simply highlights that girls with autism need to be viewed through a different, non-male autism, lens.

Many behaviours associated with autism present differently in girls with autism than boys with autism, for example the expression of frustration is more commonly internalised in girls with autism and more overtly displayed or externalised in boys with autism (Kopp & Gillberg, 1992). However, it important to acknowledge that while these differences exist, boys and girls with autism still share a commonality of preferences for repetitive behaviours and restricted social imagination while facing barriers to varying extents in what is deemed to be appropriate social interaction and social communication (Kaushke et al, 2016; Lai et al, 2011). Nevertheless, the social worlds of girls and boys, irrespective of autism, are inherently different, girls and boys have different social experiences and therefore different social interactions (Dean et al, 2017). Wing (1981) historically presents girls as having superior verbal skills to boys and this is why measuring how a girl with autism responds in social interactions using androcentric criteria for autism could be deemed an inaccurate measure of social proficiency (Vine-Foggo and Webster, 2016).

Special interests are a neurotypical expectation of autism in both boys and girls (Attwood, 2007) however it is more likely that girls’ special interests focus on people or animals rather than on objects as favoured by boys (Dean et al, 2017). Knickmeyer et al (2008) note that girls have more developed imagination and this could account for intense interests in fictional friends and imaginary worlds. Wilkinson (2008) regards these female interests as gender and age typical for all girls, not just girls with autism and are therefore are less likely to be picked up than those special interests more obviously noted in boys. In fact, Kaushcke et al (2016) note how the repetitive and
stereotyped behaviours stemming from these special interests are often considered by professionals as less significant in girls with autism than boys with autism as a result of their similarity to expected interests and behaviours in all girls, e.g. horses, kittens or famous people; collecting and hoarding. It is conceivable that if these special interests were viewed as part of “the social cognitive styles of autistic individuals” (Hipólito et al, 2020, p.196) girls with autism would not feel compelled to mask or diminish their interests. Temple Grandin is testament to the idea that quite often these areas of in-depth expert knowledge in specific subjects lead girls with autism to academic achievement and appropriate highly successful career pathways (Grandin and Scariano, 1986).

Sensory sensitivity, either enhanced or reduced, is common to both boys and girls with autism. Gould (2017) points out that investigation into these sensory differences is lacking but still Tierney et al (2016) confirm that sensory disturbances are frequent and intense experiences for girls with autism. Common to both genders, reluctance to maintain eye contact is clinically deemed to be a behavioural feature of autism however in this instance, boys who display limited eye contact are deemed to be socially withdrawn yet girls displaying the same difficulty can be perceived as “shy”, “naive”, or “sweet” (Wagner, 2006, p.16) clearly demonstrating a gender bias and gender role stereotype in the interpretation of the same behaviours.

Wilkinson (2008) describes salient social challenges in reciprocation, responsiveness and empathy in both genders with autism when examined against the expected social norms of a society not accommodating of autism. While Tierney et al (2016) reiterate that not enough is known about the ability of girls with autism in the management of social relationships during their developmental period, Pisula et al (2017) highlight the obstacles faced by girls with autism in integrating verbal and non-verbal behaviour and their subsequent ability to maintain a reciprocal conversation. Furthermore, the expectation of social reciprocity is more for females than males, regardless of autism (Mandy and Lai, 2017). Vine-Foggo and Webster’s (2016) review on the social experiences of girls with autism demonstrate that the importance of reciprocal conversation is vastly greater in female social relationships and therefore girls with autism have to work significantly harder than males with autism at developing or at least mimicking these skills. It could be argued that girls with autism, by virtue of their
gender and the resulting social experiences they find themselves in, have superior reciprocity skills which means that reduced social or emotional reciprocity as required by the DSM-5 (American Psychiatric Association, 2013) may be harder to detect in girls. Lai et al (2015) note that difficulty with neurotypical expectations of empathy and responsiveness is another key indicator of autism and is expected in both genders. Tierney et al (2016) demonstrate that girls with autism have capacity for empathy and are affronted by claims that they lack this skill. These girls make significant efforts to demonstrate it in their social groups while simultaneously honing their skills in these areas once again making neurotypical and subjective expectations of autism harder to identify in girls. Tierney et al (2016) demonstrate through their primary research with young adolescent girls with autism that empathy is a core feature of these girls’ social lives and while their empathy skills are not innate but rather learned through memory and keen social observation, these skills are nonetheless the mechanism by which the girl with autism maintains their social relationships. This is further supported by Vine-Foggo and Webster (2016) who stress that to imply that girls with autism have no skill nor need for empathy is an insult to these young women. Pisula et al, (2016) report that the need and willingness for social interaction is important for girls with autism, even though the process of acquiring these skills is hard fought but quite often mastered.

The key to understanding these different presentations of autism is engendered by the differing social expectations placed upon girls and boys with autism and the coping strategies each gender has for these demands (Lai et al, 2017). Girls are expected to be more social than boys and this puts greater pressure on girls with autism to become socially adept for fear of social exclusion in a predominantly neurotypical society not accommodating of autism (Wilkinson, 2008). Girls with autism work hard to develop skills in social interaction which consequently exposes boys with autism as more socially naive (Dean et al, 2017). The disadvantage of developing this expected social proficiency, even if rote learned (Gould & Ashton-Smith, 2011), is that girls with autism may then be missed for identification and subsequent intervention on account of their ability to camouflage the challenges they face with social interaction (Lai et al, 2017). Moreover, the inability of boys with autism to camouflage their social difficulties can lead to acute social withdrawal (Gould & Ashton-Smith, 2011) thus when compared with girls with autism, their inability to disappear in to large groups
draws attention to their parents and professionals leading to intervention being sought (Attwood, 2007).

There are further negative consequences for girls camouflaging their experiences of autism and related social obstacles such as the internalisations of these experiences which then have the potential to manifest as anxiety and depression (Pisula et al, 2017). The reluctance to be identified with autism and therefore different to other girls, demonstrates how a society not accommodating of the social behaviours associated with autism, instead favouring the pathologising of neurodiversity, may actually cause clinical mental illness in girls with autism. This reframes the importance of seeking improved and more positive support for girls with autism and highlights the individual and societal cost of missed or late identification. Wing et al (2011) acknowledge the similarities and differences between males and females with possible autism and urge the emphasis of classification to be shifted to more holistic assessments where a dimensional approach is taken to derive a female autism profile.

2.5 Gender difference within Asperger syndrome (AS)

Jarman and Rayner (2015) have previously demonstrated that some educational professionals do not believe that females can have AS and in some cases, when AS has been confirmed, other professionals working in the field have refused to accept or support this identification. This is compounded by the limited research into the female presentations of AS and girls with AS remain underrepresented and unrepresented in AS research as a whole (Atwood, 2000; Edwards, 2012). While many researchers and practitioners favour the advancement of neurodiversity (Rosqvist et al, 2020; Silberman, 2015) and viewing autism as an identity rather than a disorder (Milton, 2012) (further discussed in 3.2) both of which seek to positively illuminate the highly distinctive female presentation of AS (Pisula et al, 2017), many practitioners still acknowledge the importance of girls with AS receiving a clinical diagnosis in order to avail of subsequent intervention (Tierney et al, 2016)

Referral rates for boys with potential AS are ten times higher than for girls and girls are more likely to be identified later than boys (Wilkinson, 2008; Kauschke et al, 2016). Unsurprisingly in Jarman and Rayner’s (2015) study, 25 of the 30 female participants
were identified with AS after leaving post-primary school. Once again, the recurring root cause for this most recently documented by Dean et al. (2017) is the capacity of girls with AS to obscure their neurodiversity by masking or camouflaging the indicators with which AS is most associated.

Girls with AS are expected to have a social profile more so than girls with autism and consequently their own social expectations are high (Tierney et al., 2016). In response to these expectations, females with AS crucially observe others and learn to imitate or mimic social actions (Attwood, 2007). Described by Carrington et al. (2003) as masquerading, Lai et al. (2011) suggest that females with AS are critically aware of their social challenges and due to this social sensitivity (Tierney et al., 2016) they develop the skills to mask them to inordinately high degrees of perfectionism. While this is undoubtedly a skill in girls with AS, Wilkinson (2008) warns that this masquerading ability is limited to superficial social skills and this initial assumption of social competence becomes challenged developmentally when typical adolescent female friendships become more intense and demanding (Kopp and Gillberg, 2011; Cridland et al., 2014). The social worlds of adolescent girls can become impenetrable for girls with AS as these friendships demand high levels of intimacy and intensity often unsustainable for girls with AS (Vine-Foggo, and Webster, 2016). This could possibly and partly explain the deferred presentation and detection of insurmountable social challenges and the consequent late identification of AS (Kaushcke et al., 2016; Tierney et al., 2016).

When compared with boys with AS, Wilkinson (2008) notes that females with AS have enhanced communication and language skills and demonstrate higher levels of reciprocity and empathy. Restricted normative empathy is understood as a marker for AS and yet Tierney et al., (2016) concur with Wilkinson (2008) by reporting that in their research the girls with AS consistently demonstrated proficient empathy albeit idiosyncratically. Milton (2012), who advocates for the use of identity first language (further discussed in 3.8), argues that empathy is a social construct applied by neurotypical people to autistic people and that the subjective neurotypical understanding of empathy should not be used as a measure of autistic behaviour as non-autistic people cannot understand how empathy applies in an autistic reality.
Finally, the presentation of AS in boys is often associated with aggression and physical behaviour whereas aggression or hyperactivity are not commonly noticeable behaviours in girls with AS (Wilkinson, 2008; Jarman and Rayner, 2015). Social situations are known to cause anxiety among people with AS but as before, girls are more likely to conceal or internalise their anxiety whereas boys with AS display this outwardly and physically through their behaviour (Attwood, 2007; Pisula et al, 2017). This is also reflected in Kaushcke et al’s (2016) discovery that girls with AS were more adept at understanding and using internal state language than boys with AS.

Wilkinson (2008) emphasises the downside to girls effectively masking AS leading to the subsequent late identification of AS limits any potential amelioration, support or intervention during their formative years in education. Yaull-Smith (2008) retrospectively documents her personal burden of and exhaustion from camouflaging noting the eventual and adverse impacts on all aspects of her life such as academic progression and mental wellbeing. Jarman and Rayner’s (2015) findings stress the importance of understanding the additional effort required by girls and women with AS to achieve academically and the increased hidden anxiety experienced by girls and women with AS due to this academic pressure.

As the literature attests identification of AS may not occur until late adolescence in girls, however it is not uncommon for the burden of camouflaging AS to have manifest itself in other negatives way prior to this (Vine-Foggo and Webster, 2016). Therefore, the improvement of the mechanisms for detection, identification and support of girls with AS becomes even more prescient.

2.6 Autism and comorbidity

Irrespective of gender, it is not uncommon for both autism (including AS) to be comorbid (co-exist) with psychological or psychiatric conditions such as ADHD, anxiety and depression (Farrugia and Hudson, 2006; Tierney et al, 2016). The clinical presentation of comorbidity can also change developmentally as can the nature of autism (Wing et al, 2011). However, the existence of other conditions co-occurring with autism can often obscure the presentation of autism and delay diagnosis (Pisula et al, 2017). Furthermore, both Rosenblatt (2008) and Helles et al (2017) longitudinally
demonstrate that when autism is comorbid with other psychiatric conditions, it has implications for later quality of life and wellbeing. The NAS (2016) further evidence this by reporting that only 32% of adults with autism (N=2080) are in paid work in the UK, with anxiety disorders and mental ill health being cited as barriers to long-term employment. Parsons (2014) acknowledges that quality adult life outcomes are most-often measured by long-term employment, lasting and close relationships and living independently but avers that these are normative measures of adult life outcomes further perpetuating the absence of autistic voices from research about autism.

Quite often an initial diagnosis of depression, anxiety, OCD or eating disorder gives way to a primary identification of autism once appropriately and knowledgeably investigated (Dudova et al, 2015). However, it may also be that the original primary condition is actually symptomatic of autism which has been missed for reasons identified with the androcentrism of the mechanisms used for diagnosis in girls (Wilkinson, 2008; Lai et al, 2011; Gould, 2017). For example, anorexia nervosa and other eating disorders such as pica may be implicated in autism and can either co-exist or be symptomatic of autism (Dudova et al, 2015). In this instance, the primary diagnosis of anorexia results in autism not being identified until a later stage and means successful treatment for the eating disorder is not realised until the anorexia is treated as part of the individual presentation of autism. Dudova et al (2015) conclude that the presentation of anorexia is often critically impacted by the co-existence of autism. Wilkinson (2008) also advises that where an adolescent girl is presenting with anxiety or an affective disorder, the possibility of underlying autism should be considered due to their frequently occurring comorbidity.

In addition to comorbidity, the burden of masking or camouflaging autism has adverse repercussions for the mental health wellbeing of girls with autism and Kauschke et al (2016) place great emphasis on the fatigue associated with “fitting in” and how it can be responsible for the development of secondary conditions. Yaull-Smith (2008), through her own personal experience, attributes the high incidence of mental health problems in women with autism to the fatigue of repressing autistic behaviour. Wilkinson (2008) suggests that anxiety and depression are linked to what Tierney et al (2016) call the internalising of autistic behaviour by females as evidenced by eight of their ten participants who describe personal experiences of suicidal ideation and self-harm as a
result of being unable to cope. The cost of camouflaging is confirmed by Pisula et al (2017) who link barriers to normative social competence with the internalisation of anxiety and depression in girls with autism. In Tierney et al’s (2016) research, all ten girls with autism cite the transition from primary school to secondary school as a trigger for their difficulties with non-inclusive mainstream education and subsequent descent into affective conditions.

2.7 Autism, education and inclusion

Inclusion is regarded as the optimum way of educating children with autism and concerted efforts have been made to encourage mainstream education for all students with autism especially those children with the previous iterations of high-functioning autism or AS (Volkmar & Klin, 2000; Ritvo, 2006). However, as attested more broadly by Byrne (2013), the inclusion or integration of children with disabilities (in this case autism) into mainstream education does not automatically mean that the child with autism can fully access the curriculum or all aspects of school life. In fact Jarman and Rayner (2015), among others, have detected an abundance of literature citing mainstream schooling as one of the most stress inducing aspects in the life of a person with autism confirming Byrne’s (2013) earlier suspicion. In Osborne and Reed’s (2011) review of children with autism’s experiences of mainstream schooling in the UK, 63% of the parents of children with autism (N=105) did not believe their child’s mainstream placement appropriate and therefore, it is unsurprising that 17% of the children with autism surveyed had been suspended at least once from these schools. In particular, Cridland et al (2014) cite the transition period between primary and post-primary as a well-documented trigger for exacerbating autism. Attwood (2007) notes a possible cause for this by explaining that in primary school, friendships are based on proximity and function but in post-primary education, friendships become based on shared interests, shared values and reciprocity, a skill that challenges the adolescent with autism.

Apart from the changing landscape of friendships, there are many other reasons that adolescents with autism find post-primary mainstream schooling particularly challenging. Sensory sensitivity, challenges with fine motor skills especially handwriting, slower auditory processing speeds and barriers to narrative competence are
among the issues that make the post-primary environment and academic success within it, particularly difficult (Cridland et al, 2014; Kaushcke et al, 2016; Tierney et al, 2016). In Australia, Jarman and Rayner (2015) also identify the lack of teacher insight into autism as a particular challenge; this is echoed by Cridland et al (2014) who highlight a lack of knowledge about autism across schools in the US and this marries with Osborne and Reed’s (2011) aforementioned UK schooling review.

Unfortunately, most of the research on the autism perspective of mainstream education is predominantly male, possibly because the educational and behavioural needs of boys are more overt and consequently more difficult to ignore in a mainstream setting and therefore easier to research (Wilkinson, 2008; Jarman and Rayner, 2015). However, as Tierney et al (2016) have discovered, for girls with autism, post-primary mainstream education is where their characteristics become most pronounced due to the increased social expectation of intense affiliations. Vine-Foggo and Webster (2016) point out that adolescent girls with autism are expected not only to perform academically but also to competently navigate the complex social context of post-primary school and the friendship dynamics that accompany it. Moreover, Tierney et al (2016) caution that girls with autism are ill-resourced to cope with these exclusive group settings and this can lead to peer rejection and isolation. They are impeded in their attempts to fit into what is deemed to be an inclusive setting and this is cited by Gould and Ashton-Smith (2011) as quite often the reason that girls are initially referred for and subsequently receive a late identification of autism in post-primary school.

Both Cridland et al (2014) and Dean et al (2017) evidence how gender roles within educational settings become increasingly complex and how this causes the girl with autism to embark on cleverly calculated social camouflage of any perceived social complications. Vine-Foggo and Webster (2016) demonstrate that while some adolescent girls with autism may appear to have developed friendships in school, these friendships are of limited quality and do not last. This social masking combined with the assumption of many mainstream teachers that autism is only present when there are outward behavioural signs makes support of girls with autism even less likely. Edwards (2012) notes the vulnerability of neuro-diverse girls to manipulation by other neurotypically developing peers and the resulting camouflage can also result in academic underachievement and dropout before intervention can be offered (Wilkinson,
Where girls with autism appear to be coping academically within mainstream education, Jarman and Rayner (2015) caution that teachers may underestimate the amount of time and effort required to sustain school life and warn that home-life may be very different due to the fatigue and fallout of camouflage. More worryingly, Tierney et al (2016) report that where girls with autism or their families divulged to teachers the inordinate level of effort sustained at home to maintain an excellent academic profile in school, the teachers expressed disbelief. This can only compound an already unsustainable cognitive and emotional demand. Inevitably, the cost of camouflage is mental wellbeing and this destructive internalising can eventually resurface as anxiety or depression (Willey, 1999; 2003). Child and adolescent mental health services are accessed for the acute treatment of anxiety or affective conditions but this further protracts girls with autism from being able to access educational support services within school settings.

**2.8 Education and autism in Northern Ireland**

The Department of Health in Northern Ireland recently reviewed the rates of school aged children (4-15) with autism (Department of Health, 2020). There are 12,544 school aged children diagnosed with autism in Northern Ireland accounting for 4.2% of the school aged population (N=298,667). The presence of autism in school aged children in Northern Ireland is now set as 4.2% (Department of Health, 2020).

The education system in Northern Ireland (NI) uses the archaic mechanism of the Code of Practice (COP) to identify and provide support for those students deemed to have special educational needs (SEN) (Department of Education NI, 1998). While the regulations for SEN were reviewed for England and Wales in 2014 through the Children and Families Act, until January 2020, a lack of government in NI prevented the revised bill for SEN in NI from being implemented. The aged COP is a five-tiered system which is not reflective of and is ill-resourced to meet the increasing SEN demographic of NI (Department of Health, 2017). Challenges include significant assessment delays, lack of SEN teaching expertise in the lower tiers of the COP and insufficient budget and time allocations of specific SEN professionals at the higher tiers of the COP (NI Commissioner for Children and Young People, 2017). The specific ramifications for
autism are discussed below. Within the COP, Stages 1-2 describe the management of SEN within a school’s own resources. Stage 3 is where a professional diagnosis has been confirmed and recommendations for educational provision have been made, most likely by an educational psychologist but other professionals such as speech and language therapists may be involved at this level also. Stages 4-5 involve the statutory assessment process carried out by one of the five Education Authority regions in Northern Ireland. In this instance, the educational psychologist and advisory officer will holistically assess the most appropriate educational provision for an individual and if a statement of education is issued on the basis of significant SEN, the Education Authority will fund and monitor this provision annually. Special schools in Northern Ireland are solely populated by children at Stage 5 on a statement, while mainstream education includes children of various SEN requirements stages 1-5. According to the parental survey of both National Autistic Society (NI) and Autism NI (2015) in the same year, 73% of children with autism (N=349) were catered for in mainstream schooling in Northern Ireland to varying degrees of success.

In recent years the acknowledgement of children with autism in mainstream classrooms is improving as is increasing flexibility in how the curriculum is delivered to learners with different profiles to neurotypical peers (Jones 2002; Goodall, 2015). While prevalence rates of autism have increased, the amount of school-aged children with a statutory assessment of education (Stage 5-Statement of SEN) on account of autism has decreased from 74% in 2008/2009 to 64% in 2019 (N=12,544) (Department of Health, 2020). This correlates with the increase of NI school-aged children with autism being placed at Stage 3 of a school’s SEN register suggesting that schools are becoming better equipped at supporting these students and therefore statutory intervention is required less often (Goodall, 2015). This may also reflect the introduction of the Autism Act (2011) part of which stipulates that the autism strategy specifically identify the educational needs of a person with autism by ensuring a mainstream education placement. However, in 2015 only 24% of the parents surveyed (N=349) by The National Autistic Society (NI) and Autism NI were happy with the mainstream placement of their children and would have preferred placements in autism-specific units attached to mainstream schools or autism-specific schools, none of which are currently available in Northern Ireland. This is further compounded by unequitable SEN
practice in Northern Ireland compared to the rest of the United Kingdom. The NI Commissioner for Children and Young People (2017) reports upon concerns over delays to statements being issued alongside a shortage of educational psychologists upon whose reports the statementing process relies and a resulting lack of specific provision by the Education Authorities, whose role it is to implement the findings of the statements. While the rest of the UK has updated its SEN regulations and practice, NI has remained in stasis with the deadline for implementing the new (and as yet unseen) framework by 2018/2019 now passed (Northern Ireland Audit Office, 2017). The new SEN framework is ready for implementation; however, its actioning remains dependent upon the momentum of the only very recently resumed government.

With regards to school-aged girls in Northern Ireland, autism rates have increased from 1% in 2016/2017 to 2% in 2019/2020 but this is still significantly lower than males with autism who account for 6.4% of the total school aged population (N=298,667) and are three times more likely to have a diagnosis than females (Department of Health, 2020). The highest rate of identification was detected in Year 7 at 5.1% which is the last year of primary school with first year of post-primary education having rates of identification of 4.9% among the school aged autism population (N= 12,544) (Department of Health, 2020) aligning with Tierney et al’s (2016) theory that transition into post-primary can foreground previously unsurfaced female autism traits. Considering parental dissatisfaction with rates for referral, diagnosis and support in Northern Ireland for the broader understanding of autism, it is fair to assume that for females with autism, unidentified in the statistics for Northern Ireland, their experiences remain unheard.

2.9 The missing voices of girls with autism in Northern Ireland

As the literature attests, the voices of girls with autism are missing from almost every aspect of autism inquiry. Historically under-identified (Kopp & Gillberg, 1992; Rutter et al, 2003; Attwood, 2007), autism treatments and interventions potentially neglect the nuances of girls’ presentations of autism (Wilkinson, 2008) and the profusion of research into autism is dominated by samples that reflect a gender bias (Jarman and Rayner, 2015; Kauschke et al 2016). Yet the infinitesimal research that does exist
beseeches practitioners to acknowledge the very real and complex existence of the female constellation of autism (Gould & Ashton-Smith, 2011). Moreover, this research delineates how the discounting of the identities and voices of girls with autism further perpetuates misunderstanding of autism in girls and exacerbates any comorbid or underlying mental health condition (Tierney, et al 2016) making it very difficult for these girls to access the quality of adult life afforded to other adult women.

Advances are being made with regard to specific identification criteria for females and autism which have the potential to more accurately represent rates of autism in girls and women. In the UK, Wing et al (2011) devised the DISCO (Diagnostic Interview for Social and Communication Disorders) which is reviewed by Gould (2017) as being useful in the identification of girls and women with autism. More importantly the DISCO is beneficial in profiling the specific needs of the individual with autism potentially informing intervention and support. In Sweden, Karlsson et al (2013) have devised an Autism spectrum disorders questionnaire with an eating assessment aimed at detecting eating disorders in individuals with at least average intelligence aged 15-25. Both new assessments demonstrate that clinical criteria are becoming flexible in terms of identifying autism in girls and women.

Gould and Ashton Smith (2011) have vehemently argued for the inclusion of a social curriculum in support programmes for girls with autism however, Milton (2012) cautions against intervention and treatment programmes that exist to malleably squeeze autistic people into mainstream social culture. The dawn of critical autism theory (discussed in 3.8) where autistic researchers present positive discourse on empathy as opposed to the previous deficit theories on autism means greater understanding of autistic culture is beginning to emerge.

It stands to reason that the quality of the lives of adult women with autism will be directly impacted by their preceding school experiences and the understanding and support from those professionals who have worked with them. However, as demonstrated by Jarman and Rayner (2015), the educational experiences of girls with autism have been largely overlooked as they are constantly framed against the experiences of boys with autism. Reframing the educational experiences of girls with
autism, without need for comparison with the opposite sex, could potentially expose these experiences and clarify how best to give academic, emotional and social support to these girls where support is required.

Cridland et al’s (2014) research provided valuable, qualitative insights to the lives of adolescent girls with autism however, their findings foregrounded their mothers’ interpretations of their experiences rather than the girls themselves. Using written accounts and interviews, Vine-Foggo and Webster (2016) employed an inductive thematic approach to explore the perceptions of seven adolescent girls with autism and by eliciting these unique experiences justifiably challenged theories concerning the challenges in reciprocity and social interaction for girls with autism. Tierney et al’s (2016) interpretative phenomenological analysis of interviews with ten females with autism from the UK gave voice to the challenges faced by these girls and the coping strategies they used to overcome these social hurdles. The three pieces of research avoided imposing neuro-typical assumptions of autism and sought to elicit what adolescent girls with autism want to represent about themselves to others and more importantly how they want to be supported with their autism.

In conclusion, these researchers all make the same recommendations: more understanding of the experiences of adolescent girls with autism is needed and by gaining this new perspective, parental support and professional practice could be expertly informed potentially improving mental health wellbeing in these girls and positively affecting the life outcomes of adult women with autism. It is clear that the voices of girls with autism are there for those willing to listen. While the written accounts discussed above are practiced in uncovering these neurodiverse voices it would appear that the use of an arts based approach such as Photovoice offer a particular opportunity to access the lived experiences of girls with autism. The means of extraction through the potential of Photovoice (3.11-3.13) are discussed at length in Chapter 3 following a consideration of how autism should be viewed as a neuro-diverse culture and not a disorder of deficits as evaluated in this literature review.
Chapter 3: The ontological and epistemological underpinnings of “Missing Voices”

This chapter explores the methodology for the research considering the different ways autism can be viewed from a medical standpoint through to viewing autism as a culture. It interrogates the multiple ontologies and epistemologies for explaining and subsequently researching with people with autism. A conceptual framework underpinned by epistemic injustice and feminist theory is discussed and the chapter culminates in the researcher’s positionality giving context to the participatory research method of Photovoice in light of the following research questions:

1. What are the challenges faced by girls with autism in the transitional years of post-primary school?
2. What are the coping strategies used by girls with autism in the transitional years of post-primary school?
3. How can the personal experiences of girls with autism be used to increase educational awareness and inform educational practice in supporting other girls with autism during their post-primary education?

3.1 Ontological Assumptions of Autism

The nature of autism as presented from a neurotypical perspective cannot accurately capture the truth about life with autism (Chown, 2014). The privilege and power of neurotypical meaning makers has inevitably influenced the perpetual exclusion of people with autism in defining their own condition or identity (Milton, 2012). Furthermore, the promotion of the neurotypical perception of autism in a socially constructed, ableist society poses autism as a ‘disability’, ‘defect’ or ‘disorder’ which in no way encompasses the multiple realities of autism especially those from within an autistic reality (Gibson 2006; Lim, 2015). The consequence of this medicalised, ‘deficit’ perspective of the perceived reality of autism is the further marginalisation of the community of people with autism (Mertens, 2009). Moreover, it is the application of positivist, androcentric ontologies, as discussed in Chapter 2, that are potentially further
marginalising girls with autism. The checklists that are derived from reductionist classifications of autism have historically under-identified girls with autism and denied them access to any subsequent intervention further oppressing this minority group. Chapter 2 argued that a significant proportion of girls with autism are overlooked by the classification systems designed to expose the reality of autism and this is further support for the notion that autism cannot be defined by one single truth or in a solely positivist fashion.

Even within positivist, ontological explanations of autism there is disagreement on its causation. Hollin (2017) notes the ontological uncertainty that exists among proponents of candidate genes, phenotypes, neurological correlates, and vaccinations, and demonstrates that members of the scientific community are respectively in disagreement with each other. Hollin’s (2017) theory of indeterminacy adds further weight to the multiplicity of the reality of autism. Indeterminacy positions autism as inherently heterogeneous at both an inter and intra personal level meaning that no individual with autism is like another individual with autism nor is there a singular identifiable cause for all aspects of autism within an individual. This is predated by Happe’s (2006) call to give up on finding a single explanation for autism and her warnings against the use of parsimony in such research. It stands to reason that if no single explanation for autism exists it is therefore unlikely that a single reality also exists. The assumption that autism is a ‘deficit’ within a person, needing amelioration, is not always the reality accepted by people with autism (Gobbo and Schmulsky, 2016). Therefore, it appears society has constructed this truth to impose such negative labels, decentring or minoritising people with autism by centring and majoritising neurotypical people, in order to maintain a neurotypical power. Both Mertens (2009) and Ormonde et al, (2006) consider these concepts in relation to Deaf and Maori people respectively, highlighting the social injustice faced by these marginalised groups and the same application could be made to people with autism. By continually pathologising neurodiversity, this takes the onus off an ableist society to remould itself to be inclusive of neurodiverse identities such as autism (Lim, 2015).

Collectively, these medicalised explanations are used to set about a pathway of ‘cure’ or ‘treatment’ for autism and while some (but not all) people with autism experience benefits in terms of support and successful integration to independent life, this ‘deficit’
reality is not the only way of seeing autism (Lim, 2015). Autism can be regarded as neurodiversity, as an identity, as a culture or as a society and these versions of realities are the most favoured by people with autism rather than the pathologised version purported by positivists (Silberman, 2016). Autism is also not accepted universally, coined “The Western disease”. Decouteau (2017, p.169) demonstrated that there is no word for autism in Somalia and his research externally connected its occurrence within the Somalian race to Somalian people’s immigration to Canada and subsequent engagement with western health systems. Mandell and Novak (2005) suggest that the lower incidence of autism among Puerto Rican families is due to parental acceptance of the behavioural characteristics of autism as inside the boundary of ‘normal’ behaviour while other Latino cultures see children displaying behavioural characteristics of autism as blessings from God or as a result of fatalismo, a belief that a child’s fate is already decided. Previous to this, Silberman’s (2001) seminal article “The Geek syndrome” investigated the surging numbers of children being identified with autism in California’s Santa Clara county aka Silicon Valley and intimated towards an ‘autism epidemic’ centred around a particular culture. This has since been explained through the heterogeneity of the parents of these children working in the Silicon Valley, a population who share multiple traits associated with autism (Silberman, 2015). The multiple realities of autism, irrespective of culture or context, continue to be presented by neurotypical researchers seeking truth about autism from at best, parents or advocates of people with autism, but rarely from people with autism themselves, perpetuating the ‘invisibility of the autistic voices’ as described by Milton (2012). Pisula et al (2017) have already demonstrated the high level of discrepancy between the perspectives of children with autism and their parents’ perspectives suggesting once again that the reality of autism is different to the reality presented by neurotypical informants and researchers.

Interpretations of autism from the direct perspective of people with autism appear to be a more plausible route to enhancing understanding and this mirrored by Harris et al’s (2009, p.116) assertion that “research in the Deaf community should be by Deaf, for Deaf and with Deaf”. The socially constructed meanings of autism could be counter-explained by researchers with autism and this type of transformative research has the potential to shift the status quo of society’s failure to include neurodiverse people.
including people with autism into a more accommodating society (Lim, 2015; Silberman, 2016).

3.2 Autism as an identity

Autism permeates every aspect of a person’s life and it is therefore unsurprising that adults who have wholly accepted neurodiversity wish to be referred to as ‘autistic people’ (Robertson and Ne’eman, 2008). Unlike positivist ontologies which label a person with ‘disorders’ or ‘defects’, Williams (1973) argues that each person should seek out their own identity and he encourages that society should then view each person through that distinct perception of their own reality and not be merely viewed as a surface upon which labels are attached.

Applying this to autism conjures up the heated autism semantics debate: ‘autistic individual’ or ‘individual with autism’ (Brown, 2011). Identity first language: ‘autistic person’ presents autism as a way of being and Sinclair’s (1993) paper “Don’t Mourn for Us” eloquently conveys how a person and their autism are inextricably linked. Brown (2011) also presents the other side of this debate: ‘person with autism’ as most often heralded by parents and professionals in a sincere and protective effort to steer the child’s identity away from the negative connotations of the word ‘autistic’ that have been historically used to stigmatise. Gobbo and Schmulsky (2016) counter that framing autism using person first identity goes against philosophies that seek respect for diversity and that this framing may be detrimental to a person’s healthy identity.

The lack of agreement regarding the language of autism can perhaps be best explained by Gibson’s (2006) three stage model of disability identity development. The ‘person with autism’ identifier fits in with Stage 1’s ‘Passive Awareness’ of disability whereby the medical needs of the disability are met while simultaneously denying any social aspects of the disability in the family setting. Continuing to apply Gibson’s (2006) model, the person ‘with autism’ comes to a state of ‘Realisation’ at Stage 2 which is prefaced by both anger at having a disability and an awareness of how others may negatively perceive them. Gibson (2006) also describes the superhuman complex at this stage where the person overcompensates for their disability. It is only at stage 3 of ‘Acceptance’ that the person with autism may change their identifier to ‘autistic
The use of person-first language, “girls with autism,” is intended. Person-first language was the preference of this study’s participants.

In this study and as outlined later in both Phase 1 and Phase 2 of Chapter 4, the acceptance of the preferred use of person-first language, ‘girls with autism’ is intentioned.
subsequently positioning the participants as girls with autism at their request and the researcher as neurotypical. This inevitably has epistemological implications for the research and is discussed further in 3.8.

3.3 Epistemology and autism

Transformative research is acknowledged as having the power to emancipate various marginalised groups within society and across class and gender, inferring that transformative research has the power to expose the voices of young people (Anderson et al, 2015; Christensen and Prout, 2002). Mertens (2009) uses the prism analogy to describe the transformative research process as it easily conveys the idea of multiple realities and the multiple ways that knowledge about realities can be produced. The success of this knowledge production is largely dependent on the successful collaboration between the researcher and participants and the representation of their lived experiences (Cresswell, 2007). In this study my relationship, as a neurotypical researcher, with the participants with autism is pivotal in the nature of knowledge production on autism. Gould (2017) stresses the importance of insights from people with autism in providing a deeper understanding and so effective collaboration between the researcher and participants with autism is fundamental to the transformative power of the knowledge gathered.

Before collaboration can begin, every researcher has a responsibility to interrogate their own worldview and identify the areas of researcher subjectivity that will shape the research and more concerningly, impose assumptions upon the research and its likely participants (Mertens, 2009). It is impossible for a researcher to be value free and aspects of ethnicity, class, gender and disability all contribute to inevitable researcher subjectivity (O’Leary, 2009). While I share the minority identity of female gender with the girls with autism in this study, I do not share the minority identity of a ‘perceived disability’ which has implications for my researcher subjectivity.

Irrespective of whether they identify as ‘people with autism’ or ‘autistic people’, this community is decentred by the non-accommodating, neurotypical majority where I belong (Lim, 2015). This neurotypical majority are historically responsible for the imposed etic of autism classification systems devised by white, westernised researchers.
who have traditionally medicalised autism, made people with autism an object of research and commodified treatment thereof (Gibson, 2006; Milton 2012). This social positioning also favours neurotypical lives in terms of access to health and education (Ripamonti, 2016). A neurotypical researcher must acknowledge the privilege of their level of education as a result of their class, colour and being neurotypical in a socially constructed neurotypical society. In order to build a trusting collaborative relationship with participants with autism, a researcher must demonstrate cultural competence by acknowledging the impact of their own intrinsic values on the values held by people with autism assuming the researcher has established what these values actually are (Mertens, 2009).

Throughout their “Looking behind the mask” study, a qualitative Interpretative Phenomenological Analysis (IPA) with young women with autism, Tierney et al (2016) continuously challenged their own neurotypical assumptions about how theory and societal contexts interplayed with the perspectives of these young women. The researchers’ use of reflective logs helped to maintain an awareness of their subjectivity throughout the research enabling them to elicit a true insight from the young women with autism in their study. Reflexivity in research is regarded as a useful mechanism by which researchers can cyclically foreground their values and biases and subsequently challenge how these impact upon and throughout the research process and its participants (Cresswell, 2007; O’Leary, 2009).

As previously mentioned, the girls with autism in this research are also doubly minoritised by their gender. Females have been historically oppressed by social and political mechanisms in terms of democracy, education and privilege (Mertens, 2009). In terms of autism, not only could the autism classification systems be considered ethnocentric in terms of their derivation but also androcentric in that the aforementioned classification systems have been based on largely male samples of children with autism and it has been historically assumed that what is autism in males is also what is autism in females (Kopp and Gillberg, 1992). Put simply, the production of knowledge about autism could be reframed as the production of knowledge about male autism. The distinct paucity of research into the community of girls and women with autism, their invisibility from the statistics of the population with autism and the lack of female
oriented interventions and support easily alludes to a concerted exclusion of both the voices and identities of girls and women with autism (Wilkinson, 2008).

In the transformative paradigm, a researcher must take steps to redress the inequity that exists between the researcher and the participants in order to adhere to representing the lived experiences of the participants (Cresswell, 2007). A key component of transformative collaboration is communication as the researcher’s choice of language can shift the power balance towards or away from the participants. Mertens (2009) advises that where the researcher has already established that a community is being marginalised, a conscious decision to use language favoured by the participants, as opposed to the researcher, has the potential to counteract some of this power imbalance. For example, to assume that neurotypical people and people with autism have different identities, subsequently assumes that each community communicates differently. Therefore, cognisance of this must be heeded by the researcher’s use of language so as not to detract from the position of the participant as an expert in their own reality.

Brown’s (2011) discussion on the significance of semantics among ‘autistic people’ and ‘people with autism’ readily demonstrates the gravity of this consideration. Ignoring this could easily undermine the collaborative relationship and trust required to produce transformative knowledge. In this study, there is contradistinction, as critical autism studies promote the use of identity first language whereas the girls with autism in this research opted to use person first language. The latter is therefore adopted as a result of foregrounding the participants’ preferences in the production of their own knowledge.

Communication skills are a key component of ensuring power balance within the research setting especially where the participants have different communication skills to the researcher. The selection of appropriate communication formats is crucial to eliciting the truth of the matter under investigation, irrespective of paradigm. In the interpretive paradigm, Milton’s (2012, p.883) seminal writing on the “double empathy problem” demonstrates the difficulty in communication when two social actors have two different dispositional outlooks and so social interaction is restricted in communicating meaning. Milton (2012) argues that while lack of empathy, as defined by neurotypical societal constructs, is considered a core feature of autism, neurotypical researchers also demonstrate a lack of empathy towards people with autism who have to navigate a social world set up to marginalise them. More evidence of the disconnect
between neurotypical and neurodiverse perceptions and the way in which they are communicated comes from Pisula et al’s (2017) research where the disagreement between the perceptions of children with autism and their parents’ perceptions dominated the study when discussing the children’s mental health. Vine Foggo and Webster (2016) contend that to understand girls with autism, the researcher must encourage the girls to use their own style of communication to convey their experiences rather than the researcher’s preferred style. It is then up to the researcher to interpret and give meaning to this phenomena. The communication skills of the girls with autism in this study have been foregrounded, however the meaning produced is still largely derived from a neurotypical interpretation of these descriptions and inevitably can lose authenticity in translation.

In order to bridge this gap and to expose authentic insight into autism by the girls in this study and not my neurotypical insight, I must position myself as an ally to the girls. This requires me adopting the role of critical inquirer where, as the researcher, I facilitate knowledge production from within the marginalised group, using methods of communication decided by the group. In the transformative paradigm, Mertens (2009) acknowledges the importance of eliciting authentic insights but cautions that this can only be achieved when the researcher has built a significant level of trust and mutuality with the participants. The ethical implications of this relationship building consequently require careful consideration as there is an enduring historic tradition of omitting these voices.

3.4 Epistemic injustice

Epistemic injustice is the first lens through which this research focuses and refers to the unfair treatment of the different and inevitably unequal voices practising and participating in the production of knowledge and understanding (Kidd et al, 2017). The concept of epistemic injustice is divided by Fricker (2007) into two categories: testimonial injustice and hermeneutical injustice. Testimonial injustice refers to prejudice within the hearer as most often the hearer, acting as a social agent, possesses more power than the speaker. This exists in the form of identity power for example men over women, abled over disabled and in this study, neurotypical over neurodiverse and the injustice created exists both actively and passively.
In this research, an example of the active use of identity power is the previous deliberate exclusion of children with autism from mainstream neurotypical education in Northern Ireland whereas the phrase ‘passive identity power’ could be used to describe the omission of the voices of girls and women with autism from autism research. This passive omission was not deliberate but the consequence of an unsubstantiated assumption that autism was predominantly a male condition and therefore only males were the focus of research. Issues of identity power and epistemic injustice are present when the hearer makes a judgement on the credibility of the speaker and subsequently “the speaker is wrongly undermined in her capacity as a knower” (Fricker, 2007, p17). The omission of the voices of girls and women with autism from research undoubtedly undermines their expertise in their own lived experiences. More worryingly, Milton (2012) warns of autism becoming a fetishised commodity and that the emerging industry surrounding autism where services are provided for those caring for individuals with autism, further silences ‘autistic voices’ and disempowers advocates for autism.

Hermeneutical injustice is described by Fricker (2007, p. 152) in a way that wholly aligns with the experiences of girls and women with autism to date: “if someone has a medical condition, affecting their social behaviour, at a historical moment, at which that behaviour is still misunderstood and largely undiagnosed, then they may suffer a hermeneutical disadvantage that is, while collective, especially damaging to them in particular”. Gibson (2006) similarly notes that people with disabilities often overcompensate for their disability, which can ultimately lead them to rejecting beneficial support in favour of portraying membership of and belonging to a wider society which is undoubtedly individually damaging.

This is echoed by Kotzee (2017) in the context of education, who notes that people belonging to a disadvantaged culture (in this case autism) often lack the ability to articulate their experiences as they have been educated in a culture that is more dominant and vastly different to their own. The hermeneutical injustice lies not in the fact that people with autism are uneducated in their ability to articulate their experiences but rather that the education systems in which they find themselves, rely on adept proficiency in social language and communication to convey and articulate experiences, a concept which presents barriers to people with autism. Furthermore, we are aware of the ability of girls and women with autism to portray a sense of normality through adept
camouflaging and masking of autism, the burden of which is ultimately detrimental to their mental health (Tierney et al, 2016).

Epistemic injustice “interpenetrates with major social and intellectual movements such as feminism, hermeneutics, critical race theory, disability studies (Kidd et al, 2017, p.1). This study upholds hermeneutical responsibility and is keen to avoid further perpetuation of the epistemic injustice already experienced by girls and women with autism. Significant consideration of how the knowledge exposed by the girls with autism in this study may be transformed by my interpretations thereof demands deep researcher reflection through the critical lens of the following sections.

3.4.1 Hermeneutics

The concept of hermeneutical injustice focuses on the obstacles faced by oppressed subjects during the meaning making of their experiences (Medina, 2017). These obstacles are not of their own making but are quite often positioned by those with more power, namely the ‘hearers’ (Fricker, 2007). This leads to the idea of hermeneutic responsibility on the part of the researcher (Blaikie and Priest, 2017). Without due consideration of the potential for hermeneutical injury, Medina (2017, p. 41) warns that poor research has the potential to cause so much damage to a person that it can lead to ‘hermeneutical death’ whereby the capacity for self-development is annihilated.

Hermeneutics is concerned with the theory of interpretation and is used to make sense of a person’s interactions with the world in which they are embedded and immersed (Smith et al, 2012). The knowledge extracted is both illuminating and elicits the perception of the meaning-maker (Porter and Lacey, 2005). The hermeneutic cycle is both iterative and reflective which enhances hermeneutical responsibility when working with an oppressed group or person (Blaikie and Priest, 2017). By removing barriers to articulation the speaker becomes the meaning-maker and can begin to make sense of their own lived experiences (Fricker, 2007). The researcher acts as a detective or sense-maker of the person’s understanding of their own experiences, a concept known as double hermeneutics (Smith et al, 2012).

Adopting a hermeneutical approach encourages the development of empathy with participants and prioritises the idea of ‘verstehen’ or understanding (Elliot, 2005). In
autism research, adopting this approach goes someway to redressing Milton’s (2012) double empathy problem as previously outlined. Brown (2011) notes that a person cannot be separated from their autism, that it is all pervasive and absolutely characterises the way in which they see the world. Hermeneutics, and the empathy it elucidates, has the potential to develop in people with autism a critical consciousness that truly exposes their experiences and makes meaning of it for both the participants and the neurotypical researcher. This critical consciousness not only develops personal understanding but more importantly has the potential to make participants “masters of their thinking” enhancing their responsibility to tell their story as it is only then as Freire (1994, p.105, p.162) concludes that “knowledge of an alienated culture leads to transforming action” thereby freeing the alienated cultures. Wheeldon and Ahlberg (2012, p. 29) cite the purpose of such education as being emancipation, reflection and evaluation and it is only by creating “autonomous persons” that this can be achieved.

3.6 Oppression and intersectional feminism

Freire (1996) in the revised edition of his seminal work on the pedagogy of the oppressed, cites education as being the mechanism by which people who have been oppressed or marginalised can be released from the ‘culture of silence’ in which they have been submerged to a new state of “concientización” (consientization). The oppressed person is now critically conscious of their own place in the world and can subsequently take action into moving out of social and political oppression simultaneously seeking cultural solidarity.

The idea of oppression is most notably considered through feminist theory which refutes the concept of objectivity within research with Holliday (2007, p. 258) arguing that the idea of objective research simply exists to mask the masculinist views predominant within social science research and that no research is ever without the subjectivity in that “all views come from somewhere”. Confirmed by Coffey (1999), all knowledge is situated and partial in a particular temporal and historical context within human society. Feminist theory, which is the second lens underpinning this research, acknowledges the multiple power imbalances within society and the emancipatory aims of movements to usurp them (Gillies and Alldred, 2008). Feminist research actively
encourages the exploration of difference and diversity while also promoting reflexivity in research relationships (Mauthner et al, 2008) and enables the researcher to act as both an ally and an activist on behalf of those whose voices are being silenced (Tickle, 2002).

Mertens (2009) is critical of the layers of discrimination faced by women across the multiple and interconnected levels of race, sexuality and education but this takes on an added dimension when intersectioned with the construct of ‘disability’. As previously noted by Gibson (2006), people with disability are also traditionally victimised within the education system, the workplace and the medical profession. In this research therefore, the participants are doubly discriminated by their gender and the normatively perceived disability of autism. Intersectional feminism acknowledges the interplay between gender and other variables (in this instance autism) and considers how our behaviours and experiences are shaped by this interplay (DeFelice and Diller, 2019). More importantly intersectional feminism considers that it is only by understanding the discrete and specific interaction of gender with another variable that can effectively lead to the challenging of social injustice faced by the girls or women affected (Moradi and Grzanka, 2017). The authentic understanding of this interplay can only come from those facing it and as suggested earlier by Freire (1996) any emancipation can only come from the oppressed becoming critically aware of one’s own situation and understanding of it and subsequently taking action against this.

While this study has so far aligned with the multiple realities of autism I have aimed to conduct the research with the hermeneutical responsibility of a critical inquirer, feminist in standpoint. I am invested in actively transforming the knowledge production from the research and consequently, by acting as an ally to this marginalised group of girls with autism aiming to emancipate this group by also acting as the conduit by which this new constructed reality is presented to those stakeholders with the power and capacity for change-making.
3.7 Criticisms of Epistemic Injustice and Intersectional Feminism

The intersectionality of gender and disability for a marginalised group is not without controversy. Post-modernist feminist researchers warn of universally generalising the oppression of females which ultimately further marginalises some women from other women (Gillies and Alldred, 2008). Furthermore, Tremain (2017, p.175) is highly critical of feminist philosophy actively contributing to epistemological ignorance of disability theory citing the use of terms ‘gender-blind’ and ‘epistemic deafness’ as evidence for this. Posing ableism against disability is also a controversial position, in that all disabilities are not equal nor equally oppressive. This is echoed most recently by Byrne (2019, p.6) in her discourse in response to the United Nations Convention on the Rights of Persons with Disabilities’ (2006) inclusion of people with disabilities on its monitoring committee noting that “Each member will have their own disability experience and will come with a particular perspective”.

It could be argued that specific disability theories go farther than both epistemic injustice and intersectional feminism when considering the oppression of this group. The social or minority model of disability considers the consistent failure by society to acknowledge and accommodate people with disabilities while Critical Disability Studies align with the social model belief that research concerning people with disabilities should be carried out by people with disabilities as non-disabled researchers have the potential to harmfully overanalyse research from their position as outsiders (McNamee, 2002). However, Bridges (2002) makes a compelling argument for the inclusion of outsiders in disability research by refuting Carlton’s 1998 work on “Nothing about us without us” stating that as long as the outsider researcher and the research participants work together to collaboratively address the concerns of misassumptions and misrepresentation, research outcomes can be both mutually beneficial and promote increased understanding.

The emergence of Critical Autism Studies moves away from disability theories shifting autism away from the medical deficit model to the current preference of autistic people to acknowledge their autism as integral, positive part of their identity (Ripamonti, 2016). The neurodiversity movement re-categorises autism as a neurological form of the human brain and not a lifelong disability and Silberman’s (2015) Neurotribes is
testament to this paradigmatic shift of seeing autism as a neurologically different way of being. However, it is extremely important to ensure that this progressive way of considering autism does not unintentionally exclude those people that it intended to pedestal, those with no ‘autistic’ voice. If autism is to be regarded as a culture, and all cultures have diversity within them, it could feasibly be argued that there are both ‘girls with autism’ and ‘autistic girls’ and it is up to each girl to choose how they wish to be identified without fear of oppression from within or outside the neurodiversity of autism. That is why both epistemic injustice and intersectional feminism becomes the crucial lenses for this research as by actively listening to the voices of those previously marginalised girls with autism, my role as a researcher ally can help to ensure that these girls’ voices are no longer omitted from discourse on girls with autism.

3.8 Conceptual framework

Figure 1: Conceptual framework for Missing Voices.
Figure 1 is an illustration of this study’s conceptual framework, the embedded theoretical standpoints and the subsequent justification of the use of participatory methods. Currently, the dominant knowledge on autism is socially constructed by and constituted in a neurotypical society that medicalises and pathologises difference in order to marginalise neurodiversity. This means that people with autism are treated unequally to neurotypical people and that the voice of people with autism is largely missing from the production of knowledge about autism. This is epistemic injustice and is the first of two theories whose lens’ are used for this critical inquiry (Fricker 2007).

Secondly this research specifically considers the marginalised voice of girls with autism. Doubly discriminated against due to their neurodiversity and by the absence of specific gender related knowledge production on girls with autism resulting in their subsequent oppression as a distinct community within neurodiversity. Therefore, the second lens used to interrogate the missing voices of girls with autism is intersectional feminism.

The research is both participatory and transformative in that the girls with autism in this study are the meaning makers and valued as experts in their own communities. However acting as an ally, I recognise the importance of using the knowledge produced and need to act as a conduit on behalf of the participants and their peers to emancipate girls with autism from the social and political barriers they face in accessing appropriate educational support and intervention in post-primary schools subsequently improving quality of life outcomes for adult women with autism. The upwards direction of Figure:1 is reflective of this study’s aim of inciting transformation for girls with autism.

3.9 Researcher position and intersectionality

As a critical inquirer, I believe autism to have a multiplicity of realities and align with both critical disability theory and critical autism studies by acknowledging autism as neurodiversity. Adopting a both epistemic injustice and feminist theoretical perspectives exposes the inequitable practice of the positioning autism through a ‘deficit model’ and surfaces the inequality experienced by girls with autism.
Endarkened feminist epistemology demonstrates that a researcher should be a supporter and a reflective activist in the community (Mertens, p. 59), therefore I am positioning myself as an ally to the adolescent girls with autism in this research. Identifying as a white, female, educated, neurotypical researcher positions me as an outsider to this group however my occupation as an experienced specialist teacher in autism is the starting point for building trust within the community I am working with. Furthermore, recognising these identities and how they have subsequently shaped my values, enables me to be critically subjective. This has exposed in me a hermeneutical responsibility to engage in research with girls with autism founded on the privileged position I find myself in, coupled with the desire to reduce the marginalisation of this community of girls by eliciting how their educational experiences could be transformed.

To copper-fasten the research as emancipatory, I take on the responsibility of ensuring that significant action takes place as the results of the participation of the girls with autism. This cannot be tokenistic, it has to be meaningful and transformative, inciting change. Therefore, the careful selection of a research method is integral to ensuring that these oppressed voices are heard and that change, both social and political, occurs as a result of their participation. Furthermore, to address any power imbalances created by my position as an outsider researcher, the method selected should seek to be participatory and collaborative, engendering partnership. Of paramountcy, the participatory method chosen should reflect the strengths of this research group and should avoid creating challenges for them. Considering autism is associated with barriers to neurotypical social communication, the employment of language or narrative based participatory methods would seem unsuitable (Mesibov and Howley, 2003). Therefore, the research method most befitting this intersectionality of position is participatory arts research (PAR). A specific form of PAR, a type of documentary photography was proposed to a group of critical friends in Phase 1 of this research (discussed in Chapter 4) as a suitable research method adept at detailing the lives and exposing the voices of girls and women with autism. On the basis of critical friend consensus with this and in light of the use of smartphone technology among adolescent girls, the use of this method is employed.
3.11 Research Paradigm

Research with children and young people is deemed by Tisdall et al (2008) to be the most excluded from political mobilisation more so than any other group. This is evidenced in Catalani and Minkler’s (2010) meta-analysis on the use of Photovoice in public health research which demonstrates the limited political impact of participatory research from marginalised groups. In this study, the political paradigm of transformative research is still considered to be most appropriate for eliciting the marginalised voices of girls with autism as participants considering the potential for influencing decisions that will ultimately impact on their own lives.

Mertens (2009) locates participatory research within the transformative paradigm at the intersection of social research and evaluation, highlighting its power to include and emancipate members of a community. Despite overlapping constructivist and transformative methods Clark (2010, p. 115) also demonstrates how the use of participatory tools positions young people as participants and power sharers. Returning to Bridge’s (2002) review of the ‘Nothing about us without us’ concept, the use of participatory methods potentially rectifies power imbalances, the redressing of which is at the heart of emancipatory or transformative research. According to McNamee (2002), participatory research still positions the researcher as an ‘outsider’. However, Mertens (2009) crucially acknowledges that many marginalised groups are unable to represent their own voices and that transformative research enables another voice to represent them. She expounds that transformative research assumes mutual trust between the researcher and the marginalised group, that authenticity of voices are always represented and that positive action for that community is induced as a result of community participation. To ensure these goals, both Langhout and Thomas (2010) and Punch, (2002) agree that critical reflection on the part of the researcher is critical in repositioning the ‘outsider’ as a power-sharer and not simply the investigator enabling the resolving of power imbalances. In keeping with the goals of transformative research, this continued critical reflection, the valuing of participant perspective and the acknowledgement of participant agency subsequently increases the potential for the informing or changing of practice while simultaneously elevating participant status.
3.12 Participatory research

Figure 2: Roger Hart’s ladder of Young People’s Participation

Participatory research is founded on the concept of discussion with communities and the quality of the participatory research will depend on how many phases the research participants have been involved in throughout the research process (Groundwater-Smith et al, 2015). Echoing Mertens’ (2009) human rights agenda and capacity for social change across all marginalised groups, Punch (2002) argues, if research is to be transformative, it must hear the participants’ voices and the ultimate aim must be to empower the participants involved. Duckett et al (2010) carefully distinguish participation in research from tokenistic consultation, considering the latter to have limited capacity for affecting change. In her evaluation of Hart’s (1992) ladder of participation, Nieuwenhuys (2004) further acknowledges this concept of full participation, noting that only steps 7 and 8 of Hart’s ladder have the potential for political impact. Therefore, the participatory methods selected must reflect careful consideration of the cultural complexity of the community of participants (Mertens 2009) especially where that community exists in an educational setting (Seale et al, 2014). Participatory research must benefit the participants in some way (Cohen, Manion...
and Morrison, 2011), build practical competence and capacity (Kellet, 2010) such as developing resistance in communities that have previously suffered (Frank, 1995).

Langhout and Thomas (2010, p.61) demonstrate how participatory research has the potential to position children and young people as “collaborative change agents” in their own lives with Tisdall et al., (2008) outlining the numerous benefits to involving young people in participatory research. Lundy and McEvoy [Emerson] (2012) further demonstrate how young people can potentially elevate their status from research participants to peer-researchers and research advisors eloquently articulating authentic voices. Lundy (2018, pp.340-341) warns of the damage of tokenistic children’s participation in research as having the potential to cause “disaffection and disillusionment and ultimately disengagement” but equally acknowledges that tokenism can be a useful starting point towards “respectful and meaningful engagement with groups of children.” This is preceded by Lundy’s (2007) conceptualisation of how pupil voices in research can be truly reflected in research through the careful use of space; voice; audience; influence in response to the misinterpretation of Article 12 of the United Nations Conventions of the Rights of the Child (UNCRC). Kellett (2010) further outlines how young people in research can have their capacity built from the outset by contributing to the research, by formulating and designing the research questions, being trained in and performing the data collection and finally though analysing and disseminating their findings. However, Kellet (2010) caveats the researcher’s assessment of the young people’s skills and competence as a pre-cursor to their participation. Punch (2002) and Clark (2010) both demonstrate the use of innovative techniques in adapting participatory research methods developmentally across age groups and contextually within specific societies and cultures as a means of addressing participant competence.

According to Alderson (2005), full participation in the research process, increases the potential for young people to achieve a level of consciousness. Hart (1992) describes this as the empowerment of young people in research and notes how the subsequent consciousness they develop materialises from being embedded in the entire research process which is clearly the essence of Freire’s (1994) “concientizacao”. However, Alderson (2005) also cites that this empowerment is closely followed by a sense of
frustration at the lack of political change subsequently experienced by the young people, as conjectured previously by Tisdall (2008). Furthermore, Seale et al (2014) demonstrate the limitations of Hart’s (1992) full participation of children in research when it occurs in educational settings where other gatekeepers form part of the research community.

In this study, any anticipated lack of political mobilisation due to the age of the girls with autism is not the only way this group could be considered to be marginalised and Clark (2010) stresses the importance of considering the other marginalised groups that young people may belong to before engaging them in participatory research. This is where intersectional feminism becomes an important underpinning in this research as the participants are further marginalised by their gender and also the normatively perceived ‘disability’ of autism. However, Wang and Burris (1997), Kellet and Ding, (2004) and Ball, (2005) have all demonstrated the successful navigation of voice-enhancing participatory research with doubly marginalised groups. Furthermore, Kauschke et al (2016) espouse the benefit of participatory research with females demonstrating that gender specific characteristics become more evident in natural participatory settings than in structured controlled research settings. Finally, Bottema-Beutel and White (2016, p.362) argue that children with autism do “display some sensitivity to discourse contexts when formulating narratives” but acknowledge that they may well face barriers in expressing the emotions behind their stories. To counteract this difficulty Teti et al, (2016) encourage facilitating the use of arts based methods to aid with discussion as a means of enabling a young person with autism to participate in the research process.

3.13 Arts-based participatory research

Participatory research often involves the use of narrative and interview. Considering the girls with autism participating in this study and bearing in mind Kellet’s (2010) respect for participant competence, the adoption of fully language based research methods may be inappropriate considering that girls with autism can sometimes experience barriers to social communication scenarios. Kauschke et al (2016) list a multitude of studies that outline obstacles to communication for people with autism such as coherence, description, use of conjunctions, evaluation and recounting. Furthermore, there is
limited research into the differences in narrative competence between genders in autism. When language competence is centred on personal introspection, people with autism are further disadvantaged by difficulties in identifying and conveying emotions (Pisula et al, 2017).

Considering the vast array of participatory methods, Banks (2007, p.30) advocates a “shift away from language and linguistically derived models…to feeling, emotion and memory,” while Walsh, Bickel and Leggo (2015, p.2) expose writing as “only one way of being in the world.” Barone and Eisner (2012, p.1) similarly acknowledge the restrictions of solely using language as a process for meaning-making identifying arts based research as being superior at extending understanding through the use of “a spectrum of sensory modalities.” Put best by Leavy (2009, p.215-216; 228) visual images are “typically filed in the subconscious without the same conscious interpretive process people engage with when confronted with a written text,” however she adds later that while arts based participatory methods can convey multiple meanings, they can still act as “a springboard for more conventional qualitative inquiry” that channels propositional knowledge.

Macpherson et al (2015) demonstrate the use of art based participatory methods as being conducive for researching with neurodiverse people with Stein Safran (2002) purporting the use of these methods of expression for people who are challenged by normative expectations of contemplation. For example Schwartzberg and Silverman, (2016) demonstrated the benefit of using of music and singing in increasing cognitive arousal in children with autism which ultimately led to improved story comprehension. This echoes Leavy’s (2009) earlier view that the careful selection of arts based methods in educational research has the potential to gain deeper insights into the world of young people and improves critical consciousness, reflection, empathy and social action. Put simply, arts-based participatory methods makes participating in research more accessible to a wider range of potential participants by removing the necessity for language proficiency and enabling participants “to be open to what is not yet known” (Walsh, Bickel and Leggo 2015, p.1). Furthermore arts based research transforms both the propositional and unconscious knowledge of the participant into a form better suited to wider public understanding (Scott-Hoy and Ellis, 2008).
Embodied knowledge is knowledge that is not conscious nor rational however it is the manner by which we process our experiences in the world (McMurray, 1988). Barone and Eisner, (2012) and Leavy (2009) both cite arts-based methods as having the power to raise consciousness, to give value to the embodied experiences of participants. Arts-based methods have the capacity for elucidating a more comprehensive understanding of a person than could be gained through the use of narrative methods alone and encourage the unconscious experiences to become conscious (Derry, 2005; McNiff, 1998; McMurray, 1988). In fact Leitch (2006, p.551) suggests that “many emotional, sensory and embodied dimensions of experience lie below the threshold of consciousness and are thus often impossible to articulate in words.” Bergum and Godkin (2008) acknowledge the transformative process that participants undergo while making art due to the enhanced scope for the self-expression and the subsequent surfacing of deep-seated emotions and related experiences that narrative methods alone cannot uncover.

The potential for unlocking embodied experiences certainly favours the use of arts-based methods, however Rose (2012) warns of the controversy of using art as a research method due to its historical existence in the domain of aesthetics and concerns over disregard for artistic process and creativity. In contrast, Leavy (2009) avers that in visual arts-based participatory methods, aesthetics becomes less of a priority to the actual process. This is what makes it accessible to neurodiverse people and in this study, girls with autism. Considering Cohen, Manion and Morrison’s (2011) edict that transformative research must ensure positive reinforcement for its participants, arts-based participatory research is known to be both deeply personal but equally enjoyable for participants (Diamond and Halen-Faber 2005) and has the potential to build capacity rather than create barriers to participation (Kellet, 2010). There exists a multitude of arts-based participatory research methods which can be used for transformative goals, among them are various forms of photography and one such method is Photovoice (Punch, 2002; Barker and Weller, 2003; Clark, 2010).
3.14 Photovoice

Edwards (1997) denotes the use of images, especially photographs, as having the power to evoke messages that words alone cannot convey. More recently, Clore and Schnall (2008) endorse the use of image production, hailing it as a multidimensional way of accessing the emotional state of the artist while Leavy (2009, p.254) describes how the image can depict a “tapestry of meanings”. Banks (2007) traces the historical use of image to portray social and cultural experiences with Bleck (2015) heralding the use of photography as a means of portraying human experiences especially in cross-community collaboration. Used first as a research method by Collier in 1957, ‘photo elicitation’ was a means of prompting memory to encourage gentle discussion and this anthropological method continues to be used today with children and non-literate research participants (Pink, 2002).

Photovoice takes photo elicitation a step further by using the images produced as a stimulus for inciting social and political change for marginalised communities (Gubrium and Harper, 2013; Rose 2012). It could be argued that Photovoice takes interpretative documentary photography into the transformative paradigm and is regarded by Jurkowski and Paul-Ward (2007, p. 363) as “a useful method for engaging people with limited social and communication abilities.” However, it is important to note here that these perceived limited communication abilities may simply be the assumption of previously ill-selected research methods less responsive to the participants’ actual abilities.

Photovoice straddles feminist theory and the aforementioned Freirian (1994) concept of “concientizacao” or empowerment education for critical consciousness and the very inclusion of ‘voice’ in its title demonstrates its goal of addressing epistemic injustice. It is the breakthrough participatory arts-based method of Wang and Burris (1997) first using this in 1994 when collaborating with rural Chinese women. Photovoice has the potential to span gender, race, age, neurodiversity and location upholding its link to intersectional feminist theory and by collaborating with participants rather than researching on them, it recognises epistemic injustice and gives value to the voices and experiences of unheard and underrepresented groups in society (Catalani and Minkler, 2010).
Participants act as documentary photographers, creating their own ‘photo novellas’ and in becoming the documenters of their own communities, the multiple truths or social realities behind the photos emerge, which in turn, infers implications for future wealth, health and education (Wang and Burris 1994, p.171). The subsequent narratives created upon discussing the photography according to Gubrium and Harper (2013) are critical in extracting the truth behind the photo and Smith (1998, p.188) describes this part of the Photovoice process as the necessary anchoring of meaning. The use of narratives does not detract from the power of the photovoces alone but contributes to the creation of a third space or hybridity that occurs when pictures are put into words (Leavy 2009). Created by the Photovoice participant, this liminal space between the photographs and subsequent discussions of them is what makes photovoice a powerful mechanism for illuminating both propositional and non-propositional embodied knowledge (Smith, 1998).

Both Photovoice and photo elicitation have previously demonstrated their capacity as appropriate research methods for working with marginalised societies. Freire’s (1994) critical consciousness theory, through his research in literacy pedagogy in Brazil, is reflected by both Collier (1957) and Wang and Burris (1994), who enabled rural people, through photo elicitation among other methods, to become aware of their own oppression and effect change within cultural and educational policy as a result (Rose, 2012). Conrad et al’s (2015, p. 24) “Uncensored” participatory arts project demonstrated that positioning the youths as the “experts of their lives” encouraged them to become active agents of change through their collaborative problematising within their particular community. In educational settings, Gruenewald (2003) directly acknowledges the importance of place urging researchers to give the students agency over their own experiences especially concerning where these experiences have occurred with Pink (2002, p. 44) noting that “the agency becomes shared between the researcher and informant”. With specific relevance to young people with autism, Teti et al (2016) used Photovoice with 11 young people aged 16-22 to document their strengths as young people with autism and Obrusnikova and Cavalier (2011) used Photovoice with 14 young people with autism, aged 8-14, to document the barriers they faced in attending after-school activities. Both research groups found Photovoice to be expert in recording the finer details of the lived experiences of young people with autism.
Furthermore, it is the potential for illuminating multiple realities or “multivocality” (Miller, 1998, p. 68) that positions Photovoice as the optimal research method to generate increased understanding of the educational experiences of girls with autism.

In terms of practicality, Gubrium and Harper (2013)’s review of visual and digital research methods, lists Photovoice as the method requiring the least amount of training, requiring only a basic knowledge of photography. In addition, Catalani and Minkler’s (2010) review of thirty-seven different public health research projects, using Photovoice as their method, found Photovoice to be conducive to researching with groups of young adults facing challenges to their learning and mental health. Teti et al (2016) attest that in their study all the participants with autism had no difficulty with any aspect of Photovoice, in particular the use of digital cameras, making this research method easily accessible. Finally, and with caution, Wang and Burris (1997, 1994) are careful to acknowledge the skill required to maintain the integrity of the creative process and outline the necessary pre-training for Photovoice, the adherence to which is addressed later in the methods chapter.

In conclusion and in consideration of the positionality of the researcher, Photovoice is the proposed research method selected for this study. Photovoice ably embodies intersectional feminism, adheres to the hermeneutical responsibility within the perspective of epistemic injustice and makes critical enquiry worthwhile by providing the opportunity to elevate the research to different levels of power, observing the emancipatory nature of transformative research. However, in light of aforementioned considerations of tokenism in children’s participation in research, the use of Photovoice is not confirmed until after Phase 1 of this study whereby, through the use of conferences, critical friends are consulted upon Photovoice’s appropriateness for this study and this is discussed in Chapter 4.
Chapter 4: Methods

This chapter outlines how the study was carried out through three phases. Phase 1 considers critical friend conferences to establish Photovoice as a meaningful research method appropriate to this study’s aim and questions. Phase 2 considers all aspects of the actual research. Phase 3 describes the curation of the exhibitions. The chapter culminates with the ethical considerations for the study. The figure below directionally demonstrates the order of Phases 1 and 2 of the research and positions the roles of the critical friends, participants and my own role within these research phases.

Figure 3: Diagrammatic explanation of Phase 1 and Phase 2 of research.

4.1: Phase 1- Critical Friend Conferences

Prior to beginning the research, it was necessary to establish if the proposed project was feasible and was an appropriate way of representing girls with autism. This form of purposive sampling, whereby experts in the field are consulted to act as informants to the study (Knox et al, 2000, p.97), involved approaching three young women with autism over the age of eighteen (18-19). The three young women had previously attended mainstream post-primary school and this was used as an indicator of their capacity for contribution to this study. Ethical approval for this phase was obtained
from the Ethics Research Committee of the School of Social Sciences, Education and Social Work (SSESW), Queen’s University Belfast (QUB) in August 2018. This phase began immediately after ethical approval in August and September 2018 and was distinct from Phase 2 in that the girls engaged as advisors and did not take part in the actual research project.

I had presumed to recognise the need for social change in this area and this assumption would lead to the “initiating, facilitating and constructing meaning” around this research but would not, as outlined by Gillies and Aldred (2008, p. 43), counter my researcher power nor ensure participant empowerment. I was crucially aware that this doctoral research was my own idea and Photovoice my preferred research method which meant that I was imposing my preferences on the way the research would be conducted. If this research was to be participatory and at least constitute Level 6 of Hart’s (1992) ladder of participation, it needed to be more participant led. The research aimed to adhere to Porter and Lacey’s discussion (2005) of “Nothing about us without us” in terms of the inclusion of adolescent girls with autism however, this research was compromised by time and the logistical constraints of working across four schools. Fully participatory research involves the participants at all stages of the research process (Gillies and Alldred, 2008), however I knew that the research could only take place across any schools recruited non-collaboratively due to the practical restrictions of school timetables, distances between potential schools and my own full-time teaching role. Therefore, any potential participants would not be working as one complete group but rather individually or in smaller groups depending on school and participants’ preferences within each recruited school. Therefore, I needed to create a framework for the research that could be consistently replicated across potentially different school settings. To offset the limitations to full participation for the research participants, significant prior exploration through critical friend conferences took place to ensure the intended method fulfilled the research aims while also optimally representing any potential participants.

Critical friends are engaged by the researcher at the preliminary stage of a study as experts of their own lived experiences and are consulted with to act as informants to the study (Knox et al, 2000). I aimed to present the intended research to each critical friend, a young woman with autism (aged 18-19), and demonstrate the research method to them.
to gain their feedback and to ensure the research would be attuned to needs of adolescent girls with autism. This would enable me to amend my research plan in accordance with their feedback. This type of ancillary, exploratory conference is regarded a useful exercise to complete prior to a research project (Bloor et al, 2001). Therefore, for the preliminary stage of this study, individual exploratory conferences were deemed more appropriate than advisory groups and the subsequent conferences positioned the critical friends as “cultural brokers” for the research context of girls with autism (Hennink, 2017, p. 61). This would somewhat elevate their expertise above mine re-adjusting any power imbalance in this particular phase. The term ‘critical friend’ was adopted from educational practice as not only could the critical friends approached offer their expertise but they could provide an alternate lens through which the educational context for girls with autism could be viewed. The critical friends could also critique the proposed research and build my capacity for reflection as a researcher (Swaffield, 2007; Williams and Todd, 2016). Described by Costa and Kallik (1993, p. 50) as “conferences”, meetings between a critical friend and the researcher, in the new position as a learner, take approximately 20 minutes and follow a systematic process where the learner presents the research and the desired outcomes. The critical friend subsequently offers their queries, reflections and feedback to enable the learner to proceed with the research where the critical friend remains an advocate of the research.

**The details of the conference plan for the critical friends are contained in Appendix 1.**

**Outcome of Phase 1**

The Phase 1 Critical Friends was an extremely useful piece of preliminary research as it confirmed that the young women with autism (critical friends) had previously felt marginalised and certainly unheard among their families, peers and wider educational and social contexts. Therefore, the value in proceeding with such a piece of research was upheld. In terms of use of language, the young women with autism were all very assured in their opinions regarding this with none identifying themselves as autistic but rather as a girl/woman with autism. This would later prove an interesting finding when compared to the actual research itself (Chapter 5.9 Findings). Finally, all 3 critical friends agreed that Photovoice was a most appropriate research method to use,
sympathetic to any communication issues the participants may face while also being culturally appropriate in an era of selfies and smartphone technology.

4.2 Phase 2: Photovoice Research Project

Research Setting and Participant Recruitment

Ethical Approval was granted for Phase 2 in November 2018 and immediate recruitment began through the SENCOs (Special Educational Needs Coordinator) of schools identified as potential participatory schools. The selection of the five schools* approached was determined by proximity to my own school, previous collaboration with these schools and an ability for each school to demonstrate a different demographic to my own school. This was important as the aim of the research was to represent the mainstream schooling experiences of girls with autism in Northern Ireland and mainstream comprises of a mixture of types of school as follows (Boroah and Knox, 2015):

- Co-educational Catholic Grammar *School A
- Co-educational Protestant Grammar *School E
- Single-Sex Catholic Grammar *School B
- Single-Sex Protestant Grammar
- Co-educational all ability Catholic secondary *School C
- Co-educational all ability Protestant secondary
- Single-sex all ability Catholic secondary
- Single-sex all ability Protestant secondary
- Co-educational Integrated school *School D

Four types of schools were not approached simply because of proximity and time constraints and while this underrepresents some single-sex schools and those of protestant faith, neither of these criteria featured in any of the Phase 1 critical friend conferences as being an important aspect of representation despite the researcher’s attempt to be demographically representative. Despite several attempts to contact school E through the various gatekeepers of SENCO, Principal, Vice-Principal and Assistant
SENCO, their participation was not forthcoming and so this demographic is also absent from the research. What is most important about the schools recruited is that the varying academic levels of mainstream education are represented from selective grammar to combined selective and non-selective integrated school to non-selective secondary. As ability to cope with mainstream curriculum would become a key feature in the later findings and discussion of this study, this inclusion of all academic levels within mainstream was important.

In the four recruited schools the SENCO was first asked to approach the principal for initial gatekeeper consent (Appendix 2). Once this was approved, the SENCOs then used the SEN register in their schools to identify girls aged 12-18 years with a confirmed identification of autism from either the Education Authority or Health and Social Care Trust. This would inevitably limit my control over the recruitment of potential participants except for my own school and I was entirely dependent on the support of each school’s SENCO. I had no control over the ages or profiles of the girls that I would eventually work with nor how many would initially be approached, however, this was an essential part of the selection due to General Data Protection Regulations with regard to identifying a person on the SEN register. In my own school there were only three girls with autism and so all were approached and had the opportunity to become participants. The information sheets and consent forms were distributed by the respective SENCOs to both the potential participants and their parents/guardians simultaneously. In line with the Ethics Research Committee of the SSESW, QUB, parental consent is deemed paramount when participants are under the age of 18, however in this research, the girls’ consent to participate was considered as important as their parents’ and different formats of the consent forms and information sheets were provided to parents and girls to reflect this (Appendix 2). The ethics regarding capacity to consent, coercion to participate and recruitment of under 18 participants are discussed later in this chapter under Ethics. From this a total of 9 girls were recruited as participants and it was only at this point that I became aware of their names. The following table demonstrates representation across the four different school sectors:
The intended recruitment had been N=12. Phase 2 recruitment initially concluded with 4 out of 5 schools agreeing to participate with 10 consenting participants from a possible 13. Before beginning the research, a participant from my own school, who had initially agreed, withdrew their consent to participate resulting in N=9. At this point, I considered approaching two further schools but on advice from my dissertation supervisor, waited to complete the research with the initial 9 participants to ascertain if data-saturation point would be reached later confirmed in Chapter 5. One of the participants requested that her classroom assistant attend the sessions with her and this was facilitated for all 5 research sessions.

At the beginning of the research, all participants were identified using a number only and were treated anonymously until the first session where I established with each participant how they would like to be addressed throughout the research process. This was revisited during each research session as I anticipated a change in this as the research project progressed. Due to the highly participatory nature of Photovoice and as predicted by Gubrium and Harper (2013), ownership and responsibility for the research intrinsically increased in some of the participants with some of them changing how they wished to be represented in both the exhibitions and the final write up and are therefore identified as follows:

<table>
<thead>
<tr>
<th>School</th>
<th>School Type</th>
<th>No. of Participants approached</th>
<th>No. of Participants confirmed</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Selective Co-Educational Catholic Grammar</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>B</td>
<td>Selective Catholic Grammar for Girls</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>C</td>
<td>Co-Educational Catholic Secondary College</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>D</td>
<td>Co-Educational Integrated College</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>4</td>
<td>13</td>
</tr>
</tbody>
</table>

Table 1: Participating Schools
On the basis of prior research into the use of Photovoice, the research project was devised into 5 distinct sessions to run consecutively for 5 weeks. Part of the ethics process (discussed later) involved the SENCO identifying if participants would participate individually or as a group. Where girls opted to participate individually, sessions would be kept to a maximum of 40 minutes. Where girls opted to participate as a group, sessions would last one hour. The participants’ timetables from each school and my own timetable were cross-referenced to identify mutually suitable session times. The specific session details for each school are listed in Appendix 3.

Pre-project collaboration was also conducted with a professional stills photographer, Helen Sloan, who works professionally on Game of Thrones among other projects but also has a background in community arts based research. Due to Helen’s reputation and the likelihood of this influencing consent to participate, her attendance was not discussed until the end of session 1 so that consent had been established without the influence of this incentive. It was also likely that Helen would not be able to attend all the schools due to her work commitments. However, association with Helen as a result of participation was seen as a positive benefit for the participants taking part and the impact of this is discussed in the findings chapter.

The research was scheduled to begin in January 2019, staggering each school start in order to facilitate researcher reflection and improvement as advised by Cresswell (2007), before beginning the following week’s session or new school group. The

Table 2: Participant identifiers.

<table>
<thead>
<tr>
<th>Initial Participant Identifier</th>
<th>School (as listed before)</th>
<th>Participation in Individual /Group research sessions</th>
<th>Name/Initial under pictures at exhibitions</th>
<th>Name in research write-up *pseudonym</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>A</td>
<td>Group</td>
<td>A</td>
<td>Anna*</td>
<td>17</td>
</tr>
<tr>
<td>2.</td>
<td>A</td>
<td>Group</td>
<td>N</td>
<td>Niamh</td>
<td>17</td>
</tr>
<tr>
<td>3.</td>
<td>B</td>
<td>Individual with Classroom Assistant</td>
<td>Cara</td>
<td>Cara</td>
<td>16</td>
</tr>
<tr>
<td>4.</td>
<td>B</td>
<td>Individual</td>
<td>Dearbhail</td>
<td>Dearbhail</td>
<td>18</td>
</tr>
<tr>
<td>5.</td>
<td>C</td>
<td>Group</td>
<td>Lauren</td>
<td>Lauren</td>
<td>15</td>
</tr>
<tr>
<td>6.</td>
<td>C</td>
<td>Group</td>
<td>M</td>
<td>Megan</td>
<td>16</td>
</tr>
<tr>
<td>7.</td>
<td>C</td>
<td>Group</td>
<td>Samantha</td>
<td>Samantha</td>
<td>12</td>
</tr>
<tr>
<td>8.</td>
<td>D</td>
<td>Group</td>
<td>H</td>
<td>H</td>
<td>16</td>
</tr>
<tr>
<td>9.</td>
<td>D</td>
<td>Group</td>
<td>NM</td>
<td>NM</td>
<td></td>
</tr>
</tbody>
</table>
research was scheduled to conclude in March 2019 but due to many methodological challenges discussed later in the findings chapter, the final session of research in the final school took place in May as outlined below:

<table>
<thead>
<tr>
<th>Participants</th>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
<th>Session 5</th>
<th>No. of Reschedules</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anna*</td>
<td>25th January 2019</td>
<td>29th January 2019</td>
<td>5th February 2019</td>
<td>12th &amp; 14th March 2019</td>
<td>2nd &amp; 16th April 2019</td>
<td>2</td>
</tr>
<tr>
<td>Lauren</td>
<td>12th March 2019</td>
<td>19th March 2019</td>
<td>26th March 2019</td>
<td>9th April 2019</td>
<td>16th April 2019</td>
<td>0</td>
</tr>
<tr>
<td>Megan</td>
<td>12th March 2019</td>
<td>19th March 2019</td>
<td>26th March 2019</td>
<td>9th April 2019</td>
<td>16th April 2019</td>
<td>0</td>
</tr>
<tr>
<td>Samantha</td>
<td>12th March 2019</td>
<td>19th March 2019</td>
<td>26th March 2019</td>
<td>9th April 2019</td>
<td>16th April 2019</td>
<td>0</td>
</tr>
<tr>
<td>H</td>
<td>5th April 2019</td>
<td>12th April 2019</td>
<td>1st May 2019</td>
<td>8th May 2019</td>
<td>15th May 2019</td>
<td>1</td>
</tr>
<tr>
<td>NM</td>
<td>5th April 2019</td>
<td>Missed</td>
<td>1st May 2019</td>
<td>8th May 2019</td>
<td>15th May 2019</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3: Sessions schedule.

Session 1:

This was an introductory PowerPoint comprising of 8 slides using both text and photos to establish the nature of the research (Appendix 4). The participants were initially asked to confirm that they were happy for the sessions to be recorded and a mobile phone was then used for sound recording only. Once this was established, I introduced
myself personally and professionally in an effort to build rapport but also to introduce the scope of photography from the outset. The research was contextualised historically using statistics from Wing (1981), Ehlers and Gillberg (1993), Brugha et al (2012) and the National Autistic Society (2015), to present an enduring timeline regarding girls and women with autism and possible reasons for their underrepresentation. In the penultimate slide, I revisited their consent forms and linked this to the use of photographs and the importance of the omission of identifying features in photos. The final slide confirmed the role of the participants in the project and the researcher sought clarification of the participants’ understanding of the first session and subsequent consent for continued participation. From this session on, and in line with Strnadová and Walmsley’s (2018) “Peer reviewed articles on inclusive research” which stresses the importance of giving voice to people with neurodiversity, the girls would be considered as experts in the research with the researcher emphasising the girls’ control over the images they produced. I also introduced the possibility of the photographer attending subsequent sessions and sought consent for this. I also explained to the participants that while they may wish for her to attend, she would be constrained by work commitments but that I would let them know if and when she was available to come.

**Session 2:**

This was a practical capacity-building session whereby the participants were given a 12 page handout on photography composition and how photos can be used to portray a story, mood, feeling or atmosphere (Appendix 5). Composed by Helen Sloan, the handout focussed on simple aspects of photography such as rule of thirds, leading lines and lighting. The handout then considered ways to convey identity without using faces through the use of feet, silhouette and shadow, masks, personal objects, reflections in water and curated scenes. Throughout this session, discussion around mood and identity was encouraged as participants were asked to explain what they thought the meaning was behind each photo. This was in acknowledgment of Wang and Burris’ (1997, 1994) deference to maintaining the integrity the creative process.

Once this exploratory work was done, a short PowerPoint on Photovoice was then presented (Appendix 6). Its definition and background were explained and examples of
previous Photovoice projects were shown. Significant emphasis was placed on the ability of Photovoice to encourage discussion, engender social change and potentially have political influence. This was then linked back to the necessity of enlightening others to the lived experiences of girls with autism. At this point, the findings of Phase 1 were discussed specifically regarding the three critical friends’ views on the research, the research method and the tension around the use of identity-first language. This generated significant discussion around the importance of the research as discussed below in collective outcomes.

A final task was given to the participants. They would use the time in-between the second and third sessions to compose 3 photos that incorporated some of the skills they had learned during this particular session. The photos should reflect some aspect of their lives outside of the school setting and participants were asked to take the photos following the brief of having no identifiable people in them. They were encouraged to use their mobile phones or cameras and to be open to presenting their photos at the following week’s session.

Three photos were suggested as this would be the minimum number required from each participant in Session 4 and so in line with the perceived need for consistency among people with autism, it was kept the same for Session 3. Furthermore, if the research was to reach exhibition stage, a minimum number of 25 photos would be required with a maximum of 35 so it was important to keep participant expectations manageable while also not presenting them with an onerous task. Finally, I had a limited amount of time with each participant with which to discuss the meaning behind each photo and so 3 was the optimum number for this allowing 15 minutes for each participant in a session. However, this was not set as a rule, and participants were reassured that if they could not compose any photos or found themselves with too many to choose from, neither of these scenarios would be an issue and the task was presented as ‘Have a go!’ Not all participants followed this specific brief and this is discussed in the findings section.

**Session 3:**

As the home task was not deemed to be homework and in anticipation of some participants not completing the task, Helen and I had our own personal Photovoices ready to present should a participant be unable to do so. This would remove any
pressure they felt to participate and aimed to deescalate what could potentially be a stressful situation for an unprepared participant. In either situation, the participants’ or the researchers’ own photos would be discussed for the meaning conveyed about their identity. Each participant would lead the discussion by expressing if they wanted their co-participants to deduce the meaning behind the photos or if they simply wanted to explain it themselves. This was done by explicitly giving the participant this choice at the beginning of their turn. The discussion would include how the colour, lighting and position of the objects within the photographs contributed to their overall meaning at both a physical and metaphorical level. This part of the session would serve an initial attempt at Wang’s (2004) VOICE (Voicing our Individual and Collective experience) or SHOWED (See, Happening, Our, Why, Empowered, Do) methods (Wang and Burris 1997, p. 381; Wang et al., 2004, p.912) discussed in the next section.

Once discussion around the personal stories was complete, I then used a Photovoice from my own school setting to demonstrate how Photovoice could be used to depict the life of a SENCO in her own school environment (Appendix 7). In light of the suggestions from Phase 1’s critical friends, the use of titles for photos was then introduced as a mechanism of producing deeper meaning to the photos (Banks, 2007).

A final task was then set for the participants. In between sessions 3 and 4, they were asked to consider their experiences in mainstream education, both good and bad and compose three photos either in school setting or representing school experience. They could choose if they wished to represent positive, negative or both types of experience and they could decide how to represent these experiences through photography. Once again the participants were asked not to have any identifiable features of people or their respective schools. These photos would form the discussion in the following week’s session.

Session 4:

The participants were individually asked to present their education-based photos. Initially, both the lead researcher and the other participants (when done in a group setting) would surmise the meaning behind each photo and its significance to the photographer and the lens of autism. Depending on the meanings elicited, the photographer would then clarify any misinterpreted connotations and this would elicit
further discussion around the particular educational experience highlighted and where possible, if others in the group related to this experience or could share a similar one. The use of colour, lighting and positioning within the photographs was also considered in terms of what these added to the meaning of each photograph. This discussion was based on VOICE and SHOWED methods (Wang and Burris 1997, p. 381; Wang et al., 2004, p.912) The original acronym of VOICE means Voicing Our Individual and Collective Experience whereby photovoice is used to present the issues and concerns within a particular group to influence how their wider community responds. The potential dialogue initiated is designed to instigate social change. “SHOWeD is a five-step questioning technique: (i) What do you See in this photograph? (ii) What is Happening in the photograph? (iii) How does this relate to Our lives? (iv) Why do these issues exist? (v) What can we Do to address these issues? and is employed to initiate discussion about the photographs” Wang et al., 2004, p.912.

Therefore, this would be the most important session as what was produced during all session 4s would form the basis of the research findings and any subsequent exhibitions. Titles for these photos were discussed on the basis of the meanings elicited and whether or not these titles were finalised. Direct and paraphrased quotations from these discussions were used in the production of the brochure that would accompany the subsequent photographic exhibitions (Appendix 8).

Once this was done, the participants were asked to take the final week to reflect on their photos, amend or retake any they felt displeased by and confirm which photos they wished to be used for the research. Where titles had not been assigned, participants were also asked to consider giving titles to these photos now that they had explored both the photos’ face and hidden meanings (McNiff, 1998). Participants were also assured that I would assist them in entitling their photos in the following week’s session if they were unable or reluctant to do this alone.

**Session 5:**

This was the final session of the research project where I confirmed the photos each participant wanted to include as their research. Participants discussed any titles they would give to their pieces or co-constructed these with the help of their group. The potential for two/three possible exhibitions was explored with the participants and
consent for both was sought for this once more. At this point, aspects of anonymity and confidentiality were re-explored and amendments were made to names/identities where appropriate (as presented earlier in Table 2).

The researcher thanked everyone for taking part and asked the participant to evaluate the project and its usefulness in achieving the original aim. The researcher also asked the participants about any ethical issues that surfaced for them as they progressed through the research. Any issues raised would be further planned for, in line with safeguarding and SEN policies in each school as previously agreed with school SENCOs.

Finally, the researcher explained how the participants would be notified of the prospective exhibitions through their schools’ SENCOs or through any personal email provided to the lead researcher. The participants were also reminded that they would be offered the opportunity to withdraw their work up until the point of exhibition.

4.3 Phase 3: Curation and Exhibitions
The final part of Photovoice is the exhibition of the photographs generated by the participants. This is a fundamental aspect of the project as up until this point the research only meets the criteria of photo documentary or photo elicitation (Rose, 2012). The exhibition part of Photovoice is what makes the research both transformative and emancipatory as it seeks attention from those stakeholders with the power and status to effect social change. Three levels of audience were identified corresponding to micro, meso and macro levels of social analysis (Serpa and Ferreira, 2019) and the curation of the corresponding exhibitions are discussed fully in Chapter 6.

4.4 Ethical Considerations

The ultimate ‘baseline’ of ethics is to protect the human being within the research process. (Mockler and Groundwater-Smith, 2015, p. 127).

Both Phase 1 and Phase 2 of the research required ethical approval from the Ethics Research Committee of the SSESW, QUB. Phase 1 ethics were approved with minor revisions and Phase 2 was approved on the first application. (Appendix 9). Phase 1 required an Information sheet for the critical friends and a corresponding consent form. As the critical friends were over 18 and at University, they were therefore deemed to
have capacity to give informed consent, however, critical friends were also offered information sheets and a consent from for a trusted friend if they wished to nominate one (Appendix 2). This was reviewed by the Ethics Research Committee of the SSESW, who required a parental consent form for this phase. Phase 2 required information and consent forms for the principals of the selected schools, the parents of the nominated participants and the participants themselves. Both Alderson (2004) and Scott (2008) stress the importance of addressing ethical issues using language that is both comprehensible and reflective of participant need. As autism is more widely regarded as a social and communication disorder, the participant consent form was adjusted to make consent a more accessible process to navigate and the information sheet had a photo of me on it to introduce the person with whom they would be working (Appendix 2). In line with ethical approval, the forms are stored securely and separately from other identifiable information for a minimum of five years and will then be destroyed.

**Issues of Power**

A key component of the ethical considerations for the research was the power imbalance between the lead researcher and the participants as both critical friends and as participants under the age of 18. In any research, the methodology selected has the potential to inflict loss of power and status (Christensen and Prout, 2002), however, as with this methodology, when research is transformative, it has the potential to redress any power imbalance by empowering the participant involved and by hearing participant voice (Punch 2002).

In school settings, volunteer participants for research are quite often not willing volunteers in that they are signed up by their parents or guardians who wish to revere those supporting and conducting research with/on children (May and Perry, 2011). In the context of a school, children and young people may experience coercion by their gatekeepers to participate in research (Morrow, 2005; David et al, 2001). Where the teacher is the researcher, there is even greater consideration required as professional relationships already exist between the teacher-researcher and parents/guardians and between the teacher-researcher and the students (Osler, 2010). This can lead to participants or their guardians signing up to research because they feel they ‘ought to’ as
it is their teacher/child’s teacher conducting the research and as outlined by Walsh (2005) they can lack the capacity to fully understand what they are consenting to.

Clark (2010) posits that when research is participatory or participant led, the inverting of this power balance towards the participants as opposed to the researcher-as-facilitator is crucial but this becomes problematic when a reverse position of power has previously existed (as in this instance). This power imbalance also has implications for right to withdraw in the sense that participants or their families may feel they will be letting the researcher-as-facilitator down if they wish to pursue a withdrawal from the research (Punch, 2002; Langston et al, 2004; Cuskelly, 2005).

Four of the participants involved in the research already had an established connection to me. In Phase 1, two of the three critical friends had been past-pupils of my school and I had directly worked with both girls and their families. In fact, it is this involvement with them, that led me to having the details of their diagnoses and the ability to contact them for their critical advisory support. To further redress any power imbalance in the conferences, these two critical friends were invited to choose the place they felt most comfortable to meet and any association with their previous school was discouraged. As a result the meetings took place in one of the girl’s home, with her mother in the next room and the second took place in a pre-booked study room in Queen’s McClay library where both the critical friend and I are students. I encouraged both girls to refer to me by my first name as opposed to the “Mrs” title they would have used in school. Initially they both found this awkward but the humour caused by referring to me in this way broke down barriers and put us on as equal a standing as I could have hoped to achieve.

In phase 2 of the research, two of the participants were from my own school where I am the SENCO and also Head of Psychology. Both of the participants are on the SEN register I coordinate for the school and one is also in my A-level psychology class. The participants were also from the same friendship group in their year group. Again I approached the participants first rather than their parents to gauge their interest in participating. It became apparent that they were genuinely interested as they divulged to each other privately that I had mooted their possible participation. It was only then that I approached their parents for consent as I did not want the girls to feel under pressure to participate.
I have no real way of knowing if this redressed the power issues regarding participation however, I did approach a third potential participant in my school, who initially agreed to participation and after parental consent was also granted, she later withdrew prior to the research beginning. I reassured her that there was no issue with this and have maintained the same positive working relationship with her that I have always had. Perhaps the fact that she felt comfortable withdrawing demonstrates that my role and the power associated with it had been diminished during the recruitment phase.

The organisation of the Phase 2 sessions with the girls from my own school was prefaced by the understanding that by positioning myself as ‘least adult’ in the research setting, I could potentially circumvent the power imbalance within the research context, enabling the participants to vocalise how comfortable they were with the proceedings (Christensen and James, 2008). The research was held in an informal classroom not associated with my role in the school, lunch was ordered through hospitality services from the school canteen as would be done for visitors to the school and Helen Sloan was able to attend 3/5 sessions. By elevating their status in this way, this significantly detracted from my position as a teacher in the school and put into practice Lundy and McEvoy’s [Emerson] (2012) concept of elevating research participants’ status to peer-researchers, research advisors and participants resulting in the rebalancing of power issues within the research setting.

However, the girls involved opted to continue referring to me as Miss, while referring to the photographer as Helen. This was different to the other schools where the other participants referred to me by my first name from the outset. However, this was reflective of my historic relationship with them and I did not pursue this as would have been tantamount to Duncombe and Jessop’s (2008, p.106) ‘doing rapport and … faking friendship’ and once the research was over I would have to return to my role as their teacher and SENCO.

In the other participating schools, I had little control over how the participants were recruited. All contact was through these schools’ SENCOs who I knew from previous SEN professional collaboration. In terms of power imbalance through gatekeeper recruitment, my understanding was that the consenting participants and their parents were excited to be participating. This was evidenced by their later attendance at the
exhibition launches. In all schools there was under-recruitment of the prospective participants initially identified which potentially means the process for declining to participate was clear and easy to declare.

Each school had organised its own set-up for the research to take place. In all schools I was given a quiet, informal meeting room in which to conduct the research. All the participants were familiar with the respective rooms which were most often used for one-to-one meetings with visitors or support services to the schools. I wore an identifiable visitor’s badge in each school which positioned me as an outsider to the participants’ educational environments and therefore their experiences. This framed them as experts in their own learning environments of which I had limited knowledge and assisted in creating a power-sharing dynamic throughout the research. This is supported by Clark (2010, p. 115) who, while spanning the overlap between constructivist and transformative methods, demonstrates that using participatory tools, situates children and young people as participants and power-sharers within a research setting.

Critical reflection can be considered an antidote to power imbalances. Demonstrative reflexivity within each culturally and socially bespoke research context is imperative as it continuously repositions the researcher as the participant and power-sharer and not simply the investigator (Christensen and Prout, 2002; Punch, 2002; Barker and Weller, 2003; Langhout and Thomas, 2010). From the outset of this research, I have kept a reflective journal which has allowed me to interrogate my own motives and subsequent behaviour during the research process. In line with Bridges (2002) concept of sufficient self-censorship as part of reflection, I have re-listened to the audio-recordings of each week’s sessions to analyse my own behaviour during the sessions, subsequently adjusting my behaviour the following week. For example: in the initial weeks of research, I noted hearing my own voice too much during sessions, sometimes finishing other people’s sentences and jumping to conclusions before the participants had articulated their points. Considering the title of the research “Missing Voices”, I needed to quickly ameliorate my behaviour as a facilitator, taking a step back from discussion and giving others the space and time to construct their points. During the sessions I also tried to be open and honest with regards to sharing my own personal and professional
Photovoice in an effort to accompany the participants through the research experience rather than leading them through it.

Pendlebury and Enslin (2002) use Lane’s (1992) ‘Mask of Benevolence’ to describe how one can learn to know a culture from the outside by being a trained and attentive listener. They also postulate that using one’s power to give voices to those who are oppressed is a moral commitment and that each researcher is entrusted with discretionary powers that they can choose to use for good or questionable ends. Critical reflexivity of one’s autobiography leads to the distilling of the researcher’s position and the effect it will have on their research (Usher, 1996) and continued reflexivity promotes “honesty, transparency and overall accountability in research” (Doucet and Mauthner, 2008, p. 125). I have been self-consciously aware of the power I possess as the researcher in this study in terms of being a middleclass professional with access to Master’s degree level education and without ever having been labelled with a disability. At all times, I have tried to use this position for the benefit of both the critical friends and participants, by positioning myself as a research facilitator.

**Right to Withdraw and Informed Consent**

Participatory research inevitably changes focus throughout the process meaning consent must be continuously re-established (David et al, 2001; Christensen and Prout, 2002). The researcher, through consistent dialogue with the participants, must repeatedly outline the research intentions before and during the research process and, more crucially, in language that reflects their level of understanding (Punch, 2002). A young person may struggle with this concept (Alderson, 2005) and this potentially means that a participant may wish to withdraw their initial consent but will not do so due to feeling pressured into continuing to participate. Unequal power relations in the research setting make it very difficult for participants to opt out (Punch, 2002).

Consent was revisited throughout Phase 2 of the research. In the first session when the full nature of the role of the participant was discussed, the girls were asked to confirm if they wished to proceed with the research. This was also an opportunity for me to establish that they were participating of their own free will and not because their parents had signed them up as previously discussed. During session 2, when Photovoice and the use of photography was explored, consent was reconsidered as now the participants
were being asked to complete certain photographic tasks regarding their identity and this may have been difficult for them to undertake. This was reiterated during sessions 3 and 4. In the final session, details of the prospective exhibitions were revealed as they had not been confirmed until this point. No-one had anticipated the scope the Photovoice project would reach and with such diverse exposure forthcoming, it was imperative to regain informed consent for each exhibition level and recheck the permission to use the girls’ photos, titles and names.

**Right to Withdraw and Protection from Harm**

When researching with young people a responsibility lies in the researcher’s understanding of their participant group and thus they have a duty to be extra vigilant for cues and signs of distress in their participants and be adequately competent in dealing with such instances (Alderson, 2004; France, 2004). Furthermore, a young person, especially a young person with autism, may struggle with recognising emerging negative emotions in themselves and may therefore be unable to express their distress at which point the onus is on the researcher to protect the participant (Langston et al, 2004).

Throughout the research, several of the participants missed sessions. Quite often this was due to school-related anxiety as explained by their respective SENCOs. On return to their rescheduled sessions, it was important to re-establish consent and check that the participant was happy to proceed. It would be unethical to continue with the research if participation was compounding any pre-existing anxiety or causing it. Acting within my own level of competence and professionalism, at no point did I feel that any of the participants were being negatively affected by participation and I checked with their SENCOs to confirm this.

Kellett (2010) outlines the importance of the researcher’s attention to the participants’ skills and competence and the importance of scaffolding throughout the research. As previously mentioned, I had alternative tasks in place for sessions 3 and 4 should any of the participants attend a session without their tasks completed thereby reducing any associated stress. The aim of the research was to build capacity not expose any weaknesses in the participants nor cause them to doubt their ability to be an integral part of the research process.
Right to Withdraw and Anonymity.

Protecting anonymity is often not prioritised by younger participants who may be proud of their identity, and may feel devalued if it is not used during and in the culmination of a research project (Osler, 2010). Consenting to have their research included in the photograph exhibitions required interrogation of how they wished to be represented in the research. As previously stated, initially each participant had been given an identifying number. This was revisited in the last session as the extent of the exhibitions and subsequent levels of exposure were clearer and therefore an informed decision regarding anonymity could be made. Aligning with Christensen’s (2004) discovery of the importance of assurances of confidentiality to her young participants, the participants were similarly assured that they could continue to be represented by their number. However, other identifiers were then proposed by the participants themselves such as a single initial, two initials, first name only or pseudonym. Each participant selected their preference for the exhibitions and for the research write-up. This ensured bespoke anonymity for each participant and reflected their personal level of comfortableness with their ownership and exposure of their research.

Conclusion

In conclusion, 27 research sessions were conducted over the course of 5 months and the data generated from the nine participants during this time was sufficient for the Photovoice objectives. The ethical wellbeing of the nine participants was central to the entire research process and this was supplemented by sustained interrogatory reflection on the part of the researcher throughout the process. No major ethical concerns emerged during the process and the following two chapters are testament to the positive experiences shared by the group taking part in the study. The findings are considered in two ways: Chapter 5 analyses the findings using Interpretative Phenomenological Analysis and Chapter 6 considers the exhibitions and their impact in relation to the research questions.
Chapter 5: Findings and discussion of photographs

This chapter considers the photographs generated as a result of the research and how they have been narrowed down to the exhibition size of 34 photographs. An Interpretative Phenomenological Analysis (IPA) was then conducted to identify the emerging themes of the study. Six themes have been identified as part of the research: “School as a Safe Place”; “Obstacles to Learning”; “Importance of Idiographic Curriculum”; “Sensory Overload”; “Coping Strategies”; “Identity and Challenging the Assumptions of ASD”. Each theme is presented and analysed in turn. The corresponding photos from the exhibitions are also included under each theme. The numbering of each photo comes from its sequence in the exhibition brochure presented in order in Appendix 8.

5.1 Photographs

From the nine participants, a total of 62 photos were generated. Five of the participants followed the brief exactly and submitted 3 photographs each while Dearbhail submitted 21, Lauren submitted 6, H submitted 6; and NM submitted 14. The latter four participants all cited issues with not being able to shortlist which photos were most important or which ones they felt they could use and asked for support in shortlisting their photographs. The four participants were encouraged to shortlist their photographs to a maximum of 6. This was done for a variety of reasons. Firstly, had all the photographs from these four participants been submitted, this would have given an imbalanced perspective of their experiences of autism and would have undermined the contribution of the other five participants who had conscientiously followed the brief of submitting 3 photographs. Considering the title of the study, it was imperative that everyone’s voice was given equitable regard. Secondly, some of the participants’ photographs were retakes of the same composition, from different angles and with varying degrees of photographic clarity and focus. The physical composition of a photograph is an important aspect of the interpretative and embodiment level of a photograph where focus and clarity act as metaphors for hidden meaning and so it was critical that I did not influence selection here. Furthermore, the very fact that several photographs of the same composition exist, demonstrates an urgency on the part of the
participants in ensuring the message behind this composition is heard. In Lauren’s case there were multiples of two of her four compositions, making it easy for her to select her best two to use with some reassurance from her group. In Dearbhail’s case, there were several takes of the same composition. Dearbhail and I considered the multiples of these compositions and then selected the photograph from each group that she felt best represented the meaning she was trying to convey. This did not account for all Dearbhail’s shortlisting. For Dearbhail, H and NM, the final mechanism for short-listing to a maximum of 6 photographs came through revisiting the brief of session 4 with regard to educational experiences and by refocussing on the research questions, the remaining participants were able to choose the 6 photographs that they were happiest to submit. Most of this short-listing came from the girls recognising that some of the photos they had included had no connection to autism, they had “just really like(d) that photo” (H). NM was able to combine four photographs into two.

The process was most difficult for Dearbhail who had the most photographs to choose from. In hindsight, this demonstrated Dearbhail’s willingness to explore her own identity and a sense of urgency in taking her opportunity to express herself to others. This absolutely demonstrates the underpinning assumption of this research, that girls with autism are effusive in portraying their identity and telling their story if given the platform to do so. At no point during this process had any thematic analysis begun and so the resulting 34 photographs were not in any way influenced by my expectations of the data.
Table 4: Participants’ photographs.

The critical research group from Phase 1 had suggested that the participants should present both positive and negative aspects of their lives as girls with autism and this was discussed with the participants in sessions 1 and 2 in each setting. Of the 34 photos selected, 10 photos have negative experience connotations and 24 have positive experience connotations. The 28 photographs not selected for shortlisting were either retakes of the included photographs, positive non-educational photographs that saturated the data in terms of theme or photographs not connected to autism in any way. The original research questions centred around the educational experiences of girls with autism however, it became very clear in sessions 3, 4 and 5 and consistently across all 4 school settings that the participants wanted to represent their whole lives and not just their experiences pertaining to school. With respect to the participatory process, the girls were subsequently encouraged to photograph whatever was meaningful to them and their experiences as a girl with autism. This resulted in 9 photos representing non-educational experiences and 25 representing some aspect of their educational experiences.

Seven of the girls generated their photos independently whereas two of the participants found the compositional part of the research difficult to navigate. Reasons for this were a fear of not getting the task right and not knowing what to photograph that could represent how they were feeling. Both of these girls belonged to group research settings.
in two different schools. When it became apparent that they were finding the task difficult, the other members of the group offered assistance and I took a back seat to this assistance in order to ensure that my position as a non-autistic researcher did not influence their participation. Ideas were subsequently discussed for how they might be able to represent what they wanted to say through a photograph and the photos were then taken during the sessions with the assistance of the other participants. This was a hugely positive part of the experience as all the girls emerged from the sessions with work that they were proud of and the process of assisting each other had indirectly engendered even more collegiality within the group settings. This was also reflected in the group discussions about the meanings of each photo with all group members contributing verbally to the process and congratulating each other on how beautiful their photos were and how they had aptly depicted the experiences they were trying to share. This allowed me as the researcher to take a less dominant role in the sessions, facilitating the discussion but not leading it.

The photos were then produced by a professional printing firm on high quality Foamex boards to A3 size. The accompanying brochure was designed by the mother of one of the participants who is a graphic designer and a different printing firm was used to produce high gloss brochures to be distributed at each event. This was an important part of presenting the research as we wanted to demonstrate the professionalism of the girls’ work and also acknowledge their efforts. The girls did not receive any remuneration for their work however, significant investment was made in its professional presentation to elevate their status as participants and photographic documenters.

The photos were then used to curate the Missing Voices photo exhibition which would be displayed three times in Belfast across three different venues: Queen’s University; Northern Ireland Assembly at Stormont Buildings and University of Atypical as part of the Belfast International Arts Festival. These exhibitions fulfil the final requirement of Photovoice as a research method which is to create awareness at all levels of power and across stakeholders with a view to inciting social or political change, the impact of which is discussed in Chapter 6.

To allow in-depth analysis and considering the previously discussed careful short-listing of the photographs, only the final 34 photos were analysed. However, once the IPA was
complete, the themes were checked against the omitted photographs to verify consistency and congruence across the themes. This was done using Interpretative Phenomenological Analysis to address the following three research questions:

1. What are the challenges faced by girls with autism in the transitional years of post-primary school?
2. What are the coping strategies used by girls with autism in post-primary school?
3. How can the personal experiences of girls with autism be used to increase educational awareness and inform educational practice in supporting other girls with autism during their post-primary education?

5.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) was considered to be the most appropriate tool for analysis in this study due to its close connection to hermeneutical injustice (Smith et al, 2013). In this study, 25 of the 34 photos elicited represented educational experiences clearly depicting a disconnection to the educational settings these girls find themselves situated in. This wholly aligns with Kotzee’s (2017) consideration of dominant educational contexts silencing the voices of disadvantaged cultures within them and therefore confirms the existence of the hermeneutical injustice imposed upon this group of young women.

Embarking on hermeneutical enquiry requires careful navigation in order to avoid hermeneutical injury (Medina, 2017) including the subsequent meaning making and analysis that forms part of the hermeneutic cycle (Blaikie and Priest, 2017). It is therefore imperative that the interpretation of the knowledge extracted through this process amplifies the voices of girls with autism and does not serve to further marginalise or silence this group. Considering the embedded and immersed nature of the participants’ experiences, the analytical method selected must meet the criteria for comprehensively interpreting the phenomena of the experiences of these girls with autism at both a surface and embodied level (Smith et al, 2013). Photovoice is a visual arts enquiry method with feminist underpinnings that has the potential to evoke both
conscious and unconscious experiences of the oppressed group engaging with it and therefore the analytical tool employed in this research must do justice to the participants’ meaning making and the researcher’s interpretation thereof. Smith et al (2013) demonstrate how IPA fulfils these criteria for analysis and both Tierney et al’s (2016) “Looking behind the mask” and Fitzgerald’s (2018) “Under the radar” competently demonstrates how appropriate the use of IPA is in eliciting the voices of girls with autism and their families. Therefore, IPA is selected as the most appropriate process of analysis for this research.

Smith et al (2013) have the definitive text on the use of IPA which they loosely define as the qualitative phenomenological examination of how people make sense of their major life experiences and their personal interpretative reflections on the wider significance of these experiences on their lives. IPA is different to thematic analysis by virtue of the consideration of the theoretical framework in which the research is positioned (Freeman and Sullivan, 2019). In this critical enquiry, there is an assumption that girls with autism have been previously oppressed and marginalised and deserve the opportunity to have their voices and experiences heard thereby transforming knowledge about girls with autism as a result and possibly enabling emancipation of this group. Therefore, there is a clear political standpoint to this research. Smith et al (2013) outline that there is no standard process for conducting an IPA, rather it is dependent on the nature of the enquiry and reflective of the data collected. Most evidence for this comes from their narrative enquiry examples and there is no protocol for how IPA should be used for the interpretation of a Photovoice. There are however, guided stages that can be applied to appropriately engage in an IPA. In this instance Smith et al’s (2013) stages have been applied in the following way to analyse this Photovoice:

1. Initially each photo was interpreted individually using a layered approach. This was to reflect Smith et al’s (2013) reading and re-reading stage which encourages the researcher to immerse themselves in the data. As the main source of data is photographs, each photo was viewed independently, the added layers of photo title, photo caption and corresponding audio-recorded explanation of each photo were added on until each layer was exhausted for meaning.
2. **Exploratory comments** were applied to each photo concerning possible emergent themes and these were adjusted as the layers of meaning were applied to each photo. The comments were descriptive of theme but also noted any corresponding linguistic or conceptual features supplemented by the captions or photo discussions. Smith et al (2013) point out that embodied meaning can begin to emerge at this initial analysis stage.

3. **Emergent themes** are the result of this type of layered analysis. In light of the Gadamerian discussion outlined in Chapter 2, key themes quickly emerged and the researcher had to ensure that these themes were emerging in their own right and not because of personal invested knowledge in this area. Therefore, several rechecking of these emergent themes was conducted to authenticate this process. The themes were noted on the back of each photo alongside title and caption added earlier in the process.

4. **Next case** or photo by photo. Even though each participant had taken several photos, the photos were analysed in consecutive order according to how the exhibition had been curated to ensure that this was a theme within case analysis (Smith et al 2013). Therefore, once the researcher felt they had abstracted all possible interpretation of one photo using this layered approach, the next consecutive photo was analysed.

5. Once each photo had been considered in its own right, the final part of the IPA could begin, which was the investigation for **patterns across cases** and **connections across themes**. The careful deliberation of this would instigate discussion of both surface and embodied meanings within themes which aligns with the critical consciousness of Freirian (1994) theory that underpins Photovoice. This would eventually lead to the positioning of the key findings within the research questions. Therefore, the findings and discussion of the major themes and subthemes are inextricably linked and are therefore presented together as the final part of the IPA.
5.3 Thematic grouping of photos using IPA

Following the individual analysis of each photo, the 34 photographs and corresponding quotes were initially categorised in four ways: positive or negative experiences of autism and whether these experiences were in educational or non-educational settings. This resulted in 4 superordinate themes with the photos being classified as 15 positive educational photos, 10 negative educational photos, 9 positive non-educational photos with no photos classified as negative non-educational. This classification process was done twice to ensure the same classifications were derived each time.

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Educational</th>
<th>Non-educational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive experience</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Negative experience</td>
<td>10</td>
<td>0</td>
</tr>
</tbody>
</table>

*Table 5: Initial grouping of photographs into superordinate themes.*

The three superordinate themes identified above: positive educational; negative educational; positive non-educational; were then further analysed to abstract major recurrent themes and this was done using a “case within theme” sequence in that participants’ photos were spread across the emerging themes rather than being considered participant by participant (Smith et al, 2013, p. 109). This abstraction of major theme was done in a layered approach using the different information gleaned from the participants. Initially the photos alone were grouped into recurrent major themes, then the titles of the photographs were applied to the photos to check that the proposed major theme still applied. The next layer of interpretation involved correlating the corresponding caption from the exhibition brochure along-side each photo and title to ensure the participant’s personal interpretation of each photo aligned with the recurrent major themes identified. This was further verified by listening to the full audio recordings of sessions 3, 4 and 5 where participants discussed their photographs.

As a result of this process 6 recurrent major themes were identified from the 34 photos with one photo having a connection to another theme. Once again and in line with advice from Smith et al, (2013) the process of looking for patterns across cases was carried out twice to clarify if a different theme or classification should be used. As
predicted by Smith et al (2013), this led to the rewording of one of the major themes from “Processing difficulties” to “Obstacles to learning” which was deemed to be a more reflective major theme title. As represented in the following table at least three participants were represented by each of the 6 major themes. The following table sets out the 3 superordinate and 6 major themes in the order in which they are subsequently analysed and discussed:

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Major recurrent themes</th>
<th>Anna</th>
<th>Niamh</th>
<th>Cara</th>
<th>Dearbhail</th>
<th>Lauren</th>
<th>Megan</th>
<th>Samanta</th>
<th>H</th>
<th>NM</th>
<th>No. of photos</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive-Educational</td>
<td>“School as a safe place” 5.4</td>
<td>Yes</td>
<td>Yes*</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td>Negative-Educational</td>
<td>“Obstacles to learning” 5.5</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
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*Table 6: Grouping of photographs into major themes.

The next section presents the 34 shortlisted photographs generated from the study. The photographs are presented with the 6 major themes identified: School as a Safe Place; Obstacles to Learning; Importance of Idiographic Curriculum; Sensory Overload; Coping Strategies; Identity and Challenging the Assumptions of Autism. Within each major theme, further subthemes are identified. The number of each photograph corresponds to its place in the exhibition brochure. Within each subtheme the photographs are analysed at two different levels corresponding with IPA. A first rudimentary surface level analysis is discussed followed by a deeper interpretative interrogation of the significance of the photographs to the wider significant experiences of the participants as girls with autism.
<table>
<thead>
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<th>Superordinate Themes</th>
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<td>Identify and challenging the assumptions of autism</td>
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<td>Autism as Beauty 4 Photos 1 PPS</td>
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*Figure 4. IPA thematic findings of Photovoice.*
5.4 Theme 1 - “School as a Safe Place”

The major theme of school as a safe place was represented by 5 of the participants with 6 photos demonstrating the importance of school in the lives of the participants. Within this major theme, three subthemes were identified a good place (Photographs1 24, 25 & 5); safe people (19) and safe inside (13 & 15). Each subtheme is presented and discussed separately and the section culminates in an overall conclusion for the major theme identified:

5.4.1 “School as a Safe Place” subtheme - A good place

‘School at sunset’ - 24. “I thought the light was really nice and it made me think, wow school is not bad all the time.” Samantha.

‘School in the snow’ - 25. “they took away the grass and made it all concrete which I didn’t like. This day the snow made school look pretty again.” NM

1 The number of each photograph corresponds to its place in the brochure.
‘Go on, go out there’ – 5. “I can’t wait for the next chapter of my life after school, but that’s also a scary thought so for now this school is a safe place.” Cara.

At the surface level, the first three photos demonstrate the importance of each school as part of the participants’ overall sense of belonging. Three of the four participating schools feature in this section demonstrating the consistency of the theme. These first three photos focus on each of the school’s physical presence yet there is a concerted attempt to present the school in an aesthetic and therefore positive way. The participants discuss their sense of belonging to these schools and there is an emerging sense that being a student in these schools has a positive effect on them. The photos all feature the physical external surroundings of the school using light, weather and natural aspects to enhance the aesthetic of each photo and the corresponding titles attempt to do justice to the same with an enduring positive message from all three photos: “wow school is not bad all the time” (Samantha), “the snow made school look pretty again” (NM), “for now this school is a safe place” (Cara).

At a deeper more interpretative level, there is also contradiction here, where the students cite negative or challenging experiences within these physical settings: “not bad all the time” (Samantha) (therefore bad some of the time), “They took away the grass” (NM), (perceived loss of power/control within school setting) and “escape to the closed off
world,” (Cara) (looking forward to the confines of school being over). However, it could be argued the three participants are showing resilience here, in that the difficult times they have had within their schools do not dominate their overall perception of school. Their explanations suggest that their negative opinions of school are not fixed but rather fluctuate contradicting the rigid thinking others have previously associated with an autism profile (NAS, 2012). The participants are clearly able to take stock, weighing up the positives and negatives of their educational experiences, with the positives coming out as stronger. “Yes I’m here and I have difficulties, but it’s not all bad, I’m sort of here for the moment but I’m also looking ahead, you know I won’t be here forever!” (Cara). This is mirrored by the overall group desire to feature both positive and negative aspects of their educational experiences rather than just the negative as originally thought. School is both a landscape and identity at a significant point in these girls’ lives and one which they feel part of, “it is lovely” (Samantha); “I thought it looked real nice, (NM).

Dean et al (2017) consider camouflaging a key component of female ASD and it could also be argued here that these photos reflect the skill of the participants at masking or making things look normal and pretty from the outside with the inside reality telling a different and possibly more negative story. However, each of the participants involved in the production of these photos already represent their negative experiences elsewhere in the Photovoice and their discussions around these photos elicit feelings of comfort, safety and belonging to an institution that has the potential to support them. This is again contrary to Osborne and Reed’s (2011) finding of the dissatisfaction of students with autism with their placements in mainstream schools across the UK.

It is also important not to underestimate the importance of belonging here. If the participants feel comfortable in these places, then this is where focused intervention should start as the feeling of comfortableness with each institution is already there. The therapeutic relationship has already begun within this setting and this is reflected in the findings of Tierney et al’s (2016) research whereby girls with autism are shown to actively engage in interventions within educational settings.
5.4.2 “School as a Safe Place” subtheme – Safe people

The second subtheme within “school as a safe place” was the recognition that within the school, students had safe people who could offer support. One photo depicted this (19).

‘Helping hands’ – 19.

“My friends are really good, they know about my ASD and they just treat me normally, but they’ll know when I need help with something.”

Megan.

The photo shows the hands of the research group in one of the schools representing collegiality, friendship and supportive working partnerships. This photo was taken during one of the research sessions as the participant wanted to demonstrate that there were lots of people in school, both students and staff, who had helped her overcome difficulties in school. “I think if I didn’t have my friends school would be a lot harder” (Megan). More importantly, Megan did not feel the need to hide her autism identity and saw it as positive that her friends knew about it as they could respond appropriately to her when required. “I don’t want my friends to look at me in a certain way but they make sure I’m alright” (Megan).

At a deeper and conceptual level, the construction of the photo and its meaning demonstrate the importance of collaboration for girls with autism. The participant knew
the experience she wanted to express, but she struggled to compose it and furthermore, found it difficult to articulate how important it was for her for people to understand her difficulties and help her when she needed it. Therefore, the group suggested using everyone’s hands to represent the people in school who can help her. Several test shots were taken and what stood out for Megan was the individuality of the hands in the photo. The variations in nail colour and length along with fake-tan or not, attest to the individuality of the people around her and how they all have a part to play in supporting her either as individuals or as a group, “even though they don’t really know what it is” (Megan). The light bouncing off the middle of the photo had appeal to the participant Megan in demonstrating that when everyone worked together things got lighter almost as if a solution had been achieved. This led to a discussion among the group about how friends responded to the participants and both Samantha and Lauren confirmed the same helpful experiences even though “my friends might know or might not know about my ASD” (Lauren).

When the photo was composed and edited, Megan was thrilled with how well it conveyed meaning for her and from this her discussion flowed enabling her to articulate her point. “This shows that socialising and being together is important”, (Megan). This demonstrates the importance of finding the right conduit to help girls with autism convey their individual needs and as Kopp and Gillberg (1992) avoiding the use of those interventions constructed around boys’ presentations of autism. This also stresses the importance of peer support which contravenes earlier assumptions regarding the lack of social engagement to procure support. This finding is mirrored by Pisula et al (2017) who demonstrate that girls with autism are adept at finding key people who can help them.
5.4.3 “School as a Safe Place” subtheme – Safe inside

The third subtheme within “school as a safe place” was the Safe inside school. Two photos appear to depict this scenario (13 & 15).

‘The Quiet Stairs’ – 13.

“I only use these stairs in school. They are never very busy. When people pass me on the stairs it disorientates me.”

Dearbhail.

‘Recharge station for the rejected’ – 15.

“I need a break and a quiet space in between classes but nobody else is ever here, I’m mostly alone.”

Cara.
Photo 15 was difficult to initially classify as there is a negative connotation to the loneliness being experienced by the participant. “I know it sounds really negative but for a while I was kind of jilted,” (Cara). However, the overriding meaning from the interview transcript was the importance of having a quiet space in between classes, where she could sufficiently recharge before the next class began and even though this made her lonely, she had to prioritise the need to recharge. “The recharge bit comes first because crowds do dazzle me, no not dazzle, confuse me a bit and will give me anxiety and being alone generally does help me to recharge,” (Cara). Therefore, having a physical safe space in which to decompress between classes in school was seen as the primary meaning. There is a negative element to this photo also suggesting that she feels rejected as a result of needing time alone. This photo could therefore also be classified as a negative educational experience. “Being alone is both good and bad,” (Cara).

Both photos depict physical spaces within the same school that enable both participants to engage in their education without feeling overwhelmed or anxious, an aspect of autism consistently documented by Jarman and Rayner (2015), Fritschie, (2010) and Yaull-Smith (2008). In both cases, the participants have sought out quieter spaces that they are permitted to access in their school enabling them to navigate their school day both physical and emotionally. “They (stairs) can be busy but you need to know when to use them, if they were busy I would wait”, (Dearbhail). In discussions with the participants, the schools had facilitated the use of quieter stairs and quieter study rooms (as opposed to the general study room) and the girls felt this was a positive response to their needs from the school and demonstrated the school’s enhanced and supportive understanding of autism. “There’s probably a lot of other people, other girls with Asperger’s who feel like this and I’m trying to tell people who maybe don’t know”, (Cara).

The use of the pronoun “I” in both accompanying quotations stands out, demonstrating the participants devising and owning of coping strategies they have found for themselves within their educational environment. Tsai and Ghaziuddin, (2014) outline the frequent adverse impact of school on girls with autism and Dearbhail’s use of very strong wording here: “It disorientates me” aptly conveys the indelible connection between the potential triggers of the physical environment of school on emotional
wellbeing for girls with autism. However, rumination on the need for quiet spaces at all causes feelings of isolation which in turn can lead to feelings of rejection: “I need a break ... I’m mostly alone” (Cara). There is a tension or sense of conflict presented by the participant at having to prioritise what she needs over what she wants and there is a sense of unfairness at having to forego the latter. Wilkinson (2008) warns of the adverse impact of social exclusion and in this instance, it is self-imposed creating a further gap between the girl with autism and her peers. “It is isolation”, (Cara).

5.4.4 Conclusion and Implications for overall theme of “School as a Safe Place”.

In summary, the overall theme of school as a safe space has developed in the participants ways of being in their educational establishments that support their learning. It is therefore important not to underestimate the importance of belonging here. Adolescents with autism often exclude themselves within school settings due to an increased awareness of their “social blindness” (Ritvo, 2006, p.111) but this is often a self-protection mechanism and not because they do not want to be a part of their school community. Wishing to belong to their school community could be the very reason that girls with autism try so hard to camouflage the challenges they face in the first place (Dean et al, 2017). Having a sense of identity and belonging appears to be just as important for girls with autism as it is for girls without autism (Powell, 2016). This study demonstrates that it is that sense of identity and belonging to a school that increases a feeling of comfortableness making it easier to engage in support in these already established safe spaces. Furthermore, the participants have been able to identify what they need and who might be able to provide for this need. What is important though, is that responding to these needs does not unintentionally isolate the vulnerable individual and Edwards (2012) cautions that equal measures are taken to ensure social integration alongside bespoke provision. In fact, there are instances here where social inclusion and collaboration actually enabled identification of the provision needed.

Both Ritvo (2006) and Volkmar and Klin, (2000) confirm that inclusion in these safe spaces of mainstream schooling is the starting point for improving outcomes for girls with autism. Their inclusion can only promote increased understanding of what autism in girls looks like in an educational setting and bearing in mind the US, Australian and UK findings of limited teacher insight in this area, this is an important opportunity for
enhancing understanding (Cridland et al, 2014; Jarman and Rayner, 2015; Osborne and Reed, 2011). Without increasing awareness, the continuing late identification of girls with autism as depicted by Kauschke et al (2016) will continue to perpetuate the late application of appropriate support and interventions (Wilkinson, 2008). There is an onus on those working in schools to cultivate this safe space ideology as presented by the girls here. Dearbhail explains: “I’m not really productive at home, I like in school settings where I can get my head down and not have my family come in and disrupt me.”

5.5 Theme 2 - “Obstacles to Learning”

This theme was represented by 4 of the participants with 5 photos demonstrating impediments to progress. This was not a surprising theme to have uncovered considering the literature attesting to the difficulties experienced by girls with autism in accessing and maintaining their education. Three linked subthemes were identified within this theme: In-class triggers (1&21); Workload and time management (9 & 18); and masking feelings (32).

5.5.1 “Obstacles to Learning” subtheme – In-class triggers

Starting with the most localised, the first subtheme discussed is the in-class triggers that created difficulty for the participants on account of their autism. Two photos demonstrated different aspects of this (1&21).

‘Out of order’ – 1. “It takes me so long to process information in class that by the time I have they’ve already moved on.” Niamh.
‘Mixed messages - Rules vs Creativity’

“I don’t understand how I’m supposed to be creative when there are so many rules to follow, rooms I can’t get into and times I can’t be there.” Dearbhail

Both photos depict a student in a classroom environment. The first picture uses the analogy of a laptop with three post-it notes stuck to the screen saying ‘Out’ ‘Of’ ‘Order’ to depict what is happening in the participant’s brain when in class. Cridland et al (2014) cite slower processing speed and working memory index, concepts used as part of a measure of intelligence, as a common feature of autism. Niamh explains: “I’m slower at receiving things and sometimes I might not get it at all.” Atwood (2007) previously confirms that students with autism may have higher than average IQ but will be challenged by discrepant below average measure for processing speed. The deliberate distortion and colour applied to the first photograph enhances the message with regards to how the student feels in class. Niamh linguistically sets herself apart from everyone else: “they’ve already moved on” showing that she cannot keep pace with everyone else, making learning more difficult for her than her peers. Niamh explains further: “It embodies the negative side of having ASD, when I received my diagnosis at first, I was like “shit” as you can’t fix that and that was a problem for me for a long time.”

However, Niamh is apportioning this blame to herself: “It takes me so long” implies that she sees herself as the problem and not the fact that the teachers are not giving her sufficient time with which to complete a task. Niamh is in her final year of school suggesting this experience has been reinforced throughout her mainstream school experience. This links back to the socially constructed theories on disability where normal classroom environments are set up to expose those who are different, in this case
those with different processing speeds. While some mainstream settings purport to being inclusive, proclaiming that individuals with a learning need are included in the same environment as the majority without a learning need, this tokenistic practice of inclusion is trite considering inclusion actually means creating an educational environment that does not aggrandise the norm but positively responds to the individual needs of its students by making sure everyone has equal access to the curriculum.

The second photo conceptually centres the student between two noticeboards in an art classroom, one where the school rules are listed and the other where art work is displayed as if she is caught in the middle of this quandary. There were three different versions of this photo taken from different angles and at the short-listing stage, Dearbhail selected the photograph the placed the student dead centre to either wall to demonstrate being caught in the middle. The rigidity of the rules impinges on her ability to demonstrate her creativity in a subject that she excels in. This makes no sense to her, yet she feels she cannot challenge the situation because the rules have been imposed by a higher authority “how I’m supposed to be creative when there are so many rules to follow”. Fritschie (2010) recognises rigidity and adherence to rules as characteristics of autism and Dearbhail is demonstrating the juxtaposition that she is faced with as she eloquently describes “I feel agitated when things are not right.” Other students not challenged by autism are likely to find ways around this situation, possibly flouting some of the rules or manipulating the situation. Cleary and Hayes (2012) note that understanding of hidden curricula in school, whereby it is acceptable in some instances to bend the rules, is not easily understood by students with autism who are likely to take things literally or pedantically. Furthermore, these mixed messages cause rumination which interrupts learning or in this case Dearbhail’s creative flow.

Improved inclusive practice here could have been an explicit and individual adjustment to the rules for Dearbhail, reflecting her particular learning style over a perceived necessity for order, something Dearbhail was unlikely to disrupt. Dearbhail describes all the impediments to her success here: “I have no time to do art after school but I’m made to go to the library and you can’t bring the (art) equipment down there and the storeroom is always locked, it’s like an 8/10 on the agitation scale.” If the objective of the subject of Art is to channel creativity, then maximising potential for this is optimal rather than limiting originality by enforcing the same rules for everyone. This again
links theoretically to the construction of curriculum delivery based on the assumption that everyone included in mainstream can be catered for in the same way. It would appear that some instances of inclusion in education mean that individuals are only included as long as they concede to the normative way of doing things constructed by the normative majority.

The overriding feeling from both of these photographs is frustration and this aligns with the internalising of problems as discovered by Pisula et al, (2017) in their youth self-report study. The frustration at not being able to keep up with everyone else and that the teacher is not being mindful of how long it takes a girl with autism to process information and the subsequent distress that falling behind causes. There is also frustration at the school in terms of their lack of understanding of the creative process and the adverse impact of applying unhelpful or “pointless” rules to this situation. In agreement with Kauschke et al (2016), it is fair to argue that frustration and challenging authority are expected adolescent girl behaviours and so in this instance girls with autism are no different than their peers. However as abundantly outlined academically by Vine-Foggo and Webster (2016) and personally by Yaull-Smith (2008), it is the opportunity cost of this mental toll and subsequent fatigue that sets girls with autism apart. Their reactions to events that cause frustration are inordinate and quite often debilitating leading to behaviours such as avoidance of task, class or even school. “I’d rather do it at home” (Dearbhail). Both Gould and Ashton-Smith (2011) and Duvekot et al (2017) articulate the considerably higher levels of perfectionism in girls with autism than boys with autism resulting at times in crippling pressure which in turn puts a strain on mental health wellbeing. Therefore, it is of paramount importance not to underestimate the inordinate negative impact of the frustrating minutiae of classroom life.

5.5.2 “Obstacles to Learning” subtheme – Workload and time management

Outside of individual subject experiences comes the negative accumulation of autism interacting with the time management requirements of school. The second subtheme presented now under the theme “Obstacles to Learning” reflect the difficulties for
Girls with autism to understand **Workload and time management** with two photos depicting this (9 & 18).

‘Lost in time’ – 9.

“I never know how long anything is going to take me to do. Sometimes an hour will pass and I’ve hardly done anything at all.”

Anna

‘Mountain of work’ – 18.

“This is how I feel about my GCSEs, there is so much to do, I don’t even know where to start and it makes me panic.”

Megan

Both photos are adept in portraying the stress involved in managing workload at school. The first picture features three overlaid clocks to depict the unknown passing of time. “I
never know how long anything is going to take me to do” (Anna). In schools, students are expected to manage short-term and long-term homework, extended project and coursework tasks using planning and time management skills. Jacobsen (2005) and Atwood (2007) concurrently conclude that students with autism can struggle to appreciate how long a task will take due to issues with executive function and can have difficulty switching between higher-order thinking and planning skills. “I physically can’t force myself to do something even though I want to”, Anna’s conceptual pictorial distortion of the photo, using different coloured layers, readily demonstrates her difficulty with present and future and how pervasive this obstacle is. “Time and procrastination are my biggest problems” (Anna). This is confirmed by another participant in a different setting: “I don’t have the focus to read a book,” (Samantha).

When this first picture is combined with the second which displays ‘a mountain of work’ (Megan), the root of the problem becomes abundantly clear. Described by Powell (2016, p. 109) as being “lost in a sea of time”, the girl with autism cannot even begin to attempt a mounting workload when they are unsure of how long each of the tasks will take. Once again, these tasks are imposed by education systems that do not respect this aspect of autism. Curriculum deliverers make the incorrect assumption that all individuals implicitly know how to plan and manage deadlines across subjects because the normative school majority copes. Schools do not specifically teach individuals how to cope with a varying workloads and for a girl with autism, individually planning out their work becomes impossible leading to feelings of ‘panic’ as described by Megan.

Analysing the photographs at linguistic level, Anna describes feeling overwhelmed by workload and how she lacks the skills to systematically plan for it in a time-bound way leading to procrastination “an hour will pass and I’ve hardly done anything at all.” (Anna). When probed on this, Anna’s explanation is that “there’s no point in starting something unless you know it’s going to be right”. Jacobsen (2005) notes that it is common for students with autism to want to give up before they even start but this extreme fatalist attitude is less to do with feeling overwhelmed as she suggests and more linked to the earlier consideration of levels of expected perfectionism in girls with autism. Powell (2016) confirms this increased tendency for perfectionism and control and Anna’s response here ratifies this “all or nothing” way of thinking, akin to the black and white thinking associated with autism. However, not being able to surmount
workloads in the requisite time inevitably impacts on progress or success and the mental
toll of these challenges is undoubtedly negative and links with the anxiety and
depression detected by Pisula et al (2017) in their sample of girls with autism. Tierney
et al (2016) further this by outlining how this anxiety further increases with the
transition from primary to post-primary schools inevitably increases unmanageable
workloads for these girls. This certainly offers an explanation towards Wilkinson’s
(2008) earlier presentation of the educational underachievement and drop-out rates of
girls with autism from educational settings.

Hence readjusting the personal expectations of girls with autism is crucial at allaying
the sustained need to be perfect all the time. More importantly, the academic
expectations of schools may equally need readjustment. Having access to this
information about how girls with autism manage workloads presents those with power
an opportunity to revise how inclusive education is constructed to support girls with
autism. Every school has the autonomy to review and subtly revise its overall
curriculum, considering how girls with autism could be appropriately assessed and
examine whether these increasing workloads are actually meaningful in engaging girls
with autism in mainstream education at all. “I have deadlines for certain subjects and
most of them end up being the (one) subject after each (an)other and it makes me feel
frustrated” (Megan). The onus cannot continue to be placed on girls with autism at
having to surmount the challenges they face especially those imposed by others. The
onus must be placed on those with the power and means to support the individual
learning profiles of the students within their mainstream educational settings.

5.5.3 “Obstacles to Learning” subtheme – masking feelings.

The final subtheme within the theme obstacles to learning is the skill of girls with
autism at masking feelings. Dean et al (2017) describe the art of camouflage in girls
with autism and in an educational setting this means that teachers may be unaware of
the workload pressures or struggles being experienced by students with autism as the
teachers are being fooled by the girls’ outward appearance of coping. Subsequently, less
guidance or assistance is offered as the girls with autism appears to be coping with
collective subject demands. This links with Gould’s (2017) contention of the under-
recognition of girls with autism. Furthermore, this skill at appearing to cope may well
explain Jarman and Rayner’s (2015) discovery of the reluctance of teachers to even acknowledge identification of autism in some of their female students.

‘Masking’ – 32. “Everyone’s always asking me what’s wrong as I don’t use facial expressions a lot. I could be feeling anyone of these but my face will always be the same. It’s a good way to hide.” Niamh

This photo uses emoji faces to obscure the identities of the students in the photo and aims to demonstrate the different feelings experienced by the participant at any given point during the school day “I could be feeling anyone of these”, (Niamh). More importantly, she explains that she does not give non-verbal cues through her facial expressions about what mood she might be in at any particular moment “A lot of people in my childhood were like: Do you ever smile and I’d say Yea I’m happy right now and they wouldn’t know because I wasn’t super-obvious about it!” (Niamh). While this would be a common feature of autism in both girls and boys (Atwood, 2007), what is different here is that Niamh is actually manipulating this expected behaviour for her own means of protection which is highly sophisticated. Therefore, this photo is more telling at an interpretative level. It is not that Niamh does not know how to use facial expressions as is commonly anticipated with autism, it is that she is actively choosing not to use them because to do would involve: “identifying that I have to consciously think a lot more about the expressions I use” (Niamh). She is making a conscious effort
to look neutral, so her face belies how she is feeling underneath ‘It’s a good way to hide,’ Niamh. In session Anna added to this discussion by stating that: “My Mum used to say that she thought that Niamh didn’t like her because every-time she said Hi to her, she (Niamh) seemed standoffish.” Cue Niamh and Anna roaring with laughter at how ridiculous and naive Anna’s mum’s explanation was.

Lai et al (2017) point out this concerning feature of in girls with autism concluding that girls are extremely skilled at camouflaging or masking their true feelings or emotions to their own detriment. In Parsons’ (2015) study, the 55 adult respondents with autism, 26 of whom were female, were on average less than satisfied with their educational experiences and how it prepared them for their futures confirming that schools continue to miss opportunities to support the learning of students with autism. This is why Tierney et al (2016) urge practitioners to look behind the mask however, the implication here is that at times the mask can be entirely convincing, meaning opportunities are missed for the much-needed school interventions outlined earlier. As practitioners, we therefore need to be aware that we are using non-autism cues (facial expressions denoting mood) as markers for detecting or more worryingly, not detecting mood in individuals with autism. Those working with girls with autism in educational settings need to reframe the methods they use for gauging the wellbeing of their students with autism being mindful of the fact that their own normative means of demonstrating their feelings are not the same for girls with autism.

5.5.4 Conclusion and Implications for “Obstacles to Learning”.

Taking into consideration the earlier discussions of the theme obstacles to learning, if girls with autism are actively and adeptly hiding their struggles with keeping up with class content, abiding by school rules, managing workload and time management from the staff who could support them with this, then their struggles may go unnoticed until deeper levels of mental toll surface and by which point as described by Yaull-Smith (2008) the intervention may be too late. Early intervention has historically been a stalwart of support for all populations with autism (Jones, 2002) and for girls with autism, early intervention within school systems also has the potential to ameliorate the triggers for exacerbating the features of autism in girls as outlined above. However, knowing to actively look behind the mask of the girl with autism is the starting point for
professionals in this instance of early intervention and, as jointly alluded by Jarman and Rayner (2015) and Cridland et al (2014), these professionals are likely to be school staff. This has implications for the training of school staff in recognizing the nuances of autism in girls, engendering responsibility in these educators to mould the school environment around girls with autism rather than the current educational practice of moulding the girls with autism by using interventions and support until the girls with autism learn to fit in with the mainstream in which they have been placed.

5.6 Theme 3 - “Importance of Idiographic Curriculum”

This theme was represented by 3 of the participants with 5 photos demonstrating enjoyment of school when good decisions are made regarding subject choices. Two subthemes were identified: **Objective subjects** (14&17); **Subjective subjects** (8,22 & 16). The first subtheme pertains to the assumption that positivist science-related subjects are often favoured by students with autism as they do not rely on pragmatics or subjective nuanced interpretation but deal systematically with black and white facts (Powell, 2016). Both photos (14 &17) supporting this subtheme come from the same participant but interestingly she contributes to the second subtheme also challenging this assumption. The second sub-theme within “**Importance of idiographic curriculum**” challenges the notion that students with autism struggle with more practical or creative subjects as presented by both Sansosti et al, (2010) and Betts et al, (2007). Rather these photos demonstrate that girls with autism are more likely to experience enjoyment, success and therefore progress when they are engaged in **subjective subjects**. Three photos from Home Economics, Art and Physical Education reflect this (8,22 & 16).
5.6.1 “Importance of Idiographic Curriculum” subtheme – Objective subjects.

‘Order from chaos’ – 14.

“Physics is one of my favourite subjects and I’m looking forward to doing science for A-level.”

Lauren

‘Meditative Maths’ – 17.

“I like looking at these pictures in the maths classrooms, it’s like Art and Maths together so I really like them.”

Lauren

The first two photos from Lauren are typical of our understanding of how the brain of a person with autism functions. Sansosti et al (2010) present students with autism as preferring more concrete empirical subjects where there are clear right or wrong
answers and where there is limited ambiguity or reasoning required in a subject. Referring to the maths photograph Lauren explains: “if I’m stuck on a question I’m like just think, just think and sometimes I look at this and feel like it could help me.” This is supported by Powell’s (2016) consideration of the subsequent careers chosen by people with autism in terms of science and technology. Therefore, it is unsurprising that scientific subjects such as Physics and Maths are popular however, this is largely a male dominated assumption and is certainly contested by the subsequent three photos which depict Art, Home Economics and Physical Education as being favourites for three of the participants.

5.6.2 “Importance of Idiographic Curriculum” subtheme – Subjective subjects.

‘Proud practical’ – 8. “

It was the best and worst thing I’ve ever done. The time management was so stressful but my Mum was so proud of me.” Megan
‘Thread work’ – 22. “I got into crochet for my GCSE art, I still like to play about with the thread and turn into some kind of sculpture. I like how the light shines through it.” H.

‘Favourite place’ – 16.

“I just love PE, when I look at my timetable and realise I have PE the next day, it makes me very happy.” Lauren

As alluded to earlier by Jacobsen (2005), autism in girls can be characterised by poor time management skills and difficulty with short and long-term planning, therefore it is surprising that the Home Economics practical is cited by Megan as “the best and worst thing I’ve ever done”. Although she admits her time management issues, “the time
management was so stressful, like ten on the stress scale” (Megan) and this is supported by both Jacobsen (2005) and Jarman and Rayner’s (2015) acknowledgement of the additional effort required for completing tasks, she has clearly overcome these issues in this instance.

Autism can be comorbid with Developmental Coordination Disorder (DCD formerly known as dyspraxia) and issues with fine and gross motor skills form part of the criteria for autism (Fritschie, 2010). However, photos 22 and 16 depict two highly practical subjects where fine and gross motor skills are fundamental and yet the photos portray the participants’ love of these subjects without any mention of challenge or difficulty with them “I love to be in there,” (Lauren). For both girls the enjoyment of these subjects has transferred into their personal lives with H continuing to use her crochet at home and Lauren engaging in team sports during her weekend. “I do socialise with other people and even if I make mistakes with a shot/score it doesn’t bother me at all” (Lauren).

There is also an emotional connection to each of the subjects for the three girls. For Lauren, whose three photos are grouped here, each of her photos represents a deeper affective connection, her feelings of hope for future success at A-level Physics; the calm feeling she experiences when looking at the linguistically eloquent “meditative maths” and a very strong feeling of happiness and love for Physical education, “I just love PE, when I look at my timetable and realise I have PE the next day, it makes me very happy ”(Lauren). For Megan, the emotional connection is linked to her mother’s reaction to her Home Economics practical “my Mum was so proud of me” and in further discussion Megan explained that her Mum had been sharing this photo with all her friends and while Megan was slightly embarrassed by this amount of attention she was so happy to have made her Mum happy in this way. For H, the emotional connection is the calm feeling she gets when she experiments with the crochet thread at home, it is something she can do to help her feel peaceful and interestingly she has transferred this to her home environment also. This is interesting as Fritschie (2010) presents the difficulty of transferring skills learned in one setting to a different setting as a stereotypical characteristic of autism, this clearly is not the case for H as she has easily transferred this crochet skill and the peace it brings her to her home environment and her photo is situated in her log-cabin despite it representing her love of a subject at
school. “I put the threads on the blind, and I just thought, that’s so nice and it made me feel really calm,” (H). NM confirms how beautiful H’s artwork at home is: “That’s full on natural, no filters or anything, Wow!” (NM)

5.6.3 Conclusion and Implications for “Importance of Idiographic Curriculum”.

The implication here is that schools should not underestimate the importance of subject choice for girls with autism and according to Jones (2002) and more recently Goodall (2015), schools are making marginal gains in curricular accommodations for students with autism. This research demonstrates that appropriate subject choices have the power to enlighten and enhance girls with autism’s experiences of education. The positive affective states activated through engagement with their subjects, give the girls resources for dealing with their emotions both inside and outside of school. Betts et al (2007) acknowledge the difficulties that can be experienced by students with autism in less empirical subjects but equally demonstrate that more creative subjects can actually provide an opportunity for students to have a break from the rigours of more academic study while also encouraging social interactions. Furthermore, idiographic subject choices can help shape the girls’ pathways through education keeping them engaged in a system that has means to support them should other challenges surface as they build positive relationships within these subject settings. This theme aligns with the earlier school as a safe place theme in that careful subject choice is another way to keep the girls connected with the environments and people who have the capacity to support them. In the same way Jacobsen (2005) presents individualised subject programmes as having the power to enhance educational experiences; a poor, unsuited subject choice has the potential to damage engagement with education. Therefore, special consideration should be given to the curation of idiographic curricula for girls with autism, with an emphasis on quality of choice not quantity and bearing in mind Tierney et al’s (2016) discussion regarding the cognitive demand required for academic study, there is an argument for reduced timetables reflecting this. This also connects with the previous theme of obstacles to learning where careful selection of a reduced number of subjects could offset the challenges of managing workload that is time-bound reducing the mental toll and fatigue previously outlined by Yaull-Smith (2008) and inevitable educational disaffection (Wilkinson 2008).
5.7 Theme 4 - “Sensory Overload”

This theme was represented by 3 of the participants with 4 photos demonstrating just how debilitating and disorientating external sensory stimuli can be in an educational setting such as a mainstream school. Two sub-themes of single sensory overload, tactile and visual (Photos 2&6) and multiple sensory overload (Photos7&26) are identified. One of the girls depicts both single and multiple overload.

5.7.1 “Sensory Overload” subtheme – single sensory overload.

‘Bound’ – 2.

“The uniform is so uncomfortable, the tights, the collars, they all dig in so much so that I can’t actually concentrate on what is being said in class.” Anna.
‘Now I have to sort them all over again’ – 6.

“I sorted them yesterday, but someone has used them and not put them back properly and I can’t start my own work until they’re organised again. It’s so frustrating.”

Dearbhail

At first glance, photo 2. is not immediately clear in terms of message. It presents an uncomfortable scenario, feet “bound” in cling film and it is an immediately striking image prompting an uncomfortable reaction from the viewer. In contrast the second photo is much, more colourful, almost glaring with light bouncing off the bottles. The image is overloaded with a variety of different shapes and objects.

It is only when a conceptual level of interpretation is applied to these first two photos that the real meaning is elicited. Anna describes how the bound feet are an analogy, intended to represent how it feels for her to wear a school uniform “especially the tights” (Anna). She has composed the image using cling film to articulate that the cling film is a transparent see-through substance and so even though you cannot really see the cling film, it is there restricting the feet. She explains that this is similar to how she feels when she wears her uniform, nobody sees the level of restriction it causes her, but it is there nonetheless. “Uniform has always been really uncomfortable to the point of distracting from work” (Anna) and this is confirmed in the same discussion by Niamh: “Yes! I hate the skirt, I hate the feeling of the lining so much, Oh God!” Anna further explains that this is not just restriction but distraction and according to Hope-West (2011) this heightened sensory response or tactile hypersensitivity (Fritschie, 2010) is commonplace in autism, only in this instance, it is invisible to others. The physical level of uncomfortableness the texture of the different materials of her uniform causes against her skin, is enough to distract her in class. “It’s more than just not liking the uniform”, (Anna). Sometimes the feel of the uniform against her skin is all she is thinking about
during class and she cannot focus on her learning as a result. The linguistic devices she employs describing this photo and the concept it represents ably demonstrate just how distressing this sensory sensitivity is.

In a similar way, when Dearbhail enters her A-level art class and the bottles and tins of paint are in disarray, it feels like a visual assault on her and she has to rearrange the bottles by type of paint and colour spectrum before she can begin her own art work. She explains: “I took it to show the chaos.” She will spend significant time doing this before she can begin and quite often, she will return the next day and the same disorganisation will have happened again, “me and my friend went and colour-coordinated everything and then they went and messed it up again” (Dearbhail). I asked if she could just have her own resources, but she explained that both money and school rules with regard to the use of your own materials blocked this possible solution. This is an example of what Betts et al, (2007) describe as a perfectly reasonable accommodation that could have been made to ameliorate this situation for Dearbhail, but in this instance the school structures are set against this. This harks back to the earlier discussion regarding how girls with autism are simply expected by school systems to find ways to cope with the idiographic expressions of their autism rather than the schools simply readjusting their expectations for girls with autism. The practice of inclusion is once again based on the expectation of individuals amending their behaviour to fit with a socially constructed norm. Both of these sensory difficulties could easily be reduced by amending expectations for uniform (trousers instead of tights and skirt) and permitting the use of one’s own art equipment but it seems the school settings are not willing to relinquish their power in rule-setting to make these simple accommodations for individual students. This leads us to question why those in power continue to make decisions that make it more difficult for neurodiverse people to be included in mainstream school settings and actualise their right to inclusive education.
5.7.2 “Sensory Overload” subtheme – multiple sensory overload.

‘No go area’ – 7.

“I feel dizzy when I walk into the canteen and it is this busy and noisy. It’s disorientating especially on curry chip day.” Cara.

‘Obstacle course to class’ – 26.

“When the corridor is this busy, I wait until it clears and then I walk down it. Even if it makes me late for class and I get into trouble, I wouldn’t risk walking down there.” Dearbhail

Photos 7 and 26 are both from the same school and show different aspects of busyness within the school day: the school canteen at lunchtime and lining up for class. Described linguistically as “no go areas”, both photos are particularly adept at visually portraying the confusion and disorientation the multiple environmental sensory stimuli cause and this sensory overload is confirmed in theory by Hope-West (2011). Cara describes the noise of the canteen at various frequencies, the noise of the trays, plates and cutlery, combined with everyone talking coupled with the overwhelming olfactory stimulus of
the food smells, especially on “curry chip” day. “I don’t like pushing through crowds where there is noise and loads of people, its unpleasant and overwhelming” (Cara). She has blurred the photo to conceptually demonstrate how she sees the canteen and once again the idea of disorientation emerges with a linguistic confirmation of feeling “dizzy”. For Dearbhail, the corridor is too noisy and too crowded: “in the morning before all my classes, it starts off clean and neat and then people start to mess it up. I want to get rid of the bags.” The linguistic interpretation of “it’s dangerous” describes not only the physical danger because of the school bags which she feels she would trip over but this also represents metaphorical danger in that she knows this will lead to her feeling totally overwhelmed. Fritschie (2010) describes the withdrawal behaviour of students with autism when experiencing sensory overload and this is mirrored by Dearbhail who describes waiting until all this is cleared before attempting to go anywhere, even risking punishment for tardiness in favour of not having to navigate her way down this corridor.

Wing et al (2011) warn against underplaying the overt, negative reactions to single and multiple sensory stimuli that are a common feature in autism and it could be argued that this is less obvious in female individuals with a higher functioning profile. However once again, just because this is not neuro-typically obvious does not mean it is not having a negative impact on the functioning of the girls with autism especially within an educational environment. It is very clear that three of the girls wanted to demonstrate just how negatively impacting these sensory overloaded situations are for them to the ultimate detriment of their ability to focus during class and in school settings and this finding certainly aligns with Tierney et al (2016) who also cite sensory disturbance in girls with autism as frequent and intense. Cara describes the noise and the mess of people as being “kinetic.” Furthermore, if this is combined with the earlier identified theme of obstacles to learning, where both this research and Tsai and Ghaziuddin’s (2014) expose how time management and processing skills impinge on the ability to cope with the curriculum, this inevitably severely limits the endurance and stamina that girls with autism actually have for engagement in education.

Interpretatively, the girls are demonstrating their frustration at the frequent misunderstanding of how very small sensory triggers can have a turbulent effect on the ability to cope with the school environment. Nobody else is adjusting the school
environment in response to the girls’ sensory needs, as Betts et al (2007) would recommend, so the participants themselves are having to engage in their own hypervigilance of the environment, anticipating any potential sensory triggers and as encouraged by Powell (2016), engage in avoidance behaviours to offset any impending disorientation. Cara was initially going to entitle the canteen photo as “I’m not dragging myself through that.” Hypervigilance is a term associated with OCD and mood disorders and both are, according to Lyons and Fitzgerald (2005), intrinsically linked to autism. Therefore, this potentially explains part of the link between poor mental health and autism. This research confirms Jarman and Rayner’s (2015) caution that the level of fatigue girls with autism are experiencing through these active hypervigilance and avoidance strategies inevitably impacts on mental health.

5.7.3 Conclusion and Implications for “Sensory Overload”.

The implication here is that schools should not underestimate the possible impact of seemingly small environmental triggers but as Betts et al (2007) warrant, the anticipation of sensory overload and subsequent minor adjustments to these environments can improve the experiences for girls with autism. Of course, a school cannot control all aspects of its environment to eliminate these triggers, but what is put in place to mitigate against the triggers is important. Schools do have the ability to make school rules more malleable in reflection of the specific populations within them. For example, in the same way a transgender male in a girls’ school is permitted to wear trousers rather than a skirt, a girl with autism could be afforded subtle changes to aspects of their uniform that consider tactile sensitivity. Girls with autism could be encouraged to use their own equipment so that the interference of others is not off-putting for engagement with curriculum. Quiet spaces could be identified for students to eat and socialise in and where a school is aware of the disorientation caused by busy corridors and crowds, permission to leave class early or late could be granted to students with autism in order to avoid these stressors. This research acknowledges that these adjustments are already documented in the management of school environments for students with autism irrespective of gender but this research is demonstrating that for these girls with autism, their schools are not acknowledging these girls’ needs for adjustments possibly because their behaviour is not externalised enough to warrant significant attention in their schools, it is hidden. Both Betts et al (2007) and Jacobsen
(2005) note examples where many of these concessions are already in place, but they are largely afforded to boys with autism as their reactions to sensory stimuli are overt and at times disruptive. The key is therefore the careful and idiographic identification of these issues for girls with autism before applying bespoke measures to offset triggers. A further note of caution should be considered in that these measures may often highlight difference in a girl with autism and subsequently these adjustments are rejected as a measure for the girl in question for fear of standing out. This makes it particularly problematic to find the balance between suitable support and singling out an individual. It is only through open discussion between the girl with autism and the “safe person” she has identified that mutually beneficial accommodations can be found stressing the importance of partnership.
5.8 Theme 5 - “Coping Strategies”

This theme was represented by 4 of the participants with 5 photos demonstrating the individual coping strategies they have devised to enable them to navigate their educational experiences. Two sub-themes are identified within this theme: Prepared (10, 30 &33) and decompression (4&23).

5.8.1 “Coping Strategies” subtheme – Prepared

‘The final touch’ – 10.

“I’ve had my ears pierced since I was young. Before I go to school each day, I pick a pair to wear and then I’m like: Now I’m ready!”

H
“Into character” – 30. “Before I go into class, I think about who they want me to be in there and so I get into character for them.”
Niamh

“Now I can begin” – 33. “I take revision very seriously but I have to be organised. It makes me feel calm when I know I have everything I need.” NM

The first subtheme “prepared” eloquently demonstrates interpretative explanations for the girls’ behaviours here. The participants are indicating how they armour themselves before school each day and how engaging in this behaviour helps prepare them for the day ahead. The first is akin to a physical talisman, a minor adjustment (earrings) but with a big impact on H’s perceived ability in facing her day, “they’re kinda like an everyday thing, whenever I go to school, I always have to have them” (H). The second picture is more figurative in that Niamh is exploring the different roles she will have to play during her school day and is ready to adjust to whichever persona is required in the
various settings within school. “It was in response to a lot of stress regarding school in general. I learned to form proper narratives as I had a problem with ruminating,” (Niamh). This demonstrates Cleary and Hayes (2012) regard for the advanced social and emotional intelligence commonly found in girls with autism when compared with boys with ASD, however, this is a concerning strategy when applied to Vine-Foggo and Webster (2016) who depict the burden of faking reciprocity in social experiences. The face value of the third photo, “Now I can begin” again mirrors this idea of being prepared for another aspect of school by visually listing everything required for a revision task. NM is expressing a need for control over her situation. “Having nice stationary with nice colours makes me comfortable and confident when you got a good set of pens you feel like you’re raring to go and it makes me feel more organised”, (NM). In light of the previously discussed sections of unpredictable sensory overloaded situations in school and being subject to variable workloads set by teachers, it appears that these participants have identified areas where they can exert control and autonomy rather than being subjected to systems which exacerbate aspects of their autism.
5.8.2 “Coping Strategies” subtheme – Decompression

‘Solace’ – 4. “When I get home from school, I need some time on my own to process the day. My Mum doesn’t even ask; she knows I need the break.” Anna

‘Running to recentre’ – 23

“Last year I discovered running, now when I have a bad day at school, I know I can go for a run at the end of the school day and it will help me get over whatever has happened.” H
Photos 4 and 23 consider that despite being prepared for their school days, things may not go well and the participants understand the importance of decompression after a day at school. The photographs depict the strategies the participants know they can employ to help overcome any challenges the school day may have caused them. “It just really clears my head, if I’m annoyed or people are bothering me, I just wanna go running,” (H). This is vital before beginning any homework tasks or even interacting with those at home. Photo 4 conceptually visualizes the removal of all sensory stimuli and presents a quiet dark place of solitude while the photo 23 is in juxtaposition to this using colour to depict the energy of the running about to be undertaken. Anna explains: “I think it’s just being away from people after being with people. It’s not like I don’t like being with people but it’s draining. Even physically having the door closed is space.”

There is an underlying thread of coping running throughout each of the photos. These girls are coping. They have identified ways and means of proactively and retroactively coping with their challenges. These means are all very idiographic and certainly not a panacea for all the participants and therefore not all girls with autism. Although during one of the sessions both Anna and Niamh realised they were both using mal-adaptive daydreaming as a coping mechanism and they were buoyed by the fact that their coping mechanisms were not as individual as they had first thought: “It’s almost like a coping mechanism, if I’m stressed I’ll do it more, it’s like an escape, it’s addictive but technically it’s not bad for you, the difference is Niamh tells people but I’m really afraid of the judgement,” (Anna). However, if there is a premeditated drive to be ready to cope, this suggests that there is also a sustained anticipation of difficulty, trigger or challenge. The individuality of each coping strategy also reflects a loneliness in that each one is a solitary behaviour not engaging the support of anyone else. It is almost that overcoming difficulty is a private struggle quietly endured. This translates very easily to our understanding of the masking and camouflaging behaviour consistently demonstrated in Tierney et al’s (2016) and Dean et al’s (2017) findings alongside those of this research. More concerningly, most students without autism do not have to regularly anticipate nor cope with the daily challenges of an educational environment set up to marginalise neurodiverse individuals, and as heralded by Ritvo (2006) and Volkmar and Klin (2000), this is where the challenge of full inclusion really lies. Pisula et al (2017) found that despite being invisible in girls with autism, social difficulties
remain a dominant feature of their presentation and Lai et al (2011) demonstrate that girls are more critically aware of these social challenges than their male counterparts. Wilkinson (2008) considers the motivation of girls with autism in avoiding social exclusion and Tierney et al (2016) confirm this by outlining the fears of isolation and rejection experienced by girls with autism. This could explain why these coping strategies are so individual and solitary as it sustains the ability of the girl with autism to appear without autism and this is reinforced by a society that continuously shuns difference. Carrington et al (2003) depict this behaviour as masquerading but Wilkinson (2008) later warns that the ability to do this is only surface level. This effort is not without cost and this interpretation brings into play the aforementioned considerations of mental health burden and overload. While seen as positive by the girls themselves, the constant invoking of solitary coping strategies only serves to further distance the girl with autism from her peers without autism while simultaneously obscuring the need for support from the school staff entrusted with this responsibility.

5.8.3 Conclusion and Implications for “Coping strategies.”

The implications for schools and families is that poor interrogation of these coping behaviours simply reinforces the need for them. If girls with autism are engaging in such rituals and this results in sustaining their ability to exist under the radar also discovered by both Fitzgerald (2018) and Tierney et al (2016), then they are unlikely to break this cycle until such time as the mental toll of engaging in this behaviour overtakes their ability to cope. This somewhat accounts for Pisula’s (2017) evidence for the late identification of autism in girls. This could also be linked to both Gould (2017) and Duvekot et al’s (2017) interrogation of the factors linked to under-identification of autism in girls, as these coping strategies have enabled them to surmount challenging experiences for a longer period than their male counterparts. Theme 5 is however a positive theme and demonstrates that coping strategies for girls with autism can be found when personal interest and preferences are used as the platform for devising ways of developing resilience around education. For those professionals working with girls with autism, the starting point for relationship building and any subsequent interventions devised can entail the strategies and preferences already established by the girls themselves. The very existence of these skills does not however take the
responsibility away from school settings who have a duty to minimise the need for coping strategies at all.

5.9 – Theme 6 - “Identity and Challenging the Assumptions of Autism”

The superordinate theme of “Positive Non-Educational Experiences” was not intended to be included in the research at the outset, however, as the research progressed, the desire of all the participants to include aspects of their worlds outside of school was tangible in all settings and it would have been remiss and non–participatory to omit them. Therefore, the photos depicting this superordinate theme were included in the final shortlist and grouped into the theme “Identity and Challenging the Assumption of Autism”. Both identity and challenging the assumptions were inextricably linked and could not be easily separated to present individually which accounts for the greater number of photographs included in this section. This theme was represented by 4 of the participants with 9 photos demonstrating individual aspects of their lives not related to school or education. Two sub-themes within this theme were identified: relationships with others (3, 12, 11, 20 and 34) and autism as beauty (27,28,31 &29).
5.9.1 “Identity and Challenging the Assumption of Autism” subtheme – relationships with others.

‘Our hang out spot’ – 3.

“Where our group of friends meet up in town.” Dearbhail

‘My friends’ – 12. “I just decided to do this, it’s a picture of all my friends. I have loads of friends.” Samantha.
‘Part of a team’ – 11. “I play badminton every Saturday, it’s very important to me.”

Lauren

‘Lean on me’ – 20.

“My friend has ADHD and I have ASD, we have both been having a difficult time lately, so we talk to each other for support. She helps me and I help her.”

Samantha
‘The comfort of these walls of words’ – 34.

“I love reading and this is one of my favourite places to visit when I go into town with my friends.”

Dearbhail

The participants view their relationships with others as being a regular, meaningful and enjoyable part of their lives. “I’ve known her since primary school, her Mummy calls me her fifth child” (Samantha). Aligning with Kauschke et al’s (2016) findings, these photographs are typical of most female adolescent relationships: friends; team sports; socialising venues and yet they are generated by what others regard as an atypical female adolescent group. Lauren even tries to make the female symbol through her badminton equipment in her photo (11) and when she revealed it to her group, there was a collective “Ahh” in response to its obvious but also metaphorical meaning. She was so delighted with everyone’s positive reaction to this photo. Checklists for autism-related behaviours list various challenges with socialising, maintaining meaningful friendships and difficulty in engaging in group interactions (Jacobsen, 2005) and yet all of these behaviours are represented here by girls with autism as being part of their regular everyday lives. As Vine Foggo and Webster (2016) concluded in their research into the social experiences of girls with autism, it could be argued that the very existence of these behaviours makes these girls appear as without autism.
This portrayal interrogates the impact of actually being identified with autism. Participants may be striving to appear the same as other girls their age and may not want to be regarded as different in the first place. This marries with Gould and Ashton-Smith’s (2011) description of the acquired social proficiency of girls with autism in order to fit in. The participants may also be compartmentalising their autism as part of their identity and not viewing it as something that entirely defines them as suspected by Gibson’s (2006) theory on the stages of disability identity. Despite the use of identity-first language being more welcomed than ever by autistic adults, none of the girls with autism in the research wanted to be called autistic. They used variations in language, ‘having Asperger’s, ‘my ASD’ and ‘being on the spectrum’. When I discussed the use of language in this research, the consensus was for ‘girls with autism’ or ‘girls with ASD’ and this aligned with the earlier suspicions of the critical friends who anticipated that the participants of this research would favour person first language, simply because none of the three critical friends used identity first language at the age of 19. This may subsequently explain why the practised criteria for identifying autism is limited and inappropriate for catching girls with autism who are trying to avoid what is a stigmatised label in society as wagered by both Gould (2017) and Duvekot et al, (2017). Alternatively, this study has provided an opportunity for the participants to finally, truly represent themselves and has created a platform for these girls to demonstrate that diagnosticians of autism are not accurately reflecting profiles of girls with autism in their criteria. Albeit through interviews and not photographs as used here, the outcomes of both Vine-Foggo and Webster (2016) and Kauschke et al (2016) are instances where girls with autism have sought to present the importance of social relationships to them. This is an example of where features of autism are ironically restrictive in their own right, in that there is no space to take into account the variations in profile of autism that might more poignantly reflect girls with autism.

All the participants have been professionally identified with autism and have sufficiently met the categorised criteria at some point during their clinical journey. Yet the yearning of the participants to include these aspects of their daily lived experiences demonstrates in them, a deeper need to portray themselves as young adolescent women with expected adolescent relationships almost diminishing the existence of underlying challenges with social aptitude. The conversations around these photos presents
language that challenges what would be expected of a girl with autism: “I have loads of friends”, “Our group of friends”, “Part of a team”, “I help her” “with my friends” all suggest meaningful relationships, a sense of belonging. This contravenes Wilkinson’s (2008) earlier portrayal of the lone female autistic persona largely incapable of forming lasting and meaningful relationships. Tierney et al (2016) more recently conclude that not enough is known about the social relationships of girls with autism and this is largely due to the lack of research with girls with autism. Our current understanding is over-reliant on parental perspectives of their daughters’ social worlds and this is likely misrepresented. This makes the inclusion of these photos vital to this research as they provide a snapshot of how the girls see themselves within their own friendship groups and the importance of belonging to meaningful social relationships.
5.9.2 “Identity and Challenging the Assumption of Autism” subtheme – autism as beauty.

27. 28. 31. Spectrums of me – “I see spectrums all the time. They are always really beautiful especially the way the light picks up the colours and it makes me think there are good parts to being on the spectrum.” NM

29. ‘Beauty in the shadows’ –

“This makes me think of me. Just because you can’t see something clearly doesn’t mean it’s not pretty. Sometimes I feel in the shadows.”

NM
The second subtheme of **seeing autism as beauty** is taken with caution as all of the photos are generated by one participant and depict her personal enquiry into her understanding of her autism. She considers the autistic spectrum to be very individual and beautiful. Three of the photos are all positive using bright spectrum of colour to represent, in her eyes, the bright spectrum of ASD. “All the contrasting colours show how autism is like a spectrum” (NM).

The “beauty in the shadows” photo alludes to a darker and less clear picture of autism which is better understood at an interpretative level of NM’s experiences of autism to date. “Half of it is in the dark and half of it is in the light cos of the way it was taken. I was thinking maybe half and half, being autistic and then having lots of other things to be good at. Having a diagnosis is really good as it helps me get support and having autism actually gives you wee quirks, some of us are really empathetic, some of us are really smart at different things like music (To H) you’re really good at music and drama, then there’s a wee darkness so maybe this could be when things are not going very good, maybe when you’re on the verge of having a wee bit of a meltdown or when you’re easily offended or when you find it hard to do stuff like Maths,” (NM).

Conceptually, NM shows an embodied determination to see her autism in a positive light and this stems from earlier negative experiences where an early diagnosis meant her parents and professionals expected little of her, assumed she would go to a special school and be on medication for her entire life. In discussion of her photos, she explains that having achieved her GCSEs in a mainstream school, she retrospectively considers the idea of being written off and this could explain her drive to portray autism as a positive and beautiful aspect to her being rather than the negative one previously used to project her future. In discussion around this experience, NM explains that she would like to go back to those professionals and tell them of her success and say to them: “Look at me now!”

NM is accepting of being identified with autism and in conversation switches between describing herself as autistic and with autism. Her developing understanding of how autism impacts on her aligns with the journey of disability delineated by Gibson (2006) and proponents of critical autism studies like Brown (2011). NM uses the term autistic several times and there is an inclination that she is moving towards using autistic as an
adjective to describe herself. It is almost as if she needs to first prove to herself the beauty and positivity associated with autism before she can finally commit to identifying herself wholly in this way. NM is the only participant of the nine to have demonstrated this level introspection on her own autism identity.

5.9.3 Conclusion and Implications for “Identity and Challenging the Assumption of Autism.”

The implication here is how schools and families treat the autism identifier given to girls and whether these identifiers are then used positively or to the detriment of the girls to whom they have been applied. Gibson (2006) has already plotted the trajectory for individual adolescent’s acceptance of their implied disabilities. The age range for this coincides with the time when most girls with autism are being identified and where mental health issues such as anorexia have come to the fore often masking any underling autism (Duvekot et al, 2017; Pisula et al, 2017). Therefore, promoting the positive aspects of the identifier of autism and using the awareness this brings, can enhance outcomes for girls with autism. The identifier of autism should be positively applied as an explanation for nuances or idiosyncrasies presented in girls with autism. As explained earlier, careful treatment of idiographic stressors and responses can actually enlighten how best to support and guide the girl with autism as opposed to Megan’s experience: “They’re putting us all in the same category.” Furthermore, each girl’s social presentation will vary but it is the consideration of these key social relationships and the foundations of these friendships that can enlighten both parents and professionals as to what actually already works for these girls. In turn, this will help shape positive educational and non-educational experiences improving the chances of quality female adult life outcomes for girls with autism.

Chapter 5 Conclusion

The use of IPA has been adept at uncovering the six main themes generated by the 9 participants’ engagement with Photovoice. The IPA has also established the epistemic injustice experienced by these 9 participants as suspected in Chapter 3 in that it has uncovered educational settings as being endemic to the barriers faced by girls with autism despite purporting to be inclusive in practice. This is put best by Samantha: “Nobody asked me!” The IPA not only uncovers the negative educational experiences
faced by the participants but points to those positive experiences that could be built upon to further support girls with autism. Parsons (2015, p417) concludes that: “Experiences at school really matter” noting that “those who felt more positive about school were also more positive about current life circumstances” and this is reflected in the key findings of this IPA which in a similar way has championed the representation of the authentic voices of girls with autism.

While some of the themes are not gender specific in that obstacles to learning and sensory sensitivities are common to both boys and girls with autism, what has emerged as being specific to girls with autism, similar to Tierney et al’s findings (2016), is the underlying thread of the considerable masking of challenges to both their academic and social performance. Elevated levels of perfectionism or a perceived need to demonstrate academic proficiency dominate educational experiences combined with a deep-seated need for meaningful social relationships. This exertion makes these girls with autism more susceptible to triggers within their sensory environments producing a subsequent mental toll or overload for which the girls in this study have devised solitary coping strategies for.

On reflection, the use of IPA has been personally very difficult to employ. IPA is a mechanism for unearthing truly embodied meaning from data that is of priceless value. However, this places an incredible and almost overwhelming responsibility on the researcher to do justice to the lived experiences illuminated. As these experiences are both positive and negative, they are wrought with deep-seated emotions that inevitably transfers to the researcher. The weight of the IPA could be regarded as positively correlating with how participatory the research has been. The researcher facilitated the participants’ deep, personal interrogations of their own experiences and they have certainly embarked on a transformative process, now embracing being the experts of their own lived experiences, but now also being expert informants for the group they represent, girls with autism. To create an IPA that comprehensively narrates the participants’ journeys has required intense self-care and consistent personal reflection on the part of the researcher to emerge confident that an adequate portrayal has been given and that the IPA truly reflects the participants’ incredible work.
Chapter 6- “Look at me now!”

Introduction:

This chapter outlines the nature and impact of the Missing Voices photographic exhibitions. For the research to fulfil the principles of Photovoice and not simply exist as photo elicitation, the photographs must generate increased social and political awareness and potentially cause change for the marginalised group they represent (Gubrium and Harper, 2013; Rose 2012). Missing Voices was exhibited in three different venues across Belfast and the attendees at each corresponded with micro, meso and macro levels of stakeholders that could possibly incite social and political change (Serpa and Ferreira, 2019). Each exhibition and its impact is discussed separately and the chapter concludes with a discussion of the overall impact of the exhibitions consolidating both Teti et al’s (2016) and Obrusnikova and Cavalier’s (2011) findings that the lens of Photovoice is expert at illuminating the finer details of the lived experiences of young people with autism.

6.1 Final stage of Photovoice

Wagner (2007) distinguishes Photovoice from other forms of visual research as having the potential to reach audiences farther than the academics interested in a particular phenomenon, citing both the social context and wider public as being crucial to creating new knowledge and awareness. While this is the goal of Photovoice, both Strack et al (2004) and Sarti et al (2018) caution that social or political change may not always happen as a result of Photovoice and therefore managing participants’ expectations of the potential impact of their work is both an ethical and practical responsibility on the part of the lead researcher. Grunewald (2003) further warns that a lack of impact can actually diminish self-worth in the participants and further marginalise their place in society aligning with Medina’s (2017) consideration of hermeneutical injury within epistemic injustice. Therefore, this stage of the research is as important as any of the preceding stages or interpretations. The objective of Missing Voices was to expose the experiences of girls with autism, to engender a deeper understanding of the perspective of girls with autism in light of the current gender bias towards its presentation and
crucially to inform others of this perspective, past the paucity of academic researchers already engaged in this interrogation as suggested by Wagner (2007), to the wider stakeholders connected to autism.

Considering the hierarchy of stakeholder power at micro, meso and macro levels (Serpa and Ferreira, 2019) it seemed appropriate that any exhibitions of Missing Voices would target these audiences. Targeting all three power-levels was an aspect missing from the previous Photovocies considered where only meso- or macro-levels were targeted and therefore, the success of this new undertaking was not guaranteed. First and foremost, engagement with family and friends most connected with the participants (micro-level stakeholders) was most appropriate. Pink (2002) notes the vulnerability experienced by those engaged in such personal research with Gubrium and Harper (2013) later confirming that Photovoice is very personal to the community in which it is based and therefore presenting this intimate research to those in a position to support the participants is argued here as the most appropriate first step. Furthermore, in light of Cridland et al’s (2014) finding that the perspectives of girls with autism were different to those of their mothers in their research, this micro level of engagement with stakeholders (in this case parents and friends) is of paramount importance in achieving the research aim of increasing awareness at this familial level. Hence the Graduate School at QUB was approached for the first exhibition which would be launched privately and attended by the family and friends of the participants. The prestige of the listed building, the location at a third level institution and the invitation of three key speakers from second and third level would enhance the importance of the participants’ research heeding Lundy and McEvoy’s [Emerson] (2012) elevation of participants and potentially addressing Blaikie and Priest’s (2017) consideration of the researcher’s hermeneutical responsibility to the participants. It should be noted that none of the participants wished to speak publicly regarding their participation in the research. This exhibition is discussed in section 6.2.

Macro-levels of research engagement consider the interaction between participators as researchers (PAR) and those policy-making stakeholders for the marginalised group represented by the PAR (Christenson and Prout, 2002). Sarti et al (2018) both critically discuss and actively demonstrate the power of this interaction using Photovoice with children experiencing poverty and deprivation in the Netherlands. Their research
acknowledges that action post-Photovoice is not always guaranteed but then evidences how the Photovoces presented by the children in their research created a change in local government policies as a result of the dialogue facilitated with policy-makers. The local government context of Belfast is the Northern Ireland Assembly at Stormont and while there was a lack of active government during the time of the research, the All-Party Working Groups for Autism, Disability and Children and Young People within it still functioned. Missing Voices was brought as an exhibition to Stormont with several key policy stakeholders invited, the impact of which is discussed in section 6.3.

Serpa and Ferreira (2019) assert that meso-level mobilisation can only be used when both micro and macro levels of awareness have been sought and in this instance Missing Voices demonstrated both familial and political mobilisation and it was therefore appropriate to seek a wider public audience for the research. Fine (2012) regards meso-level interaction as the sharing of ongoing meaning-making and the building of collective identities by groups within a social structure. Defined as local sociology, meso-level interaction links with intersectional feminism as it is concerned with presenting a distinct group’s identity (girls with autism) to the ecology of groups that constitutes a local society. In this case, the Missing Voices exhibition is heuristic in that it has the capability to present this specific group’s identity to a wider public audience who have previously demonstrated a lack of awareness of girls with autism by virtue of this group’s marginalisation. This links with Photovoice’s ability to disrupt current thinking and rally public concern (Sarti et al, 2018). The meso-level of interaction for this research is considered to be the inclusion of Missing Voices in the Belfast International Arts festival and the subsequent workshops that have stemmed from this and is discussed in sections 6.4-6.6.

6.2. Impact of Queen’s University Belfast Exhibition

The Queen’s University Belfast (QUB) exhibition was the most intimate of all of the exhibitions of Missing Voices with the exhibition launch limited to a small, private, invited audience connected to the participants. This provided a platform for micro-level interaction with stakeholders. Hosted in the graduate school building, the launch evening included light catering and was made accessible for all with the inclusion of explicit signage and use of quiet rooms/spaces. The parents and friends of all the
participants were invited to attend the launch on Thursday 13th June 2019. This shaped the nature of the three speeches made at the launch by Professor Ruth Leitch, Dr Bronagh Byrne and myself. For Professor Leitch, it was an opportunity to explain in non-academic language, how useful Photovoice could be in engaging girls with autism in exploring and sharing their identities to increase awareness. For Dr Byrne, the emphasis of her speech was the importance of challenging the stereotypes surrounding disability and how this kind of action research had the potential to change general perceptions of marginalized groups in our society, such as girls with autism. My speech was an opportunity to give a sense of occasion to the girls’ photographs and celebrate their status as researchers within this project. I was able to give anonymous, anecdotal insights to how they all had engaged with the process and this generated subsequent discussion between the girls and their families as they circulated the exhibition and explained their photos to their families. I was also able to thank the families for supporting their girls throughout this process and outline how the research would be used to take this new awareness forward to the professionals charged with making decisions as to how girls with autism are supported both educationally and socially.

This was a very emotional experience for all involved. Approximately eighty people attended the launch with six of the nine participants and their families attending. Several of the parents of the girls expressed how they had previously no idea that these were the experiences of their daughters or that they had underestimated the impact these experiences had had on their daughters. There was enlightenment within and among the families of the participants. Tierney et al (2016) and Pisula et al (2016) both cite the limitations of their studies as being that the perspectives of girls with autism came from the parents of the girls interviewed and not the girls themselves. Bearing in mind that this research directly involved girls with autism rather than a parental take on it and now considering the level of enlightenment experienced by parents at the subsequent exhibitions of this research, it could be argued that parents cannot fully represent the perspectives of their daughters. This links with epistemic injustice whereby there is passive omission of the girls’ voices when parental perspectives are foregrounded which is tantamount to testimonial injustice. Therefore, from an intersectional feminist standpoint, research on girls with autism needs to be led or co-researched by girls with
autism so that the specific interplay between their gender and their autism is fully understood by others who do not share that interplay.

The QUB exhibition would be the first time the participants would see their work presented professionally and this links back to the ethical consideration of remuneration. While no monetary reward was given to the participants for participating in the research, on the basis of Strack et al’s (2004) summation of the ability of Photovoice to enhance an empowerment construct, it was assumed that the status of the exhibitions would engender feelings of pride and increase value and self-worth. It could be argued that this could be my imposed assumption here however, watching the girls lead their families around the exhibition and specifically their photos would counter this. Furthermore, in all exhibitions, occasions were noted whereby the participants asked to have their photograph taken beside their different pieces of work both alone and with their accompanying family members. Therefore, it is fair to say that there was a positive personal benefit for the participants for having taken part in the Missing Voices research.

Due to the online promotion of the exhibition at both QUB and Stormont, several other members of the public attended the QUB launch, all of whom had some connection to autism. The exhibition was also attended by one of the critical friends, her mother and the mother of another critical friend from Phase 1 of the research. The impact of this first exhibition on one of the critical friends, Olivia, led to her becoming a spokesperson for the subsequent two exhibitions and media coverage. It could be argued therefore, that participating in Phase 1 of the research, enabled her to more openly address and embrace her autism as she had not openly acknowledged this prior to the first exhibition. As Olivia was part of Phase 1 of the research, she was older than the participants, therefore it could also be argued that her acknowledgment of her autism coincides with the expected acceptance of a disability identity as charted by Gibson (2006). However, Olivia still identifies herself as a woman with autism and not autistic which counters Brown’s (2011) expectation of the use of identity first language. This is an important aspect to consider as had identity first language been imposed on Olivia rather than her preferred use of person first language, there is a likelihood that she would not have engaged with the exhibitions and media coverage as much as she did. This links with Hens and Langenberg’s (2018) and this research’s earlier consideration.
of autistic identity first language in some instances further marginalizing those it purports to emancipate.

Following the launch night on Thursday 13th June, Missing Voices remained as an exhibition in the Graduate School of QUB from 14th-16th June. Exhibition brochures were left on display to give further context and meaning to the exhibition and both the Graduate School and the School of Social Sciences, Education and Social Work (SSESW) continued to promote it through email, Facebook, Twitter and the Graduate School summer programme promotional materials and online presence.

6.3 Impact of Stormont Exhibition

A two-week long exhibition was secured at the Long Gallery in Stormont, the home of the Northern Ireland Assembly. This was established by contacting Clare Bailey (MLA) of the Green Party. This political party was chosen as it is regarded as neutral political party in Northern Ireland, part of whose manifesto is to lead to a fairer, more inclusive society reflecting the conceptual framework for this research. The intention of this exhibition was to once again address testimonial injustice within epistemic injustice and fulfilling the emancipatory aspect of Photovoice by taking Missing Voices to the macro seat of power in Northern Ireland. The exhibition was launched on Monday 17th June 2019 in the afternoon and would this time reach politicians, lead social policy-makers and members of various civil service bodies increasing their awareness of girls with autism and challenging them to use their social power and agency to specifically respond to girls with autism in terms of provision and support. The principals and SENCOs of the participating schools were also invited as were the participants and their families.

As with the QUB launch, three key note speeches were made at the launch by Professor Ruth Leitch, Dr Bronagh Byrne and myself. This time the speeches were adjusted to reflect the professional and political bodies represented within the audience and to challenge their use of identity power in the deliberate exclusion of specific provision for girls with autism from mainstream neurotypical education in Northern Ireland. The speeches were introduced by Clare Bailey (MLA) who also made a political address regarding the omission of voices of girls with autism from our understanding of autism.
and the subsequent impact of this across education and society. This intersectional feminist standpoint was echoed in the three subsequent speeches all which focussed on the wider impact of the existing ignorance of girls with autism in terms of mental health services and quality adult life outcomes for women with autism in terms of both employment, mental health and relationships. The speeches also addressed the current cuts to special education, specifically the support services designed to accommodate autism and but more explicitly on the lack of support services especially for girls with autism.

The exhibition was attended by approximately a hundred people. In terms of political representation, members of the Green Party and the Alliance Party attended and the All Party Working Groups for Disability, Children and Young People and Autism were also represented. With regards to the civil service, the Department of the Economy, Department of Justice and Departments for Health, Agriculture and the Environment all attended. Educational services connected with the support of autism, Middletown Autism Centre, the SEND (Special Educational Needs and Disability) implementation team and the Autism Advisory and Intervention Service for the Education Authority, responsible for transition planning for students with autism, also attended. Two of the four SENCOs from the participating schools attended as did the principal of my own school. The autism charities Autism NI and Solas were also represented and the link to Autism NI would be further established with the subsequent media coverage.

The exhibition at Stormont lasted a further 13 days during which time 14 other events were hosted in the Long Gallery, among them a gathering of the Royal Society of Occupational Therapists, a profession closely connected with the support of people with autism. Exhibition brochures were once again left to contextualise the exhibition for the visitors to the Long Gallery.

Following the two exhibitions, a feedback form was emailed to all the invited guests who attended. This was done using google doc and 30 people responded with varying degrees of anonymity. 15 of these people attended Stormont, 13 people had attended QUB and 2 people had attended both exhibitions. The impact of the Photovoice can be gauged through the anonymous responses to these questions.

The four questions asked were:
1. **How did the photos increase your understanding of girls with autism?**

“They were varied, unique and at times funny. They seemed to capture the essence of some problems young people with autism face, but articulated in a more meaningful medium: a clever use of this communication that aids and ultimately increases our understanding.”

“I thought the pictures gave a really good visual representation to some of the challenges the girls face, some of the activities which they find re-energise them and showed aspects of their personalities.”

“Quite a few of the photos resonated with my daughter's behaviour and/or feelings she has expressed. A few of the photos were illuminating on the depth of feelings of isolation or not fitting in which made me feel quite emotional. The insights I have gained will hopefully help me support my daughter.”

2. **How did the exhibition brochure enhance your understanding of the photos?**

“It provided the context to the photos. Many photos presented, to the Neuro typical eye, seemed to be just regular, everyday situations and some from a more abstract view. The power behind the brochure was providing the voice of how challenging these everyday situations can be for females with ASD. It made me consider how many of these challenges are invisible to me.”

“The titles were very useful and the context helped me to understand the meaning in the photos - it added depth and took away some of the uncertainty about what I was looking at and the interpretations I was making.”

“The brochure was very informative and brought a deeper meaning to the photographs. The girls' words were hugely impactful and allowed me a glimpse into their world.”
3. **How do you think Missing Voices contributes to future understanding of girls and autism?**

“That everyone should know that we have voices to speak out for ourselves and others should listen in the future. Also that they should support us and hang out more with us.”

“It is such an accessible exhibition and will provide much understanding to educators, families and hopefully to Policy makers”

“I think it provides a very accessible medium for decision makers to enable an understanding that females with ASD have a very strong voice but that there are different ways in which that voice can be heard and in which females with ASD can be facilitated to participate directly.”

4. **Any overall feedback for the event?**

“Very professional and very insightful. It has really blown my mind. I have a male child with ASD also and the differences in behaviour and manifestations is stark.”

“An excellent way of showing the personal experiences of ASD in girls. Anyone interested in gaining a better understanding (especially those working in Education) could learn something from these photographs.”

“This was a fantastic event. I was extremely impressed with the concept, artwork and the speakers. It provoked a tangible feeling of community and mutual understanding.”

6.4 **Impact of Belfast International Arts Festival**

The third exhibition of Missing Voices took place over three weeks in the University of Atypical in Belfast from 22\(^{nd}\) October to 15\(^{th}\) November 2019. University of Atypical is the public gallery space of the Arts and Disability Forum and therefore, this would be
the first time Missing Voices reached wider audiences than just those invited to the previous exhibitions. Missing Voices was the University of Atypical’s contribution to the Belfast International Arts Festival meaning the exhibition had the potential to reach international audiences attending the festival fulfilling the final criteria of Photovoice and this could be considered as reaching Serpa and Ferreira’s (2019) meso-levels of engagement.

Two specific events were planned during the exhibition. The first was the public launch night on 21st October 2019, attended by approximately 40 people including some of the participants and their families. Three key-note speeches were made at the launch, the first by Richard Wakely, the artistic director and chief executive of the festival, who spoke about the importance of using creative visual methods to amplify the voices of marginalized groups in society. The second speech was from Helen Sloan, the photographer who has assisted the participants during the project. She focused on the viability of documentary photography as a research method but also explained how enlightened she had become about girls with autism while participating in the project. I made the final speech and focused on the importance of this opportunity to bring the perspective of girls with autism to wider international audiences.

The second event was a live Photovoice workshop and took place on the 24th October 2019. This was a public 2-hour event and people connected to autism were encourage to attend to take part in a live Photovoice. A photovoice panel consisted of 5 people: Olivia (critical friend), Frances (Olivia’s Mum), Dr Fiona McCaffrey (Head of research at Middletown Autism Centre), Helen Sloan (Photographer) and me were asked to create their own Photovoice to demonstrate their connection to autism. Each of the 5 Photovocies were presented to the attendees with each person explaining the meaning behind their photos. Attendees took part in a ten-minute workshop on how to creatively compose photographs without disclosing identity using the handout that had been used for Session 2 of Phase 2 of this research. Once this was competed, all participants were invited to use the IPads provided to compose a photo that explained their attendance at the workshop. These the photos were then displayed in the gallery alongside the original exhibition. Accompanying each photo were message cards where participants were encouraged to entitle their photo or compose a sentence or paragraph to explain their photo’s meaning. Due to the likelihood of people with autism in attendance, staff were
present to assist in all aspects of the Photovoice including scribing for any person not willing to write themselves. A business card was also provided so that anyone not willing to participate on the evening could later take part by emailing through their Photovoice at a later stage.

Thirty-six people attended the workshop: professionals/artists working with people with autism, parents of children with autism and people with autism in attendance. Sixteen new Photovocies were generated and became part of the exhibition in the gallery. Some attendees opted not to participate and others expressed an interest in participating at home. The new photos composed generated discussion between the participants due to their varied backgrounds and people exchanged phone numbers and emails as a result of these connections.

One particular group in attendance were the directors from a professional theatre company Kids in Control (KIC) who work with young people of all abilities among whom, are many young people with autism. KIC were so positively affected by the workshop, they subsequently booked another workshop in the gallery while the exhibition was on for their Saturday morning group of young people on 4th November 2019. The format for the previous workshop was slightly adjusted to be reflective of the audience and the hour slot available for the workshop. None of the rest of the original panel were present however, their Photovocies were used to contextualize the workshop. A further 16 Photovocies were composed as part of this second workshop. These were taken away by the participants for use as stimuli for their next drama performances in December 2019.

6.5 Media attention

The education and arts correspondent for BBC NI, Robbie Meredith, attended the launch of Missing Voices in Stormont. Footage was shot of people viewing the exhibition and of the keynote speeches. Following this, Olivia (critical friend), Frances (Olivia’s mother) and myself were interviewed in the council chambers. The BBC then curated this footage into three different mediums. Firstly, the exhibition was featured on Good Morning Ulster, a province-wide daily radio news programme by BBC NI. Later
the same day the research was presented on BBC Newsline, a province-wide local prime-time news programme. Missing Voices was the second part of a two-part documentary on autism services in Northern Ireland alongside input from the CEO of Autism NI regarding lack of provision for autism in schools. Finally, Missing Voices featured on the BBC NI online news page (Appendix 10). This would take the local TV and radio audiences to a wider online readership meaning that Missing Voices would reach national and international audiences.

To generate publicity for the exhibition, a Missing Voices Facebook page was launched prior to the exhibitions so that any media attention could be shared. Twitter was also used and most posts on Missing Voices were retweeted by the SSESW and the Graduate School in QUB again reaching wider audiences. When Missing Voices was aired on television and radio, these clips were posted to highlight the publicity of the exhibitions.

By securing the Belfast International Arts Festival, Missing Voices featured in both the print and online version of the festival programme and was internationally advertised by the Arts Festival and University of Atypical (Appendix 11). A0 posters were created for Missing Voices and these were placed on billboards outside the University of Atypical and one was also sent to NCAD (National College of Art and Design, Dublin). The inclusion in the festival led to increased media attention and a half page article on the exhibition was printed in the Newsletter, a Northern Irish daily newspaper (Appendix 12) and in print and online by the Dundalk Democrat, a weekly local newspaper in my hometown (Appendix 13).

Missing Voices continues to maintain an online presence on Facebook, to date has had engagement of 483 people and continues to have 126 followers. Missing voices now has its own email address to which viewers of the exhibition have been encouraged to send their own photographs and stories with a view to continuing to raise the profile of girls with autism autism.
6.6 Ongoing attention and impact

Missing Voices was displayed at the Inclusive Education conference held in QUB in September 2019. The research continues to attract attention and will be displayed at several locations in the coming year, most notably, the research and full exhibition will be presented at the British Psychological Society Northern Ireland conference in March 2020 with a further presentation at the Learner conference in Valencia, July 2020.

As a result of attendance at the exhibition in Stormont in June 2019, the Autism Intervention Service for Belfast Education Authority has requested to use the research as part of their transition support for girls with autism moving from primary to post-primary schools. The Middletown Autism Centre has requested that the research be presented to their practitioners later in 2020 to use as part of their interventions with girls with autism. Finally, the SEN team for Department of Education of Northern Ireland, have requested to meet to discuss the findings of this research in terms of ASD provision in Northern Ireland.

The final research question was to investigate how the personal experiences of girls with autism could be used to increase educational awareness and inform educational practice in supporting girls with autism during their post-primary education. The impact of the exhibitions in creating dialogue between the researcher and the different stakeholders engaged in provision and support of girls with autism, demonstrates how these experiences could positively influence educational support services for post-primary girls with autism especially in their transitional years.

6.7 Conclusion to chapter 6

Throughout the discussions with the participants, a common theme emerged: “They’re putting us all in the same category”, (Megan) and “everything is essentially a spectrum, just like the diagnosis, everyone is different, even that’s not just with ASD, that’s with everyone,” (NM). Therefore, the goal of the Photovoice was to address whoever “they” are to Megan and to show NM’s “Everyone” the breadth of autism especially in the case of girls. In line with the conceptual framework for this research I was able to act as a conduit by facilitating the presentation of insights and perspectives created by the
research participants. Presenting autism as neurodiversity to those who have previously pathologised autism challenges the stakeholders responsible for the hermeneutical disadvantage and subsequent epistemic injustice experienced by girls with autism. Moreover from a intersectional feminist perspective, the exhibitions demonstrated the nuanced interplay between autism and girls with the speeches at each exhibition actively addressing the double marginalisation of the girls with autism in terms of the rights for their voices to be heard and their rights to appropriate inclusive education in mainstream settings. The three exhibitions enabled these transformative messages to be shared across the different levels of stakeholder power at micro-, meso- and macro- levels and across the different sectors of the social and political communities connected with the participants. This was evidenced at micro-level through the familial attendance at the QUB launch, at macro-level through the attendance and feedback from the Stormont exhibition as presented earlier and at meso-level through the inclusion of Missing Voices in the Belfast International Arts festival 2019 and the reach this exhibition continues to generate.
Chapter 7: Conclusion

This thesis concludes in two ways, firstly by acknowledging the new and specific knowledge created under the three research questions and then by considering the use of Photovoice as a research mechanism for eliciting a deeper understanding of experience while simultaneously creating awareness of the underrepresented groups acting as participants. The conceptual framework of epistemic injustice and intersectional feminism is revisited throughout the chapter and concludes with an acknowledgement of the study’s limitations, the implications for my own professional practice and sets out recommendations for future research.

7.1 Conclusion of research questions

1. What are the challenges faced by girls with autism in the transitional years of post-primary school?

Nine of the thirty-four photographs depict the educational challenges faced by the participants. Presentations of sensory sensitivities and sensory overload are unsurprising as this is a well-documented aspect of autism (Fritschie, 2010). What is enlightening with regard to this challenge is how subtle and discreet these sensitivities are for girls with autism and more importantly, despite their apparent insignificance, their disproportionate and detrimental impact on the ability of these girls to cope in educational settings. When combined with the other highly documented challenges of autism: time management and organisational skills (Cridland et al, 2014; Kaushcke et al, 2016; Tierney et al, 2016), the girls’ mental fatigue and toll increases to a point where engagement in education can be hindered to the point of disaffection (Wilkinson, 2008). Due to a lack of professional awareness of the discrete nuances of girls with autism, the adverse impact of these environmental stressors is largely unknown by those professionals able to support the girls with autism (Jarman and Rayner, 2015). This is exacerbated by the limited and exhaustive ability of girls with autism to internalise and mask these challenges until other mental health issues subsume this (Pisula et al, 2017). Therefore, what is key is the early identification of these challenges in both the identified and unidentified populations of girls with autism in educational settings by
key people who are able to curate educational experiences around the needs and preferences of girls with autism.

2. What are the coping strategies used by girls with autism in the transitional years of post-primary school?

Eleven of the thirty-four photos demonstrate that girls with autism are able to identify both people and places that enable them to feel safe, resourcing them for dealing with the social communication challenges they face (Pisula et al, 2017). The girls are aware that coping with social communication challenges will have a fatiguing impact on them (Vine-Foggo and Webster, 2016) and they are able to identify coping mechanisms for this fatigue or the decompression required after engaging in social communication demands. These coping strategies are all bespoke to the individual and are often reflective of personal preference or interest in particular subjects (Betts et al, 2007). However, what is now also known is how important it is for these girls to overcome the barriers they face to social communication. Tierney et al (2016) and this research attests that girls with autism want to have meaningful social relationships with their friends and they want to experience the feeling of belonging that close female friendships engender. Nine other photographs portray this important part of their identity and this is not dissimilar to how neurotypical girls wish to navigate their social worlds (Kauschke et al, 2016).

3. How can the personal experiences of girls with autism be used to increase educational awareness and inform educational practice in supporting other girls with autism during their post-primary education?

All thirty-four photographs depict the personal experiences of the nine individual participants and while there are common themes among them, there is also true individuality. The acknowledgement of such individuality is the starting point for developing measures to assist girls with autism transitioning to post primary school. Fritschie (2010) points out that key transition points are the trigger for exacerbating features of autism with both Tsai and Ghaziuddin (2014) and Jarman and Rayner (2015) distinguishing school as the environment with the most stressors for girls with autism. This is evidenced by the fact that while there were nine photos depicting negative educational experiences, there were none in the non-educational settings. Nonetheless,
this research identifies school as a safe place with safe people to come to the assistance of girls with autism and this is supported by Pisula et al, (2016). Therefore, the identification of a knowledgeable key person who can assist a girl with autism in using her individuality to develop coping strategies for the academic and social aspects of school is paramount. This intervention also involves special consideration of the curriculum with a bespoke timetable curated to incorporate the students’ strengths while also providing opportunities to decompress or recharge during the school day dependent upon need. Particular attention should be paid to the minutiae of school life so as not to underestimate the power of seemingly innocuous triggers especially those concerning sensory overload.

7.2 Conceptual framework summary

The conceptual framework of this research identified two problems, girls with autism are a unique group doubly marginalised by both their female and neurodiverse identities and as a result of these intersecting identities, they have suffered epistemic injustice from never having had their voices included in the educational discourse that informs how we understand and support girls with autism. The lens of intersectional feminism recognises this oppression, while the lens of epistemic injustice aims to emancipate this group by empowering them in articulating their unique experiences, thereby avoiding hermeneutical injustice, while simultaneously ensuring that stakeholders in education can no longer impose testimonial injustice on girls with autism.

Adopting epistemic injustice and intersectional feminism as the conceptual framework for this study enabled the voices of girls with autism to be heard. The method of Photovoice used, which is underpinned by a feminist standpoint, removed the barriers in communicating and demonstrating the actual lived experiences of these girls in both their educational and non-educational environments. Furthermore, positioning the girls’ voices as the only expert voices of this study helped to promote a positive perspective on the identity of girls with autism thereby avoiding any further epistemic injustice. The subsequent exhibitions enabled this original understanding of girls and autism to be transformed into wider public awareness and engagement and the outcomes of this continue to remain impactful.
7.3 Photovoice and IPA conclusion

Using the innovative method of Photovoice, a method not previously conducted with girls with autism, the subsequent findings of the IPA have illuminated and foregrounded the rarely seen perspective of girls with autism. This research is ground-breaking in terms of originality in establishing Photovoice as a useful method by which the deeper embodied meaning of what it means to be a girls with autism can be elicited. Few studies have explored the experiences of girls with autism by positioning the girls as participants and so this research is an advancement of academic understanding in this area. Furthermore, Photovoice has developed in each participant a means of expressing themselves through photography, not just simply by taking a photograph but by considering how compositions of light, colour and positionality can contribute to embodied meaning making within image production. The resulting compositions have reached both private and public audiences enabling the participants to tell their story and create authentic awareness of girls with autism by girls with autism.

The research highlights the current underestimation of the severity of impact of school triggers and the potential damage it can cause to the mental health of girls with autism. The crucial finding is twofold, girls with autism will make their challenges difficult for professionals to detect and therefore the onus is on those professionals to become more adept at detecting female presentations of autism rather than relying on outdated criteria that reflect males with autism. Once this awareness is developed and students are identified, the girls themselves should lead their own bespoke support plans as they have already begun the development of their coping strategies. Unearthing this will require the careful and sensitive development of trusted therapeutic relationships where the voices of girls with autism are heard and responded to. Using a creative participatory means to amplify voices may well uncover richer and more useful data than traditional methods that rely on communication skills alone.

7.4 Limitations

While nine participants completed the study, and this number of participants is within the acceptable margins for Photovoice research, not all the participants worked collaboratively, some chose to work alone as was their preference which limited the
cohesiveness of the group. Some of the richest meaning-making elicited in this study came from the participants’ interactions with each other and the reciprocal support they gave each other during the discussions of their respective Photovocies. This is something that would have benefitted all of the participants but equally acknowledgement of their preferred method of participation was paramount. The success of the Kids in Control workshop that followed the public exhibition further evidences that full group participation in Photovoice is optimal.

A second limitation comes the culture bound aspect of the research. Limited to four schools due to gatekeeper uptake and because of time and travel constraints, the participants could be deemed to solely represent educational experiences from within the Catholic and Integrated sectors of post-primary education in Belfast, Northern Ireland. However, the experiences of these girls with autism transcend religious affiliations and schools thereof and this should not be regarded as a limiting factor for the development of the findings of this study.

7.5 Personal and Professional Reflections

The personal enjoyment I experienced during this research can only be attributed to the meaningful participation of all of the girls involved in the research. Their openness at sharing each of their individual experiences with me and each other was unanticipated. To be able to step out of teacher role and into the role of researcher where I was learning from the girls as experts of their own worlds was truly illuminating. I had embarked on my own personal Photovoice as part of an earlier module for this doctorate and while my clunky attempt at photography uncovered in me the emotional impact of many meaningful professional and personal experiences I was unprepared for the beauty and skill by which the girls in this research created their photographic compositions as a means of exposing their lives. I found myself able to bracket off my own personal assumptions and allowed myself to enter into their worlds.

Conducting the IPA was difficult having built this relationship with the girls as it was truly moving and I felt I experienced some transference from the girls by immersing myself so deeply in the research. Some of this was negative because of the litany of challenges they face daily and so careful reflection was required to compose myself in
order to do justice to their work. This was buoyed by the strength and courage shown by these girls in coping with their environments and seeing autism as positive and something beautiful to be celebrated. The humour they found in the description of some drastic situations was also humbling.

Professionally the research has and will continue to impact on me in several ways. The literature review has furthered my professional understanding of teaching girls with autism. I now understand how very important school is for girls with autism despite their outward appearance of not really liking it. School offers girls with autism a place of belonging and a place in which to find the social interactions they crave, as proven by their enjoyment of the group research settings. School can benefit girls with autism when they have people around them who have an enhanced understanding of the many challenges girls with autism face, what these challenges are and how something that seems trivial can actually have a catastrophic effect on the ability of the girl with autism to cope with their educational environment. When the support is there, school can be so positive.

The darker side of school is when these challenges are not addressed or worse overlooked. I had a personal and professional interest in finding out the experiences of these girls with autism but undoubtedly there are educational practitioners who do not want to enhance their understanding in this area or worse don’t see it as necessary. The girls in this research documented when school hurts them and they know they are being marginalised or seen as other. The experiences they shared demonstrate how difficult school becomes when the educators in them show limited understanding and empathy towards the girl with autism and furthermore how creating non-accommodating educational environments further serve to exclude girls with autism from what are deemed to be inclusive settings. In some instances, it is almost phenomenal that some girls with autism continue to attend school at all when these exclusively neurotypical environments are full of mounting challenges coupled with academic and social pressures. Herein lies my professional takeaway from this research, it is not the responsibility of these girls to surmount the barriers of the educational environments around them, it is the responsibility of those professionals in these educational environments to remould themselves in terms of knowledge and appreciation of their neurodiverse communities avoiding testimonial injustice at all costs. It is no longer
acceptable that teachers and other educational professionals have limited understanding of girls with autism and lack the skills to truly support these girls in their classrooms. For me, in my role as SENCO in my school, the staff training I am responsible for will include in the future the insider knowledge I have been privileged with. Furthermore, I will use my academic experience to inform practice within teacher training so that new educators will understand, value and want to support the girls with autism in their classes. Finally, I will continue to develop my skill as a Photovoice researcher for promoting neurodiversity, unlocking voices and raising awareness of marginalised groups such as girls with autism.

### 7.6 Recommendations

This study identifies hermeneutical injustice within autism and clearly advocates the use of participatory arts-based methods with people for whom expressing voice may be an arduous pursuit. Being creative about the production of meaning-making has the potential to expose an even deeper understanding of what it means to belong to a marginalised group within society. Moving forward Photovoice should be considered as an accessible method for continuing to work with girls with autism.

Byrne and Lundy (2015) identify that a current trend exists for seeking the views of young people but warn that the impact of these views on longer term government delivery is difficult to assess. This study brought the adolescent female perspective of autism in education to the government of Northern Ireland and made news headlines as part of the petition for autism training for teachers by Autism NI. As this research goes to print the ‘mandatory autism training for all teachers’ bill has recently been passed by the Northern Ireland Assembly. There is an onus on future research in this field to ensure that this nascent governmental delivery includes the voices of girls with autism equipping the teachers in schools in Northern Ireland to become the detectives for girls with autism in schools and to be the ‘safe people’ in the ‘safe places’ both educated and resourced to offer bespoke individual support and intervention for girls with autism.

“Everything is a spectrum essentially, just like the colours, just like the diagnosis, everyone is different, that’s not just with ASD, that’s with everybody.” (N)
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Appendices