

'Autistic [Neuro]Queer Pioneers'
Using participatory autism research, performance, and visual art
to articulate the experiences of late diagnosed autistic
women (cis- and trans-) and non-binary people

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Abstract

Background

Much autism research is predicated on the assumption that autistic people are male and/or male-brained. This gendered diagnosis has led to the marginalisation of a group of autistic people that do not have these stereotypical male autistic traits (i.e., systematising, externalised presentation of autistic behaviours such as stereotypical meltdown and stimming) being mis-/undiagnosed. This group includes autistic women (cis-/trans-) and non-binary people (AWCTN+). The author, who is AWCTN+, did not have these stereotypical traits and remained misdiagnosed with mental health issues until aged 39.

Methods

Their experience became the impetus for this thesis; to address the knowledge gap about adult AWNBT+ peoples' lived experiences using creative methods. Drawing on their performance art background, they designed nine two-hour creative workshops (CWs) to construct an autistic space that encouraged a group of adult late-/ self-diagnosed AWNBT+ university students to articulate their experiences of being autistic.

The culmination of these workshops was a 90-minute collaborative performance piece that was to be shown to the public. A series of recordings from the creative workshops plus one-to-one interviews with the participants were transcribed and analysed using elements of grounded theory and thematic analysis. Post-performance interviews were also conducted.

This thesis develops a new form which I have entitled 'embodied autieethnography performance'. A method which has built on other autistic academics' use of autieethnography as the autistic form

of autoethnography. This was the method I used for my solo performance *Adventures of Super Autie Girl* to articulate my own experience of being autistic which was further developed to incorporate the experiences of the co-performers in *Adventures of Super Autie Gang (ASAG)*.

Results

Seventeen people were recruited and participated in at least two of the CWs. Eight participants consented to one-to-one interviews and all participants consented to the CWs being recorded. All data were anonymised and transcribed before being analysed. Five themes emerged from these data: 1) Autistic Connectivity/Autistic Space; 2) Labels and Identity: Reappropriation; 3) Stimming/Body Signs; 4) Autistic Sensory Experience; 5) Articulating and Re-Evaluating Autistic Needs.

The collaborative performance piece, *ASAG*, was a culmination of all the knowledge learned in the CWs and was co-created with five of the CW participants. It was shown on April 30, 2019 at the Autism Arts Festival, University of Kent, UK.

Conclusion

The emergent themes appear to challenge the validity of the male and/or male-brained model of diagnosis, which does not appear to adequately describe the experiences of AWNBT+ people. In addition, CW participants reported increased: self-acceptance; pride; confidence to articulate their needs and stim in public. The thesis also identified the importance of autistic spaces.

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Section 1

Background

This practice as research (PaR) investigation uses performance art, and participatory autism research underpinned by phenomenology, feminism, gender, queer and crip theory to articulate the lived experiences of women (cis-¹/trans-) and non-binary people who are autistic (hence forward referred to as AWCTN+ people).

The majority of autistic² research has been male biased (4:1 male/female ratio) which has led to autistic diagnostic criteria reflecting this male bias (Bargiela, Steward & Mandy, 2016; Goldman, 2013; Mandy & Lai, 2017; Hull, Mandy & Petrides, 2017; Bumiller, 2008). As Mandy and Lai (2017) point out, '[a]fter all, all autism measures were designed and validated using predominantly male samples.' (Mandy & Lai, 2017). Duvekot et al (2017), Frazier and Hardan (2017), Allely (2019) and Antezana et al. (2019) concur that existing clinical diagnostic criteria focus on overt manifestations of 'repetitive stereotypical behaviours' (DSM5, p. 50). Autistic

¹ Cis is a term for a person whose gender identity matches the sex that they were assigned at birth or a person who expresses their gender in a way that is socially acceptable for their biological sex.

² I will use identity first language throughout this thesis. I refer to myself as autistic, or autist, as I know that autism is an intrinsic part of my personality and could not be taken away from me without irreparable damage. I am not a person with femaleness or a person with queerness and so I am not a person with autism, I am autistic (Brown 2018). I also acknowledge and respect the reasoning behind some autistic people and/or their carers, parents, and clinicians using the person first language i.e., a person with autism. The discussion about terminology regarding autistic people has always been divisive. Many parents, carers, and clinicians, to use person-first language, feel that the person should come before their disability. The autistic self-advocates favour identity first language as the many of the words used to describe autistic people such as autistic Spectrum Disorder (ASD) and Autistic Spectrum Condition (ASC) are part of the medical model and imply that they are in deficit. autistic people are autistic, they do not have or live with autism. The medical profession describes it as a lifelong condition, but most autistic self-advocates would say that language is important and autism is a significant part of who they are (Milton 2017; Sinclair 1999; Brown 2018; Sequenzia 2017).

females tend to have very subtle repetitive stereotypical behaviours, which are often hidden (self-consciousness) thus rendering these much more challenging for clinicians to spot when seeking to make a diagnosis of 'autistic' (Duvekot et al., 2017; Frazier & Hardan, 2017; Allely, 2019; Antezana et al., 2019). AWCTN+ people are less likely to be diagnosed and/or receive support services (Bargiela et al., 2016; Kanfischer et al., 2017). This is partly the results of assuming the 4:1 prevalence of autistic men to women is correct. This belief persists despite large population studies (using the ICD-10 diagnosis criteria) demonstrating lower ratios, which range between 2.5:1 (Kim et al., 2011) to 1.8:1 (Mattila et al., 2011; Baldwin & Costley, 2016).

Until recently, the 4:1 assumption has contributed to under-diagnosing and invisibility of AWCTN+ people (Pellicano et al., 2014; Milner et al., 2019). The hegemonic male-biased autistic criteria³ have resulted in many AWCTN+ people being diagnosed with dyslexia, dyspraxia, attention deficit hyperactivity disorder (ADHD), attention deficit disorder (ADD), social anxiety disorder, obsessive compulsive disorder (OCD), bipolar syndrome, and personality disorder. Many AWCTN+ people mask their experiences and, in general, their internal experiences are much more prevalent than their external behaviour. Autistic people are more likely to have a lifetime mood disorder such as anxiety, depression, and low self-esteem (Cooper, Smith & Russell, 2017). AWCTN+ people with these co-occurring life-time disorders are less likely diagnosed as autistic and more likely to be diagnosed as having a primary mental health condition (Lai & Baron-Cohen, 2015; Baldwin & Costley, 2016; Milton, 2014; Kirkovski, Enticott & Fitzgerald, 2013; Au-Yeung et al., 2019). Nat

³ When I refer to hegemonic autism, I am referring to the white, straight, cis-male stereotype of autism that is constructed through both biomedical discourse and popular representations.

Titman (2018), a neurodiversity activist and a co-host of the autistic Flappy Hour Podcast⁴, described this phenomenon at the 2018 Autscope Conference as ‘the elephant in the room’, suggesting that parents, teachers and clinicians find it more acceptable (easier) to diagnose and address these co-occurring conditions than to diagnose a child or young person as autistic, as it carries less stigma (Lever & Geurts, 2016; Lai, Kassee et al., 2019); the latter label being perceived as overly negative (Titman, 2018). Titman explains that parents and teachers are reluctant to label children as autistic, quoting a teacher who said, ‘Autism is controversial and upsetting, it’s not our place to suggest this to parents.’ (Titman, 2018, p.6). Many AWCTN+ people learn to mask their behaviour, which requires significant cognitive effort and makes them more prone to mental health issues (Lai et al., 2015).

Relating the autistic diagnosis to gender has subsequently led to clinicians and teachers referring fewer females for diagnosis (Russell et al., 2010). In the recent past, women were much less likely to be referred and receive a diagnosis unless they had the more rigid (male) indicators or they had severe concomitant cognitively and/or challenging behaviours (Dworzynski et al., 2012; Bargiela et al., 2016; Russell et al., 2010).

Skewed female-male data

When I first started my research for my PhD proposal in 2015 there was not much attention given to autistic women and girls. I originally felt that I would focus my

⁴ Nat Titman is a neurodiversity activist and co-host of the autistic flappy hour podcast (<https://flappyhourcast.wordpress.com>) and creator of the Practical Androgyny blog. Website (<https://quarriors.com/>).

research on females but in doing so my eyes were opened to the ‘gender fluidity’ of autistic people and how many identified as non-binary, trans- or other. I was influenced by articles such as: *The Ghost of Gender* by Davidson and Tamas (2016) and *Quirky Citizens: Autism, Gender, and Reimagining Disability* by Bumiller (2008) as well as my experience of talking to other AWCTN+ people at the weekly University of Kent’s Autistic Support group.⁵

This encouraged me to change the title and focus of my PhD to include non-binary, trans-- and other people. It was important to me not to exclude another group of people given my experience in the clinical and autistic community as a late diagnosed (discovered)⁶ autistic person. Early on in my PaR process, I wrote and produced a performance piece that revolved around a letter to one of the most popular and leading autism researchers, Simon Baron-Cohen, who coined the notion of the ‘extreme male brain’ as predictive of an autistic diagnosis. I used this letter in a number of performances between 2017 and 2019 (see appendix 1).⁷ Baron-Cohen (2003), an English clinical psychologist, and autism professor and researcher at Cambridge, argued in his book, *The Essential Difference: Men, Women and the*

⁵ The group I attended was originally called ‘the women’s Autism support group’ but the title was changed to the ‘Tuesday Group’ as there were several people in the meeting that were non-binary and trans-, and the facilitators did not want them to feel excluded. The group was initially set up as an alternative to the more male dominated ‘Wednesday group’ that was held at the student pub. The ‘Wednesday group’ was a much louder environment with many of the male participants dominating the conversation. Our gathering originally excluded males unless there was a consensus to accept an individual, but the facilitators soon decided that everyone was welcome to either group to make both fully inclusive. Until the 2018-19 academic year there was one male non-binary individual in attendance but no cis males. This changed when Chloe Farahar and I took over the meetings and changed the name to UoKA ‘University of Kent Autistics’ Group. We called it an ‘informal autistic meet up group’. We felt it was important to use the term ‘autistic’s meet up group’ instead of ‘autism support group’. We wanted to give agency to the attendees and move away from the negative stereotypes of the ‘pathological paradigm’ label where autistic people tended to feel they needed a support group as there was, ‘something inherently wrong with them’.

⁶ I will use the term ‘discovered’ instead of the term ‘diagnosed’ as I feel that infers that there is something wrong with me as an autistic person and feeds into the pathological paradigm. The only way to shift a paradigm is to invent new language to replace the medicalised terms. Walker (2013)

⁷ Please go to Appendix 1 to see a copy of the letter, pictures of the letter being performed and/or see a video of the performance reciting the letter is found at: <https://youtu.be/koWlx7qcVRw?t=532>.

Extreme Male Brain (2003) that autistic people could be described as having an 'extreme male brain' and that they are better at 'systematizing' than they are at 'empathising'. Baron-Cohen's theories have had a major impact on the way autism has been and is perceived. Baron-Cohen gives credit to Hans Asperger (1944) for the first theory of 'extreme male pattern of intelligence'. He quotes Asperger, "The autistic personality is an extreme variant of male intelligence. Even within the normal variation, we find typical sex differences in intelligence... In the autistic individual, the male pattern is exaggerated to the extreme" (Uta Frith's translation Baron-Cohen, 2003 : 2) This has been challenged for the last ten years by scientists and scholars (Bumiller, 2008; Fine, 2010; Jack, 2011; Jack, 2012; Ridley, 2019; Saini, 2017).

The letter starts,

Dear Simon Baron-Cohen,

I am a 46-year-old woman and I am autistic. I was diagnosed at the age of 39; after years of feeling confused, frustrated and alienated, because I was aware of my difference, but I didn't know how I was different. After years of misdiagnosis and a lifetime struggle with mental health issues, I finally had an answer, I am different, and I know why, I am autistic!

Your theories have affected the way autism has been perceived making it seem as if all autistic people are basically male or male brained. (Adventures of Super Autie Girl, 2019)⁸

⁸ Please read the letter in its entirety in Appendix 1



Figure 1 Film still of reciting letter to Simon Baron-Cohen as part of *Adventures of Super Aspie Girl* (2017) Canterbury

I recited the letter while carrying out an advanced cycle of Sun Salutation and other yoga poses (Figure 1). I used yoga as an autistic hack to regulate my sensory overwhelm and mental health as a newly diagnosed autistic person. The yoga position of 'downward dog' that moved into a 'backbend' required physical skill, strength, stamina and agility, which created strong physical sensations in my body. These positions became a metaphor to show that the stress and strain required in the practice of yoga was similar to the effort I expended to mask my autisticness⁹ -

⁹ What I mean by my 'autisticness' is my true autistic nature, that for most of my life I tried to hide due to ridicule and bullying. As autistic people like me perceive the world differently, we will talk, walk, think, speak, behave in non-normative ways. This has been pointed out to me my entire life. An example of this is my autistic gait; I have a heavy step as I heel walk and I lean forward. I am also very clumsy when I walk as I have to be aware of obstacles (like the pattern in the carpet) and sometimes have to will my feet to take a step. Another obvious example is stimming. I have always stimmed, I didn't know what it was as a child, but it was instinctive - something that calmed me, rocking was one of my favourites. When I grew older and it became apparent that this was weird and I was teased for it, I then turned to smaller, less observable stims like writing words that I saw around me on my hand. Interestingly, I started doing this after watching a film about Helen Keller, *The Miracle Worker* (Aaron 1979) and how she communicated via writing on her teacher's hand. Even then I

neither could be continued without eventually failing. I read the letter out as part of *Adventures of Super Autie Gang* (ASAG; Figure 2) in a further attempt to not mask my autisticness and learning differences. I sarcastically referred to Simon Baron-Cohen as a ‘very important autism researcher and professor who allegedly knows everything about autism’.



Figure 2 Film still of reading letter to Simon Baron Cohen, a part of *Adventures of Super Autie Gang* (2019) Canterbury

My letter was inspired by autistic academics (Milton, Arnold, Yergeau, 2013), and many neurotypical scientists and academics (Bumiller, 2008; Fine, 2010; Jack, 2011; Jack, 2012; Ridley, 2019; Saini, 2017) that questioned his theories.

Such as Bumiller’s (2018) who observed:

“From a feminist perspective, the essentialist version of autism is a disturbing

identified with a representation of a disabled person communicating differently not knowing that I was autistic myself. In the case of *The Adventures of Super Aspie/Autie Grrl* (2017), in the past I masked my memory problems especially with text when performing, usually by performing silently or only with improvised text.

reconstruction of gender and disability stereotypes in the guise of new scientific knowledge. Baron-Cohen's explanation... essentializ[es] gender differences (by rooting the condition in biological maleness). ...” (Bumiller, 2008, 973).¹⁰

I was determined to create something as an artist that helped the neurodiversity movement by positioning myself against these ideas that reinforced stereotypes about autistic people.

Baron-Cohen argues that men's brains are better at systemizing and women's brains are better at empathising. 'Systemizing' is about analysing details in a system to figure out how the whole of the system works. He states that women are more likely to be better at empathising which, "...allows you to predict a person's behaviour, and to care about how others feel" (Baron-Cohen, 2002).

Baron-Cohen (2002) theorises that neurotypical men are inherently better at systemizing than neurotypical females. Baron-Cohen (2002) also claims that all autistic people have 'extreme male brains' therefore postulating that they all have these male characteristics. Baron-Cohen (2002) further suggests this male bias is caused by exposure to higher levels of testosterone in the womb. It appears Baron-Cohen (2002) considered something very complicated; human variations of gender in autistic people, as simply mono-binary (basically all autists have a male typical brain) (Davidson & Tamas, 2016). This inclusion of theories that propose

¹⁰ Please note that throughout this project, I have adopted and used the neurodiversity paradigm to guide my language. I therefore use the terms 'neurodivergent' and 'autistic' somewhat interchangeably, however 'neurodivergent' describes all sorts of people who have a type of brain that is different from what may be considered the norm.

neurotypical men and women have different brains, and autistic people just have an unbalanced 'male brain,' essentialises gender and is an attempt to normalise disability (Bumiller, 2008).

Seemingly Baron-Cohen has finally begun to develop his thinking on this issue, writing an editorial with Lai et al. in 2015 stating, "Females with autism may have been under identified and therefore underrepresented in the past, and consequently, the previous scientific and clinical literature likely may have provided a male biased understanding of autism, however, a relative male-predominance remains a stable observation over time..." (Lai et al., 2015, p.1). Baron-Cohen remains wedded to the notion of male-brain predominance and sex/gender differences remain a key factor in trying to understand 'atypical conditions' such as autism.

Rosalind Ridley¹¹ (2019) argues that 'the extreme male brain' concept originated from behavioural rather than anatomical evidence and relied upon the Autistic Spectrum Questionnaire (AQ) that Baron Cohen himself developed. Ridley notes that if Baron-Cohen's concept is used to explain the behaviour of autistic people, "then evidence must come from a non-behavioural (e.g., physiological, biochemical or anatomical) source to avoid circularity of argument". The lack of a cognitive intervening variable linking autistic behavioural traits to brain activity casts doubt on the existence of a uni-dimensional spectrum of 'brain gender' for which autism is to be found at the *extreme male* end. Using gender stereotypes does not acknowledge the entangled multiplicity of male and female, *cognitive styles* (Ridley, 2019). Baron-

¹¹ A British psychologist and researcher who was head of the Medical Research Council Comparative Cognition Research Team in the Department of Psychology, Cambridge, UK.

Cohen's concept has led to the popular notion that all autistic people have an *extreme male brain* (Baron-Cohen, 2002). More recent literature maintains that Baron-Cohen's concept must include other phenotypes and/or amend diagnostic criteria to reflect the prevalence of non-male autistic people (Baldwin & Costley, 2016; Bargiela, Steward & Mandy, 2016; Gould, 2017).

Jennifer Connellan (2000), a student of Baron-Cohen, published results from an experimental study that reported sex differences in the behaviour of 1 day old babies. The notion was that these babies were observed before their 'nurture' would affect their preferences; to see if the babies were more interested in a human face (human interaction) or a moving mobile of a scrambled human face matched for skin colour, size, shape, symmetry, and dimensionality. They found that the male babies tended to prefer the mobile, and the female babies had no preference or preferred the real face. The results of their study had a huge impact on the scientific community with their findings being cited over 600 times to date. There has been criticism of this study, with one paper alleging issues related to; study validity, lack of control, experimenter bias, definition of the dependent variable and errors in statistical analysis and interpretation (Nash & Grossi 2007).

Baron-Cohen has made a name for himself and published his controversial book about sex differences in males and females, *The Essential Difference* (2004), and his theory that autistic people have 'extreme male brains' to substantiate why there were more autistic boys than girls. However, as Nash and Grossi (2007) state, "[d]espite the lack of rigor in research on biological sex differences in scientific abilities, the studies are published in prestigious journals and receive much attention

in the popular media. The widespread acceptance of their conclusions may be more a reflection of biases and beliefs than of scientifically-based evidence.” (Nash & Grossi, 2007:17).

This is supported by a whole new *sub-discipline* of research exposing the imbalance of diagnosis and support for non-male autistic people, and the impact on their lives (Lai, Baron-Cohen & Buxbaum, 2015). There is also an entire issue of the *Autism* journal devoted to this topic (Mandy & Lai, 2017).

Gender Bias

Bargiela, Steward and Mandy (2016) conducted a study through interview with fourteen autistic women who were diagnosed later in life to generate more in-depth information about the experiences of autistic women. They were interested in looking at how these women went under the radar with various clinicians and professionals until later in life due to the *camouflage effect* and the misconceptions about ASC (autistic) gender bias that exist in the current clinical climate. “This gender bias has serious consequences for the health and wellbeing of girls and women with ASC, and has been identified by the autism community as a key problem to be addressed by research” (Pellicano, Dinsmore & Charman, 2014). They discovered that early diagnosis with support and understanding can greatly improve the lives of autistic women. More research needs to be conducted to develop a diagnostic criterion that includes the female phenotype and the camouflaging effect, and training be provided for teachers/clinicians to recognise and support the female phenotype ASC. (Hurlbutt & Chalmers, 2002; Portway & Johnson, 2005; Russell et al., 2012; Wong et al., 2015; Calzada, Pistrang & Mandy, 2012) “*The timely identification of ASC can*

mitigate some of these risks and improve quality of life, for example by identifying needs and appropriate interventions, increasing access to services, making others less judgemental of the people with ASC and their parents, reduce self-criticism, and helping to foster a positive sense of identity.” (Bargiela, Steward & Mandy, 2016, p.3281).

In 2016 when I commenced this thesis, I was struck by the fact that much of the research in this area was gendered traditionally male. I was concerned that people who often do not fit into the common autism stereotypes were being missed. I suggest that autism is not gendered but is a human condition. The experience of AWCTN+ people has also been overlooked, perhaps in part by their unique masking behaviours and/or the lack of research in relation to AWCTN+ people, and my project aims to make these overlooked people visible.

The role of phenotypes in autistic diagnosis

Subtle altered autistic phenotype theory and camouflage effect (masking)

Baldwin and Costly suggests that there is a subtly “altered ASD [referred to as Autistic Spectrum Condition (ASC)] phenotype in females.” (Baldwin & Costley, 2016, p.483) based on literature reviews of high functioning (varied functioning) autistic women. These women have more interest in socialisation, do not display obvious stereotypical repetitive behaviour and have ‘special interests’ that are more ‘acceptable’ to society. However, these women do have more instances of diagnosed mental health issues. It is thought that these women successfully hide

their symptoms (pretend to be neurotypical), giving rise to ‘camouflage’ or ‘masking’ hypothesis (Tierney, Burns & Kilbey, 2016; Hull et al., 2017a; Hull et al., 2020; Allely, 2019; Mandy, 2019; Cage & Troxell-Whitman, 2019; Jorgenson et al., 2020; Hull, Petrides & Mandy, 2020).

Gould and Ashton-Smith (2011) found women are better able to ‘pass’ as neurotypical by disguise and by developing coping strategies. However, found this produces detrimental effects on their level of daily worry, stress, and ultimately mental health (Baldwin & Costley, 2016). Essentially, many varied functioning autistic women appear neurotypical and thus overlooked and/or diagnosed late in life. Indeed, once diagnosed, these atypical autistic *symptoms* are often downplayed.

Interestingly, a 2020 narrative review looked at various themes related to a female phenotype including; gender differences in diagnosis, the female protective effect, social relationships, relational interests, internalising problems, and camouflaging (Hull et al., 2020). Whilst they conclude that there is evidence to support a female autism phenotype, they state “most research into gender and camouflaging have used a binary approach to gender, comparing the experiences and behaviours of male and females, which leaves out autistic non-binary, gender fluid, and trans-individuals, who may have different experiences with their gender expressions throughout a lifetime” (Hull et al., 2020).

Baldwin and Costley (2016) tried to compare male counterparts as part of the same study where possible but found no distinct gender disparities came out of the study. The notion of female autism has only been discussed relatively recently (Bargiela,

Steward & Mandy, 2016; Lai et al., 2011; Hull, Petrides & Mandy, 2020). This recent work replaced the 'extreme female brain theory'¹² (Goldenfeld, Baron-Cohen & Wheelwright, 2005; Brosnan et al., 2010; Dinsdale et al., 2016).

Autistic People and Gender Identities

There has been little research looking at gender identity and the experiences of LGBTQ+ autistic people (Hillier et al., 2019). There have been several studies looking at gender variation within the autistic population from the medical model, usually referring to Gender Dysphoria instead of gender variances (Heylens *et al.* 2018). To receive help and services from the gender clinic, any trans individuals who would like to transition have to have a diagnosis of gender dysphoria, whether they believe in the term or not (Schulz, 2018). Pasterski et al (2014) used the Autism Spectrum Quotient (AQ) with 91 adults who had been diagnosed with Gender Dysphoria who were receiving care from a gender clinic. Pasterski et al (Pasterski, Gilligan & Curtis, 2014) found that 5.5% of the participants had characteristics consistent with an Autistic Spectrum diagnosis (Fombonne, 2005; Blumberg et al., 2013) which is significantly higher than the 0.6 - 2.0% in the general population

¹² The 'extreme female brain theory' was first mentioned by Baron-Cohen in his opinion article, The extreme Male Brain theory (Baron-Cohen, 2002) He describes it as people who are very skilled at empathising or reading other people's feelings and that their systemising would be compromised. He went on to say that, "these would be people who have difficulty understanding maths, physics, machines or chemistry as systems." (Baron-Cohen 2002, p.253) This idea was then taken up and tested further in relation to the connection of the extreme female brain (EFB), and psychosis (Brosnan et al., 2010), psychopathology and Borderline Personality Disorder (Dinsdale et al., 2016) This has not been looked into further since 2016. The extreme male and female brain theory in relation to autism has been highly criticised for many reasons including gendering disability (Fine, 2010; Jack, 2011; Yergeau, 2013; Yergeau, 2018; Ridley, 2019), and this binary opposition could be said to contributed to further misunderstanding and misdiagnosis of autistic people.

(Pasterski et al., 2014). This 5.5 % was also supported by a study by Heylens et al (2018).

One of the few articles looking at the intersectionality around disability status and gender identity is by Hillier et al (2019). Hillier et al (2019) conducted a focus group with autistic people who had 'various gender identities'. They state preliminary findings have suggested that autistic people may be more likely to be part of the LGBTQIA+ community and/or "experience more fluid gender identity". (Hillier et al., 2019, p.98)

Research suggests autistic people are known to be more 'gender fluid' than the neurotypical population (Bumiller, 2008; Davidson & Tamas, 2016; Hillier et al., 2019). Davidson and Tamas (2016) looked at the autistic perspective of the social construction of gender by looking into online surveys, blogs and published autobiographies to look at discussions of autistic people's own experiences with gender. Perhaps because autists perception of the world is divergent, autistic people see the world differently. In doing so, many autistic people 'discover' that gender is a 'performance' (Butler, 2006). Davidson and Tamas suggest many autistic people chose not to take part in the performance of gender, partly because it can be psychologically and physically uncomfortable and exhausting. They argue that many autistic people see gender as a social construct, a ghost, something that does not fit everyone, yet still appears to control much of what people do and say. Many autistic people do not understand why this construct should rule their lives; they decide *not to do gender*. Davidson and Tamas (2016) analysed blogs and published autobiographies one of which stated, "I'm not necessarily confused about my gender.

I just think that I lack one.” (Davidson & Tamas, 2016, p.59) “Rather than ‘fitting in’, many want space to do gender differently and to queer understandings of autism (and identity) more broadly” (Davidson & Tamas, 2016, p.63). Mounting evidence shows that autistic people are more likely to identify as gender fluid (Goldman, 2013; Jack, 2011; Odom, 2016; Strang et al., 2014; Walsh et al., 2018). From my own experience with the University of Kent Tuesday Group (See footnote 4 page 4) participants, many identify as non-binary and trans-gender (see appendix 2). I would argue that there should not be a female phenotype of autism but we need to de-gender autistic diagnosis so that all autistic people are included. Perhaps this would more accurately represent the diversity of autistic experience instead of past autism research which has been from a perspective of an outsider looking in (neurotypical researchers looking at autistic subjects). Past autism research has had an emphasis based on observable behaviour not the autistic persons experience, whether it be internal or external, and the reasons behind that behaviour. In my experience as part of the autistic community and in the last five years of working with autistic people, it is not the case that all female autistic people display ‘symptoms’ as autistic in line with the female phenotype and sometimes they present closer to the classic ‘male’ or hegemonic autism. I have also met many autistic men (-cis and -trans) who present closer to female phenotype of autism. This does not even talk about the experiences of nonbinary and trans people within this binary phenotype model. The autistic community has already started to talk about variability in autistic presentation and experience without resorting to subtypes, referring instead to ‘internal and/or external autistic phenotypes’ (inshiftingcolour, 2017). As the autistic self-advocate inshiftingcolour states,

“Therein lies the danger. By qualifying a set of symptoms as either ‘male’ or ‘female’, we encourage diagnosticians to disregard a potential diagnoses because it does not fit the assigned sex of a person. Those who research their particular presentation before seeing a therapist may feel there is something extra ‘broken’ about their brain if the ‘gender’ of their symptoms does not match their own gender expression.” (inshiftingcolour, 2017)

We hope the de-gendering autism conceptualization represents the reality of autistic development and growth across time. Autistic children become adults - development is not frozen in time - one third of the cases of an autistic persons being diagnosed with a subtype as a child is not representative in later adulthood (Wodka, Mathy & Kalb, 2013). Perhaps we need non-gendered autistic phenotypes that diagnose based on observability or unobservability of an autistic person. For example, an observable phenotype could be an autistic person that presents in a more external way in reference to the more classic hegemonic¹³ autistic presentation. This would look like externally expressed behaviours such as rocking, being non- or minimally-verbal, “tantrums”, challenging behavior, etc. Where an unobservable autistic person could be an autistic person that masks their experience or presents in a more internal way (closer to the female phenotype model just not gendered). Importantly, internal and external is not a dichotomy, but a spectrum, matching the concept of the spikey autistic profile that is individual to each autistic – and of note, an individual’s internal-external phenotype can fluctuate in the course of an autistic person’s lifetime, as dependent on development, experience, psychological wellbeing and so

¹³ In relation to the hegemonic definition of autism and its binary opposition that has appeared to counter it, the ‘female phenotype’ both often look for answers within the brain. I would suggest that a full understanding of the underdiagnosis of female, trans and non-binary autistics requires looking at social and political structures as well.

on. For example, whether an autistic person has a positive autistic identity later in life after discovering they are autistic and finding the autistic community, where they might choose not to mask their authentic autistic identity and stim more for instance. Farahar and I try to explain the complexity of autistic experience and develop a new way to describe this in our new model of autistic experience (Farahar & Foster, 2019).

A new model of autistic experience

Chloe Farahar and I presented our model of 're-conceptualized autistic experience', to challenge "the erroneous use of biological sex as a method to differentiate autistics" (Farahar & Foster, 2019). We propose an *autistic observable and unobservable experiences* to represent a 3-dimensional Internal-External-Autistic-Space¹⁴. Farahar and I would like to propose that we talk about another non-binary 3-dimensional autistic space/model that encompasses all the factors into autistic experience that can affect an autistic person's wellbeing which can then, in turn, affect whether they present as more internal experienced (camouflaged, masked autistic) or external experienced (more classic hegemonic autistic) at any given point in their life. There are no value judgements on these terms: External/Internal - one is not better than the other. No one is 100% external or internal. All autistic people are both, and as autistic profiles vary due to many factors, and these so-called spikey profiles can change over a lifetime, a day, an hour.

¹⁴ I use the word 'space' here to represent a three-dimensional model to replace the more linear 'autistic spectrum' model. Please see Appendix 2 for a poster presentation of 3-dimensional Internal-External-Autistic- Space.

How observably autistic someone is depends on autistic people's experience of the world and is effected by many factors throughout their life including context, environment, family, physical and mental wellbeing, culture/society/race, adequate and inadequate support, gender, social economic status, co-occurring conditions or experiences. These factors continually affect the way an autistic person presents themselves in the world: these factors impact that person on an hourly, daily, yearly or lifetime scale. Our model incorporates the complex reality of autistic development growth and manifestation across time. This reconceptualization of the autistic spectrum considers contextual and situational factors (among others) which *power* autistic growth and change across a lifespan. Farahar and I propose that this is a better way to describe how individual autistic people experience the world. It challenges the notion that autistic people can be explained by biological binaries such as female vs. male autistic brains.

Autistic Voice

It could be said that due to underdiagnosis, many autistic people are invisible, not only to the general public but to the medical profession and even the existing autistic communities themselves (Hull, Petrides & Mandy, 2020). Many AWCTN+ people are diagnosed or discovered later in their lives, and thus have often been unaware that they are autistic for decades. It may said that there are many other nations such as African and Asian countries that many undiagnosed autistic people are not recognised as autistic and do not receive support from medical and educational institutions (Hossain et al., 2017; Mpaka et al., 2016). Traditional autistic research has been focused on diagnosis and treatment; underpinned by a biomedical (also referred to as the pathological or disease) model of healthcare. Recently, the

usefulness of defining people 'with autism' and people 'with disabilities' in general using this paradigm is being challenged (Woods et al., 2018; Milton, Mills & Pellicano, 2014; McWade, Milton & Beresford 2015; Milton, book review Milton & author of book Dez Fitzgerald, 2017; Walker, 2012; Walker, 2016; Woods, 2017a; Friedner & Block, 2017; Runswick-Cole, Mallett & Timimi, 2016; Brownlow, 2010).

Some of these challenges can be seen in the exponential growth of 'Autie-biographies' by autistic people who have been using social media to write and disseminate their own lived experiences of being autistic. This movement started in the mid-eighties by prolific authors such as Temple Grandin, *Emergence: Labelled autistic* - (Grandin and Scariano, 1986); *Thinking in Pictures* - (Grandin, 1996) and Donna Williams, *Nobody Nowhere* - (Williams, 2002). There was a subsequent eruption of books and artwork by autistic people who used these media to articulate their lived experiences and acted to confront and oppose the biomedical paradigm and medical discourse. Yergeau (2013) argues that autistic voices have repeatedly been silenced by 'neurotypical academics' who claimed that autistic people lacked theory of mind, which "significantly limit the autistic subject's awareness of self" (Yergeau, 2013, p.18).

Adopting the notion that autistic people have limited self-awareness arguably has enabled some academics to question, discount and dismiss the lived experiences of autistic people. This dismissal has strengthened the prevailing biomedical view of autistic behaviour and simultaneously disenfranchised, invalidated, and rendered the

experiences of autistic people invisible¹⁵. The term Autism with a capital 'A' means many things to many people that differs from the actual experience of being autistic. Ultimately, I think it more important to talk about autistic sociality and autistic communication than to presume what is going on in autistic minds.¹⁶

Research by Cooper et al. (2017) found that compared to the over-all populace, autistic people have lower self-esteem, autistic identity is important to “personal self-esteem and collective self-esteem” (Cooper et al., 2017:852) and that “...having a positive Autism social identity appeared to offer a protective mechanism”. This implies that to improve mental health in the Autism population, clinical approaches should aim to facilitate development of positive Autism identities (Cooper et al., 2017:844).

¹⁵ For more information please see: Yergeau (2013) *Clinically Significant Disturbances: On Theorist Who Theorize Theory of Mind*. 'As I have noted, Uta Frith and Franscesca Happé are among the theorists who proclaim that autistic people have an impaired capacity for self-awareness. Frith and Happé (1999) take up autie-biography as a case study of sorts, examining narratives by well-known autists such as Temple Grandin and Donna Williams. What represents a mainstay and empowering genre within the autistic (non)community, however, represents for Frith and Happé evidence of autistic lack. Frith and Happé contend that autistic theory of mind (ToM) deficits not only result in an impaired comprehension of others' mental states—but also significantly limit the autistic subject's awareness of self. Of autie-biographies, they argue, “While the accounts are intriguing, it might be a mistake to take what is said at face value” (18). ' <https://dsq-sds.org/article/view/3876/3405>

¹⁶ The philosopher Gilbert Ryle (1949) in his book *The Concept of the Mind* (1949) critiqued of the concept of mind which basically proposes to describe the mind and body as separate entities, something he referred to as, “the Ghost in the Machine”. He felt that there was a dilemma with discourse about 'mind' as a noun, which is formed on the assumption that what is being discussed is actually a 'thing' that can be situated. This creates all sorts of perplexing queries about (e.g.) in what way 'the mind' relates, interrelates with the body. He says that due to all these unknowns about how the mind and body interact it would be better to refer to 'the mind' not as a noun but 'adverbially' (Ryle, 1949) to refer to varieties of representation of human behaviour. For example, “she does that 'considerately,' 'graciously' and 'cleverly'”. Ryle (1949) considers the benefit of this methodology is that we can discuss conditions in the physical world. One can discuss how she walks 'elegantly' more clearly than one can talk about what was going on in her mind while she was dancing. Ultimately, anyone witnessing can only see her dancing and not what her 'mind' is doing. Comparably, I purpose that it is more helpful to talk about different ways of; autistic socialising, and autistic communication instead of talking about 'autism' or the 'autistic mind.'

This research underlines the importance of listening to autistic voices and recognising the need to validate autistic culture/pride to better the lives of autistic people. This is something the autistic community, autistic self-advocates, and scholars have been saying for years, and so where possible I will include autistic writers and thinkers within this thesis.¹⁷

The Pathological 'Autism'

The official definition of 'autism' within the scientific, psychological, and healthcare provider communities is defined by two major texts: the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) released by the American Psychiatric Association in 2015 and in the UK and Europe the eleventh edition of the International Classification of Diseases (ICD-11) published by the World Health Organisation in 2018. Both texts categorise autism within mental and behavioural conditions and are used diagnostically amongst many other mental and behavioural conditions. The most recent definition comes from the ICD-11 (World Health Organisation, 2018) and it refers to autism as a neurodevelopmental disorder indicating six levels of Autistic Spectrum Condition including 6A02.0 to 6A02.5.

¹⁷ I suggest that there is an asymmetry between academics and self-advocates in that the ideas and views of autistics is only viewed as constituting 'knowledge' once it has been rearticulated by neurotypical scholars. This has been reflected in the current work on autism and gender (Kristensen & Broome, 2015) and on masking which that academic world refers to as camouflaging (Hull et al., 2019). It is also interesting that articles on camouflaging (the autistic community refers to camouflaging as masking as they don't see themselves as guerrilla warriors hiding but as humans masking their true autistic identities) have only been looked at until recently on social aspect, however autistic people have been talking about different aspects of masking including masking your sensory perception of the world. An article by Pearson and Rose (2020) was written with an autistic self-advocate and author on the reasons behind masking and the illusion that many autistic people have a choice whether to mask or not (Pearson & Rose 2020).

These levels almost exclusively refer to language ability but also denote intellectual ability and adaptable behaviour. The ICD-11's (2018) general definition is:

'Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.' (World Health Organisation, 2018, p.6A02).

When viewed from an autistic self-advocate's perspective, the use of words from the pathological paradigm such as "persistent deficits", "disorder", "impairment", and "restricted, repetitive, and inflexible behaviour" create a negative picture of autistic people and causes clinicians, parents, and autistic individuals to have "uncertainty, deflated, and low expectations" of their lives and experiences (Fitzgerald, 2014).

The DSM-5 (2013) definition of autism is similar but more specific as they list the deficits as a dyad of, "A. *Persistent deficits in social communication and social*

interaction across multiple contexts” and “*B. Restricted, repetitive patterns of behaviour, interests, or activities*” (DSM-5 American Psychiatric Association, 2013 p.50). This includes hypo- and hyper-sensitivity to the sensory world, which I consider a positive inclusion as it hints to the experience of autistic people not just the behaviours that are a reaction to sensory input in the first place. The DSM-5 (2013) states:

“4. Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)” (DSM-5 American Psychiatric Association, 2013 p. 50).

However this is included in the diagnostic criteria under; Section B. Restricted, Repetitive Patterns of Behaviour, Interests, or Activities which is based solely on observable behaviour.¹⁸ Many AWCTN+ people experience sensory sensitivity but will not have observable behaviours due to masking (Pearson & Rose, 2020). I would propose that different sensory experiences are the more likely cause of repetitive and restrictive patterns of behaviour and are not always observable. McDonnell and Milton (2014) suggests that autistic ‘repetitive and ritualistic behaviours’ may have been misunderstood by the research community. They reason some of the repetitive and ritualistic behaviours that have been seen in the past as negative activities may help to achieve a ‘flow state’, explained by Csikszentmihalyi

¹⁸ I suggest a peculiar facet of this is that it claims to be scientific and objective observation, but which interests gets pathologised is socially contingent. Imagine two young girls have interests of similar intensity, but one has an extensive knowledge of ballet terminology and the other has extensive knowledge about species of frogs. It is likely only one is going to be identified for assessment based on their interests.

(1990) as when an individual is deeply absorbed in a task where nothing else appears to matter, and may give autistic people a feeling of accomplishment and have a “positive outcome on a person’s physical and psychological state” (McDonnell & Milton, 2014, p.1). This could suggest that some of the repetitive and restricted behaviours associated with autistic people could be a positive coping mechanism for the overwhelm from sensory experience that many autistic people experience.

As an alternative to the DSM 5 and ICD 11 definitions, the autistic community has adopted the newer neurodiversity paradigm that sees difference instead of deficits. As Nick Walker, an autistic author, educator, speaker and transdisciplinary scholar, states,

“Autism is still widely regarded as a ‘disorder,’ but this view has been challenged in recent years by proponents of the neurodiversity model, which holds that autism and other neurocognitive variants are simply part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation (which have also been pathologized in the past).” (Walker, 2014 :1-2).

The Autistic Communities’ Definitions of Autism

I looked at several autistic websites to compile a summary of online definitions of ‘autism’ created by autistic people including The Autistic Self Advocacy Network (ASAN), autisticadvocacy.org, AutisticCollaboration at autcollab.org, and Neuroclastic: The Autistic Spectrum According to Autistic People Neuroclastic.com. I also looked at The National Autistic Society (NAS) definition of

autism and autistic experience - NAS is a large charity run by non-autistic people however they consult and work with autistic people. The following paragraphs are a summary of these websites' various definitions of autism and the experience of autistic people.

ASAN whose by-line states; "Nothing About us Without us" states their mission statement is to, "[seek] to advance the principles of the disability rights movement with regard to autism" (ASAN, 2020). ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights and opportunities (ASAN, 2020). ASAN is a non-profit organisation run for autistic people by autistic people that was founded in 2006 by Ari Ne'eman and Michael Robertson. ASAN's definition of being autistic has most accurately described my experience of being autistic and working with autistic people over the past 5 years (See Box 1).

Box 1- Definition of Autistic - Autistic Self Advocacy Network

There is no one way to be autistic. Some autistic people can speak, and some autistic people need to communicate in other ways. Some autistic people also have intellectual disabilities, and some autistic people do not. Some autistic people need a lot of help in their day-to-day lives, and some autistic people only need a little help. All of these people are autistic, because there is no right or wrong way to be autistic. All of us experience autism differently, but we all contribute to the world in meaningful ways. We all deserve understanding and acceptance. There are just as many varieties of autistic people as there are non-autistic people, all autistic people give value to the world and, 'deserve understanding and respect'.

(ASAN, 2020)

- "There is no one way to be autistic" (ASAN, 2020).
- Many autistic people can communicate with the spoken word and/or language. Other autistic people do not use mouth words and communicate by

other means such as; Augmentative and Assistive Communication (AAC) Devices and sign language.

- Some autists additionally have intellectual disabilities, and many autistic people have other co-occurring conditions but not have intellectual disabilities.
- Many autistic people may need significant help with day-to-day life. Other autists will need minimal assistance (ASAN, 2020).

But all autistic people share some similarities. These similarities include:

- differences in experience of the sensory world,
- differences in communication,
- differences in thinking, socialising, and moving.
- Some autistic people need higher levels of support on a daily basis, and other autistic people live independently, sustain employment but still have areas they need support in.
- Some autistic people need support with day-to-day living. Not all autistic people will relate to all these areas (ASAN, 2020).

I have also taken from the website Neuroclastic: The Autistic spectrum According to autistic people, a blog by Lynch (2019) titled, '*Autism is a Spectrum*' doesn't mean *what you think*. This article sets out seven main descriptors to define autism stating that you cannot be autistic unless you identify with all or most of the descriptors. The descriptors are: pragmatic language; social awareness; monotropic mind-set; information processing; sensory processing; repetitive behaviours; and neuro-motor differences (Lynch, 2019).

The Autistic Collaborative website, whose by-line reads “Creating neurodiventures and equipping autistic people for collaboration for life” (AutisticCollaboration, 2020), has created a communal definition of autism where autistic browsers are encouraged to send in suggestions, comments and explicit recommendations checking it against their own lived experience of being autistic. They point out that the experience of being autistic includes a certain set of *social objects* such as:

- Language(s), which include ‘idiosyncratic forms of communication’
- ‘Written rules of interaction’
- ‘Tools of all kinds’ especially tools related to that person’s passions
- Extensive knowledge related to these tools
- Many of these ‘cultural artefacts’ reject an understanding or value or disregard for rules around ‘abstract cultural status symbols’ (AutisticCollaboration, 2020)

Autistic people have always been a part of humankind. Autistic people are born autistic and will be our entire lives. Many autistic people are diagnosed as children and others seek diagnosis later in life however you can also be autistic without an official diagnosis¹⁹. There are many stereotypes that are unhelpful for autistic people, this can make it difficult for mature autistics, autistic girls, women (cis-, trans-), non-binary people and autistic people of colour to be diagnosed. Irrespective of gender, age, race, sexual orientation, religion, nationality or socioeconomic background, anyone can be autistic (ASAN, 2020). Although autism is found in all populations, it is under diagnosed in many of the groups identified above. Maenner et al. (2020)

¹⁹ A significant feature of this relates to how the criteria has changed over time, which includes the development of Asperger’s and the conception of autism as a spectrum. Due to the widening of the criteria and therefore including more people within the criteria for autism.

found in a study of early detection of autistic spectrum condition among children aged 8 in the United States in 2016 that based on the statistics “...the overall median age at earliest known ASD diagnosis (51 months was similar by sex and racial and ethnic groups however white boys were more likely to be diagnosed” and that “these findings highlight the variability in the evaluation and detection of ASD across communities and between sociodemographic groups. Continued efforts are needed for early and equitable identification of ASD and timely enrolment in services” (Maenner et al., 2020, p.1).

The Project Aims

My aim was to use performance and live art to explore AWCTN+ autistic people’s lived experiences and describe and articulate these in order to challenge and transition beyond the labels and definitions enshrined within the biomedical paradigm. I am aimed to use creative research methods to identify key features within this under-represented and under researched population of AWCTN+ people.

My project was underpinned by three precepts:

1. I used ‘autie-ethnography’²⁰; a portmanteau of autistic ethnography, which is defined as ethnography of autistic people by an autistic person.

²⁰ I will use Autieethnography to supplement this research. Autistic ethnography coined by Irene Rose in 2005 referred to as autieethnography in the autistic academic M. Remi Yergeau’s (2013) article, Clinical Significant Disturbance: On Theorists Who Theorize Theory of Mind and described by Robert Rourke (2016) in his blog. Autieethnography uses, ‘Poetry, disjointed narrative and other forms of expressive writing (which) may be more akin to autistic empirical experience... This threatens the sanctity of academic, non-disabled ways of writing, presenting a normative academic persona that privileges a neurotypical, or normal cognitive functioning’ (Rourke 2016).

2. Using PaR allowed me to draw upon my extensive background in performance, live visual art praxis, which will infuse the methodology of this project.
3. I also brought my own lived experience of being late-discovered autistic which includes my own autistic identity, community, and culture. This includes methods of Critical Autism Studies and Participatory Autism Research.

Author's autie-biography

I was and still am an artist first, before being discovered autistic. My work had been an eclectic mix of performance, live art, and visual art. It had always been autobiographical and informed by feminism, identity, gender, sexuality, and difference. In the last five years I have been working on a creative project as an autistic self-advocate and this has led to my undertaking a PhD at the University of Kent. My aim was to work creatively with late diagnosed and discovered AWCTN+ people to explore and discover their experiences and to create a community for autistic people. In doing so I aim to further develop my autistic identity and immerse myself within autistic culture.

I was quite isolated when I started my PhD and was just starting to reach out to the autistic community. I have learned so much throughout my PhD and I am still learning. I was not aiming for participants to experience autistic awareness²¹ but

²¹ Autistic Acceptance in Western culture is very aware of autism, the difficulty being that this awareness is built on a very narrow definition of what autistic people look like. Some of the main stereotypes were that autistic people were most likely male, a young white boy, rocking in the corner,

aspired to what has been referred to as 'Autistic Acceptance' (Robertson & Ne'eman, 2008). My workshops aimed to develop autistic pride and empowerment by expressing autistic difference that goes beyond the stereotypical representations of autism²². Through participatory visual and performance art I intended to articulate AWCTN+ people's experiences of being autistic. I developed a number of workshops that created space²³ for people to communicate their experiences of being autistic; to uncover those aspects not reflected in mainstream psychological discourses or popular media. Although I interchange the terms '*neurodivergent*' and '*autistic*' within this project, please note that neurodiversity²⁴ describes itself as a normal human neurological variation.

What is neurodiversity?

The definition of neurodiversity is quite simple, if you break the word down, neuro simply means related to the nervous system and ultimately the brain, diversity just means variety. Nick Walker (2014) states that "neurodiversity includes all humans and states that biologically there are a variety of brains, as many kinds of brains as

who likes trains, maths and computers. For more information please see an article by Penni Winters(2019) titled, *Autism Acceptance or Awareness* <https://www.altogetherautism.org.nz/autism-acceptance-or-autism-awareness/> and Ari D. Ne'eman and Scott Robertson (2008) *Autistic Acceptance, the College Campus, and Technology: Growth of Neurodiversity in Society and Academia* <https://dsg-sds.org/article/view/146/146>.

²² Some of the common stereotypes are that autistic people are savants, or eccentric geniuses, lack empathy and that autism traps a 'normal' child inside it, that autistic people are silent and due to an inability to communicate are isolated from the world. As Loftis (2015) states, "People on the spectrum are metaphorically represented as machines, aliens, or computers, and pop culture has perpetuated the erroneous stereotypes that all people with autism are savant" (Loftis, 2016, p.4). To see more about common stereotypes about autistic people please look at Draaisma (2009), Loftis (2015) and Murray (2008).

²³ It became apparent that this space needed to be an autistic Space where autistic people could uncover and be their authentic autistic selves.

²⁴ According to the National Symposium on Neurodiversity, Neurodiversity is "... a concept where neurological differences are to be recognized and respected as any other human" (Syracuse University, 2011)

there are human beings. Neurodiversity is a trait that is held by a group of people, the correct term for a person with unique neurocognitive functioning is neurodivergent” (Walker, 2012).

The neurodiversity paradigm claims all minds are equal: the so-called *normal* or so-called typical mind, is not superior to an atypical mind. The idea that some minds are normal and others are not is flawed and “is a culturally constructed fiction, no more valid (and no more conducive to a healthy society or to the overall well-being of humanity) than the idea that there is one ‘normal’ or ‘right’ ethnicity, gender, or culture” (Walker, 2012; Bascom, 2012b, p.236). Neurodiversity includes everyone and is a natural part of human variation. The neurodiversity movement is anyone that promotes the neurodiversity paradigm. This could include an activist, self-advocate, or advocates who promote the concept that no one neurological way of being is better than another (See box 2).

Box 2- Neurodiversity defence

To criticize neurodiversity for ‘highlighting differences’ is like criticizing feminism for being ‘sexist’ because it points out how women are oppressed. It’s important to understand the history of the development of the concept... The word neurodiversity was coined at a time when autism, ADHD, dyslexia, and other cognitive variations were ONLY defined as inferior and diseased.- Steve Silberman as cited by (Muzikar, 2018).

Neurodiversity began as part of the Autistic Rights Movement but, because of the nature of neurodiversity, it has become about representing all neurological

minorities, not just autistic people. Autistic Self Advocates such as Jim Sinclair (USA)²⁵, Larry Arnold (UK) and his founding of the academic journal *Autonomy* (2003, 2012) and Martijn Dekker (UK) (1999) articulated neurodiversity viewpoints without using the term, nevertheless Judy Singer (Aus) is the first person to use the word Neurodiversity in a printed piece of academic work in her chapter in *Disability Discourses* (1999). Judy Singer (1999) who identifies as ‘somewhere on the autistic spectrum’, (Singer, 2017, p.1) in a chapter titled, *Why can’t you be normal for once in your life? From a ‘problem’ with no ‘name’ to the emergence of a new category of difference* (1999). Her chapter states:

For me, the key significance of the ‘autistic spectrum’ lies in its call for and anticipation of a politics of neurological diversity, or ‘Neurodiversity’. The ‘neurologically different’ represent a new addition to the familiar political categories of class /gender / race and will augment the insights of the social model of disability. (Singer, 2017, p.1)²⁶

Fenton and Krahn (2007) wrote an article titled, *Autism, Neurodiversity and Equality Beyond the ‘Normal’* (2007) which credited Jim Sinclair’s ‘Don’t Mourn For us’ (1993)²⁷ speech, became the first piece of writing for the Neurodiversity movement

²⁵ Please refer to Sinclair’s (2005) article, *Autism network international: the development of a community and its culture* which recounts the recent history of the creation of *Autism Network International (ANI)*, which details Sinclair’s pioneer work for the autistic advocacy and the Neurodiversity Movement.

²⁶ This was first published in 1999; p.64, then republished in an ebook 2016: *NeuroDiversity: The Birth of an Idea*. Faculty of Humanities and Social Science, Sydney: University of Technology.

²⁷ This article is an outline of the speech Sinclair presented in Toronto at *The International Conference on Autism* in 1993 and was published in the Autism Network International newsletter, *Our Voice*, Volume 1, Number 3, 1993.

notwithstanding using the term (Bascom, 2012b). Kapp (2020) also recognises Sinclair as a pioneer of the Neurodiversity Movement, for his, "...pro-acceptance manifesto mainly intended for parents" (Kapp, 2020, p.12) mentioned above (as Sinclair addressed parents of autistic children who were usually non-autistic and they controlled the advocacy for autism in this period).

I refer to Nick Walker's comprehensive description of Neurodiversity as a word, identity (neurodivergent), movement and paradigm in his article, *Throwing Away the Master's Tools: Liberating Ourselves from the Pathological Paradigm* (2012; 2013) published in *Loud Hands: Autistic People Speaking* (2012) edited by Julia Bascom. Where they borrow heavily from intersectional feminist Audre Lorde (1979²⁸) and her articulation of the importance of creating new language to describe experiences of oppressed people. Lorde sees language as a tool, and that using the tools of the current paradigm will only help to propagate the ideas of that model. The Neurodiversity movement was created to challenge the pathological paradigm when it comes to the treatment, recognition and autonomy of autistic people by the medical profession and ultimately society's view of autistic people (Walker, 2012).

Ultimately this movement celebrates neurological variety, accepting all types of minds within the spectrum of neurodiversity (as stated by Daniel Obejas (Szabó, 2015) from the Autistic Self Advocacy Network (ASAN) in a YouTube video speaks at the USC institute for Genetic Medicine Art Gallery Autism Event May 17, 2015).

²⁸ This was delivered at the international feminist conference in 1979 by the poet Audre Lord titled 'The Master's Tools Will Never Dismantle the Master's House.'

Neurotypical or NT abbreviated is a name for individuals that “[have] a style of neurocognitive functioning that falls within the dominant societal standards of normal” (Walker, 2014a).

The term Neurodivergent coined by the American autistic activist Kassianne Asasumasu (2010) refers to people that neurologically diverge from the typical. This term should always be used as Asasumasu intended it as a ‘tool of inclusion’ and includes such as autistic people, people with attention differences (or ADD/ADHD) Dyslexics, Dyspraxics, people with learning disabilities, people with mental health issues, epileptic people, people with MS or Parkinsons or apraxia or cerebral palsy or dyspraxia brain trauma etc.

Many words have been created to help define what it is to be neurodivergent in relation to the neurodiversity paradigm. To not cause confusion the autistic community has started using the term non-autistic as someone can be neurodivergent and not autistic. The term ‘allistic’ is also used and was coined by Andrew Main (2002), which means someone who is not autistic. However, I still use the term Neurotypical to describe someone that is not neurodivergent as autistic people are included as a neurominority within the definition of neurodivergent.

Many people do not like the term ‘neurotypical’ as they feel the autistic community has turned it into a derogatory or negative word. I would argue that this is analogous to some people who object to the term ‘Cis-’ being added to their gender identity. Similar to the neurotypical, it was until recently relatively unmarked – usually with the

extra term only being added to the person who is in the statistical minority. As Walker (2012) states:

“The most insidious sort of social inequality, the most difficult sort of privilege to challenge, occurs when a dominant group is so deeply established as the ‘normal’ or ‘default’ group that it has no specific name, no label. The members of such a group are simply thought of as ‘normal people,’ ‘healthy people,’ or just ‘people’ – with the implication that those who aren’t members of that group represent deviations from that which is normal and natural, rather than equally natural and legitimate manifestations of human diversity...”

(Walker, 2012, p.232).

Walker also explains how important it was to develop the word neurotypical early on in the Neurodiversity movement. This word allows neurodivergent people to refer to people who are described as “members of the dominant neurological group *without implicitly reinforcing that group’s privileged position (and our own marginalization) by referring to them as ‘normal.’*” (Walker, 2012, p.232).

Neurodiversity and a social model of disability

Critical autism studies, the neurodiversity movement and autistic self-advocates are underpinned, and walking in the footsteps of, many movements like the Disability Rights Movement and disability studies (Woods, 2017b), and the Deaf Community and deaf studies (Friedner & Block, 2017) as well as the Queer and LGBTQIA+ studies activists that have come before us.

An early disability rights organisation, the Union of Physically Impaired Against Segregation (UPIAS), set up the values that the social model of disability were built on in 1976. The Fundamentals Principles of Disability Studies state, “in our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (UPIAS, 1976). They also stated that disabled people are affected by this marginalisation and inaccessibility in every part of their lives and their socioeconomic status.

The fundamental principles of disability studies was further developed in an academic context by a disabled lecture and activist Mike Oliver who coined the term ‘Social Model of Disability’ in his input to a journal article that assembled five written pieces titled, *The handicapped person a new perspective for social workers* (1981), edited by Jo Campling (1981). Oliver (2013) states the concept of the social model of disability came from the Fundamental Principles of Disability (1976) “which argued we were not disabled by our impairment but by the disabling barriers we faced in society” (Oliver, 2013, p.1024). The social model of disability makes a clear delineation between ‘impairment’ and disability. Impairment is a difficulty that is biological (different bodies and brains) and the ‘real’ pain of ‘lived experience’ of disabled people and should be acknowledged (Mulvany, 2000; Crow, 1996; Hughes & Paterson, 1997; French, 1993; Shakespeare & Watson, 1997). *Disability* is the disadvantage that is caused by society’s inability to make the world accessible for the impairments and differences of disabled people. This takes the blame away from

the individual that has the impairment, they are no longer seen as the problem, but instead disability is seen as *socially constructed* (Brownlow, 2010; Mulvany, 2000; Goodley & Lawthorn, 2006). The extent to which a person is disabled will depend on the social barriers they face.

It has been disputed by academics if Autism is even a developmental condition and said by some to be as much a 'socially defined constructed' (Hacking, 1999) as it is developmental condition (Haney, 2017).

Brownlow (2010) has analysed and compared language used by different professionals who support autistic people and their community in online forums in her article: *Presenting the Self: Negotiating a label of autism* (2010). She argues that until now the description, treatment, techniques and interventions that have been used by professionals have focused on deficit rather than difference. This has left little room for autistic people to have self-confidence and made it more difficult to discover their positive attributes. Autistic self-advocates have been very vocal online about wanting to create a more positive view of themselves and their community.

Brownlow suggests that there should be ways to help autistic people other than 'normalisation through therapy' (Brownlow, 2010). This practice was developed by professionals to identify certain childhood behaviours that were considered undesirable and then encourage, through various therapies such Applied Behaviour Analysis (ABA), a slightly less severe form of ABA Positive Behaviour Support (PBS) to normalise the behaviour (Milton, 2018).

Sometimes these children were given ABA up to 40 hours a week, this reminds me of the common practice of making clearly left-handed children write with their right hand, thereby asking them to go against their natural tendencies for the sake of 'fitting into' society.

Many behaviours/actions that autists do, have a purpose; these were then being therapeutically altered by ABA. However, if these actions are not hurting anyone and are helpful to that individual, why should they have to conform to a neurotypical world? Is this in best interest of the autistic person or the neurotypical people around them? By asking autists to conform to a NT society instead of accommodating their disability, society creates a dominant construct of autism as defective (Brownlow, 2010). This is influenced by the social model of disability (Oliver, 1983), and makes a distinction between the impairment that a disabled person has and the disability itself. In the case of autism, autistic people are asked to conform to society, in this way they are being impaired by the difficulty experienced when society does not allow for, adapt, and adjust to their needs but expects them to adapt (often after years of full time ABA therapy) to a neurotypical society instead (Brownlow, 2010).

There is value in learning about autism from autistic people. For too long the treatment and diagnosis of women (cis-/trans-) and non-binary people has been very strict in obeying *the triad of impairments* (Wing & Gould, 1979). This triad outlines difficulties with social development, social communication, and rigid and repetitive behaviour. If the criteria are not met, the individual does not have autism, but diagnostically this is flawed, as autistic people do not always fit into nice, neat boxes.

It is important that the views and personal narratives of autists be heard and valued by professionals to make the definition more accurate, inclusive, and authentic. Brownlow argues that a more positive description needs to be constructed with the help of autistic people. Only when their opinions and views are respected will we create a positive, holistic concept of autism that is beneficial to their community. We need a more inclusive view of the neurodivergent and to move from 'deficit' to the celebration of difference.

Critical Autism Studies

The roots of Critical Autism Studies (CAS) can be tracked back to the beginning of autistic self-advocacy as we know it, with Jim Sinclair, an autistic self-advocate and author's seminal speech, *Don't Mourn for Us* (1993; 2012) (Woods & Waldock, 2020). Sinclair's speech critiqued the pathologising medical model of autism and was many years earlier than Judy Singer's influential work on Neurodiversity (Singer, 1998; Woods et al., 2018; Woods & Waldock, 2020). The first meeting of the UK's CAS autistic led group was in 2011 and included autistic activists and academics Damian Milton, Luke Aylwrđ, Steve Graby and Lyte Moon (Woods et al., 2018). One of the most important features of CAS was the involvement of autistic activists and academics and in fact it "...is the only autistic led community of practice, within autism studies..." (Woods & Waldock, 2020). This was in part due to the founding of *Autonomy the Critical Journal of Interdisciplinary Autism Studies* by autistic academic Larry Arnold (2012- present). This journal was the first of its kind with an exclusively autistic editorship and peer reviewed. The journal includes autistic and non-autistic contributors' work in autism research from various disciplines (Arnold,

2012). Arnold's (2012) aim at the start of *Autonomy* was to re-publish important autistic seminal pieces that were not written for academia but important to the autistic community and the development of autistic self-advocacy. Arnold (2012) felt these ground-breaking autistic texts were at risk of being lost or overlooked especially by non-autistic autism researchers and academics such as, *Why I dislike Person First Language* by Sinclair (1999). The editorial board members of *Autonomy* and leading autistic authors within the field of early CAS were Steven Graby, Dr Damian Milton, Dr Dinah Murray, Dr Lauren Arnold and Dr Stephen Shore.

Woods et al. (2018) point out there have been several definitions of CAS, and Arnold (2013a) stated, "It is however about critical thinking, new perspectives and a channel for further debate in future" (Arnold, 2013, p.2). Davidson and Orsini (2013) also wrote a similar definition as the foundation of the book *Worlds of Autism* (2013b) which was a product of the work done in Ottawa, Canada at the inaugural CAS conference (Woods et al., 2018). Their CAS definition states:

1. *Careful attention to the ways in which power relations shape the field of autism.*
2. *Concern to advance new, enabling narratives of autism that challenge the predominant (deficit focused and degrading) constructions that influence public opinion, policy, and popular culture.*
3. *Commitment to develop new analytical frameworks using inclusive and nonreductive methodologies and theoretical approaches to study the nature and culture of autism. The interdisciplinary research required (particularly in the social sciences and humanities) demands sensitivity to the kaleidoscopic*

complexity of this highly individualised, and relational (dis)order. (Orsini & Davidson, 2013a, p.15) *World of Autism* (2013b)

Although these academics were not identified as autistic, they did acknowledge the importance of listening to autistic people about their 'lived experience' (Arnold, 2016).

There has also been some controversy concerning the ownership of CAS with a book published by non-autistic academics in 2016 *Rethinking Autism* (Runswick-Cole et al., 2016) who neglected to recognize past books in the field and ignored autistic scholarship in CAS as relevant to their CAS book, which they claimed was the first of its time. They defined CAS as only having two very narrow objectives; related to diagnosis, whether it is scientifically reasonable and whether this is useful for autistic people (Runswick-Cole et al., 2016). Autistic scholars found Runswick-Cole et al.'s 2016 definition of CAS much too narrow and have published several negative reviews of the book, and an article written by Woods, Milton, Arnold and Graby (2018) defines a more inclusive definition of CAS. Woods et al. (2018) propose Mitzi Waltz's (Waltz, 2014) description as the 'working' CAS definition:

The 'criticality' comes from investigating power dynamics that operate in Discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability'. (Waltz, 2014, p.1337).

Other CAS non-autistic academics such as O'Dell et al. (2016) who follow a definition of CAS that is more 'inclusive', point out that there needs to be a new way of understanding that is co-defined with autistic people and professionals. We need greater understanding of autism from all viewpoints (including gender, cultural, and

economic perspectives). This can only be authentic if autistic people are involved in the creation of this knowledge (O'Dell et al., 2016). Unfortunately, O'Dell, et al. (2016) are non-autistic academics who still overlook Autistic academics work on Neurodiversity movement when critiquing it.

Participatory Autism Research

Autistic academics and activists have advocated for the involvement of autistic academics, autist researchers and the use of meaningful participatory research in autism studies with autistic people for years. An example of this is the autistic-led journal mentioned above, *Autonomy* (2012-present), which publishes well known autistic scholars alongside autistic researchers who have had little experience with academic publishing (Arnold, 2020). Another example is the *Theorising Autism Project* (2014) which was a series of one day seminars that aimed to bring together autism researchers, autistic academics, and self-advocates to discuss how autistic people are being portrayed and theorised in autism research. This event focused on autistic academics presenting their theories and research, whereas in the past their work might have been outside academia or marginalised. The seminar also stressed the need for meaningful autism research that is developed for and with autistic people, that values autistic experience and gives autistic people more prominent roles in the research process (Greenstein, 2014).

The Participatory Autism Research Collective (PARC), Chaired by Damian Milton, was influenced by all these autistic-led projects and continues to support the involvement of autistic people in autism research. This includes valuing and

supporting autistic academics and researchers to carry out research that will better the lives of autistic people.

Over the period of my PhD (2016-2020) many autism researchers have adopted the neurodiversity paradigm and parallel calls for researchers to actively involve autistic people in a meaningful way in their research (Fletcher-Watson et al., 2019).

Autistic Academics' Theories on Autism: Counter evidence to ToM and biomedical definition to Autism

The Double Empathy Problem

Some autists find difficulty in relating to non-autistic people as their perceptual experiences are different. We can also sometimes struggle to understand other people's intentions or emotions. This is sometimes explained as a failure in Theory of Mind (ToM) by the medical model, however autistic academics such as Damien Milton (2012) and his theory the 'Double Empathy Problem' (Milton, 2012) offer different ways to look at this which is more congruent with the neurodiversity paradigm. This theory describes 'mutual incomprehension' (Milton, 2017) between autistic and non-autistic people. Which was once thought to be a ToM (Baron-Cohen et al., 1997) or 'mindblindness' (Baron-Cohen, 1997; Hill & Frith, 2003) problem of autistic people. However inspired by the Double Empathy problem theory (Milton, 2012) it is beginning to be understood and with a growing body of empirical evidence that non- autistic people could neglect to understand autistic people too (Sheppard et al., 2016; Crompton, Hallett, et al., 2020; Crompton, Ropar, et al., 2020; Heasman & Gillespie, 2019; Heasman, 2018) Some autistic people can be over empathetic to

other people's emotions and the world in general and may find it hard to separate their emotions from other people. Socialising with more than one or two people is challenging for some due to sensory issues, such as not being able to hear more than one person talking at a time because one can hear everything all at once.

Monotropic Mind-Set

Autistic people can have unusual ways of thinking and learning and can be good at solving problems and/or noticing detail that others may not. We might have difficulties with executive functioning such as concluding and beginning tasks, time management and making decisions. Some autistic people find it hard to focus, but when we do focus, we hyper focus usually towards our passions. Autistic people's interests are as vast and wide as the general population; from art, sport, and gardening to trains, shiny materials, and computer/electronic equipment for instance. (National Autistic Society, 2021).

The importance of small talk can often be lost on an autistic person and so they tend to have deeper conversations about things they are passionate about. Damian Milton (2014) suggests that this might be just a different cognitive style that and another autistic researcher and campaigner Murray (2005) coined the theory of monotropism,

“A monotropic interest is much more closed than a typical interest. Typical interests flow into each other through so many connections that their only stable distinctions may be culturally acquired. By contrast, monotropic interests are deep basins of attraction where attention gets caught and may be expressed in a thought or action over and over again. No alternative attractor may be apparent.” (Murray, Lesser & Lawson, 2005, p.146).

For Milton (2014), this definition is a nonconforming approach to the division of attention that the pathological term ‘restricted range of interests’ refers to in DSM-5 and ICD-11. Autistic people tend to concentrate on individual things and find it difficult to be attentive to numerous things concurrently. This could imply that autistic people overlook seemingly unimportant material that provides background to everyday experience such as dialogue, people’s expectations, and comprehension (Murray, Lesser & Lawson, 2005).

As Nick Walker (2014) a queer autistic scholar, speaker and author states in their website and blog:

“Autism is still widely regarded as a ‘disorder,’ but this view has been challenged in recent years by proponents of the neurodiversity model, which holds that autism and other neurocognitive variants are simply part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation (which have also been pathologized in the past). Ultimately, to describe autism as a disorder represents a value judgment rather than a scientific fact.” (Walker, 2014b).

Yergeau arguments against Theory of Mind

Many autistic academics have questioned the biomedical model of autism and how that in turn affects autistic people. M. Remi Yergeau wrote several significant papers for CAS critiquing many theories and interventions, such as ABA and theory of mind, that had a negative impact on autistic people. (2010; 2013; 2017). Yergeau looked at

the many problems with 'Theory of Mind' (ToM) through the lens of feminist rhetorical studies and as an autistic person. They wrote *Clinically Significant Disturbance: On Theorists Who Theorize Theory of Mind* (2013) in an autoethnographic style, and argued that ToM has become an 'empirical' fact since the 1985 article by Simon Baron-Cohen, Alan M. Leslie and Uta Frith. This article stated that autistic people could not understand that other people, "know, want, feel or believe things". (Baron-Cohen, Leslie and Frith, 1985, 38). This term has been used in a variety of disciplines to discuss neurotypical people as well and many have stated that Theory of Mind is what makes humans, neurotypically human. The author argues the problem with Theory of Mind, inadvertently or not, is that people on the spectrum with their perceived lack of, or impaired, ToM are then considered less human. This ultimately takes agency away from autistic people, so ToM is another binary that separates autistic people - the "mind blind" (Baron-Cohen, 1995) - from the "mind readers" (Baron-Cohen, 1995). Scientists and clinicians tend to talk about ToM abstractly, leading to a propensity to dehumanise, thereby denying them the capacity of empathy, and devaluing them as humans. Even though this effectively silences autistic people, it is endorsed by the scientific community.

Initial work - my own journey

I instigated this process by outing myself as autistic/neurodivergent with friends, colleagues, and students. 'Coming out' as autistic is a political and performative act²⁹

²⁹ Please see *An Act of Resistance* by Carl Cameron in the Neurodiversity Reader (2020) and Davidson and Henderson (2010) for an interesting discussion on the dynamics of coming out as autistic. <https://www.tandfonline.com/doi/abs/10.1080/14649360903525240?journalCode=rscg20> And

and regarded as an important step in obtaining a positive autistic identity. I had already 'come out' as bisexual and queer some twenty years ago and saw this experience as very similar. Coming out is not easy; Cameron (2020) states, "To disclose one's autism is a deeply personal and complex decision to make, and once revealed you cannot take it back" (Cameron, 2020, p.111). At the time I was a college art lecturer and already very 'out' about my dyslexia and dyspraxia. I felt it was important for my students to see that having a specific learning difficulty does not necessarily have to hold you back. I believe that if a young person is exposed and encouraged to accept many different types of people early in life this will be carried into adulthood.

Eighteen years later, when I was discovered autistic, my approach was the same: I was upfront with my students and colleagues about being autistic. *Coming out* can be viewed as a political act; Halperin states "...coming out puts into play a different set of power relations and alters the dynamics of personal and political struggle. Coming out is an act of freedom, then, not in the sense of liberation but in the sense of resistance" (Halperin, 1995, p.30). Halperin (1995) goes on to suggest that Foucault' (1976) describes *coming out* as homosexual as a resistance to the projection of the heterosexual. This projection makes you into a screen that projects all the stereotypical ideas that heterosexuals have about queer people. When I came out as autistic, I too felt "every gesture, statement, expression, and opinion to be totally and irrevocably marked by the overwhelming social significance of one's openly acknowledged... [autistic]...identity" (Halperin, 1995, p.30).

a book edited by Dinah Murray (2006) titled *Coming out Aspergers: Diagnosis, Disclosure and Self-Confidence*.

My project utilised Foucault's (1976) notion of 'reverse discourse', which reverses or turns upside-down the conversation between people who have power and those that do not. I wished to spin the power of language traditionally used by non-autistic people (who I will also call *neurotypical* and *allistic*³⁰) to describe autistic people (<https://psychcentral.com/blog/aspie/2018/09/allism-spectrum-disorders-a-parody>). I aimed to switch the position of allistic or neurotypical people from being representative of *normal* (the *universal subject*) to being the object of analysis and questioning; this would shift autistic people into the position of the legitimate subjective agency -- from the status of 'that which is spoken about while remaining silent to the status of that which speaks' (Halperin, 1995, p.57).

I believe that in order to change allistic people's attitudes, the autistic community must be more visible. This will assist in dispelling outdated stereotypes and replace these with positive role models for the next generation of autistic people. As part of the development, I created two performance action pieces, both of which I videoed. The first, in 2015, was about autistic visibility; I stood in two busy pedestrian areas with a sign around my neck proclaiming 'Autistic' (see Figures 3 and 4). More autistic action photos (Appendix 3) the video link is [Autistic Action 1: Nottingham](#) (Foster, 2015).

³⁰ the term 'allistic' was coined by Andrew Main (2003) who states "The word 'allism', invented for this article, is intended to precisely complement 'autism'. It is based on the Greek word 'allos', meaning 'other', just as 'autos' (in 'autism') means 'self'..." (Main, 2002)



Figure 3 Autistic Action 1 (AA1) (2015) Nottingham

This was a very strange experience as I stood on the street for several hours silently waiting for something to happen (see Boxes 2 and 3), but nothing did - or did it? Even though I wore a written sign announcing I was autistic, I also communicated so many other things to the bystanders on the street: how I stood, what I wore, my expressions, and my non-verbal interactions in relation to their looks, my eye contact, how I smelled, even the feeling that I engendered in them, I intra-acted with them.



Figure 4 Autistic Action 1 (AA1) (2015) Nottingham

Box 3 Autie-ethnographic element from AA1

Would it be possible to communicate through a
performative act

My aim was

To make people aware of the possibility
that I exist

I am not a stereotype

and not just an idea of autism

but an actual autistic person

Karan Barad was highly influential on my project. Barad proposed the theory of agential realism in her 2007 book, *Meeting the Universe Half Way* (Barad, 2007),

which draws on her theoretical physics background. The first concept I adopted is that of 'intra-action', which was used as a replacement to 'interaction' (Barad, 2007). This proposed the notion that it was impossible to have an absolute separation between the observer and that which is observed (See Table 2).

Arguably my own intra-action with people on the streets of Nottingham occurred at a quantum level, a level where classical concepts of 'the observer' and 'the observed' breaks down - I created a lived experience of autistic people with those people - as an autistic person I interacted and *touched* those people in the way that blended us for a time (*Appendix 4 contains my reflections of this piece*).

There has been a plethora of autistic people writing about their lived experience online for years on social media and blogs. On Twitter and Facebook, the hashtag #actuallyautistic has been adopted to let people know that you are an autistic person, you have a voice and that you exist. It was first used by an online autistic community on tumblr, eventually expanding to all social media platforms where there is a huge community (Eartharcher, 2017). #actuallyautistic is a way for autists to find and communicate with each other.³¹ Ironically, I am often overwhelmed by social media³² and prefer to do this in person as a performance artist.

³¹ For more information go to this blog by Laina Eartharcher titled: The ActuallyAutistic hashtag is only for actually autistic people. <https://thesilentwaveblog.wordpress.com/2017/01/02/the-actuallyautistic-hashtag-is-only-for-actually-autistic-people/>.

³² I think it is really important to note that there must be other autistic people that are also overwhelmed by social media and, I think, why autistic spaces where people can meet in person are an important addition to online autistic spaces.

“Touching’ as we know it in our everyday lives is an electro-magnetic interaction, a repulsion between electron clouds that don’t so much ‘touch’ in the sense of encountering each other’s boundaries through physical contact as sense one another’s electron clouds.” (Barad, 2007)

As an autistic, dyslexic and dyspraxic PhD student I was aware that the Lordes’ ‘masters tools’ are embedded within the institutional framework of Higher Education Establishments and that ultimately, for me to succeed as a PhD student, I would need to mask my neurodivergent nature when I was writing my thesis and receive ‘reasonable adjustments’ for help in doing this, especially with my dyslexia.

As a neurodivergent person I had to go through a process of pathologisation to receive this help as Walker states:

“Disability Services departments in the world of higher education reinforce the pathology paradigm by demanding neurodivergent students subject themselves to the process of being formally diagnosed and of having their divergences from neuronormativity pathologized as ‘disorder’ before accommodations are granted. Thus, any instructor who provides accommodations only when required by the Disability Services department is also implicitly

reinforcing and condoning the pathology paradigm.” (Walker, 2016).

I am equally aware that this masking of my neurodivergence was at odds with exactly what I was trying to achieve with my project: to support and encourage neurodivergent thinking and communication. I was aware of this conflict and worked to embrace neurodivergent thinking and communication in the practical work, and also to incorporate elements of my neurodivergent communication in the written components.

Walker does not accept the concept of a ‘normal’ person or ‘normal’ brain; these terms are inaccurate and convey an element of ‘social inequality’ (Walker, 2012, p.232). Walker builds on Lorde’s concept of ‘internalised oppression’ (Walker, 2012, p.235) whereby the language of the pathology paradigm becomes internalised within autistic people that lead to a self-labelling of ‘defective’. The feminist journalist Sally Kempton, as quoted in Walker (2012), once said, “it’s hard to fight an enemy who has outposts in your head”. As seen in (Walker, 2012, p.235), a new positive and inclusive language is needed to replace current societal scripts about autistic people.

My second piece of action art drew on a stronger and more developed sense of how I wanted to articulate my experience as a late diagnosed autistic person. In this second piece I wore a t-shirt that said, ‘Autistic’ on the front and ‘Ask me about Autism’ on the other; I stood on a pedestrian walkway in Canterbury, Kent for 2 hours (see figure 5).

I had but one 15-year-old young man and his parents come up to me, and he said “I am autistic too”. We spoke about how important it was for people to have a dialogue about this topic with autistic people, and to be more visible as a community, to break the stereotypes and empower the next generation of autistic people to be proud of their neurodiversity.

With this second piece (AA2), I wanted the video performance to be a representation of my experience of overwhelm and the sense of isolation this can provoke; this can be viewed at [Autistic Action 2: Canterbury](#) (Foster, 2017).



Figure 5 Autistic Action 2 (AA2) (2017) Canterbury

I felt it was important for it to be filmed in the middle of a busy pedestrianized city street as I find it very difficult to spend too much time in places like this. My sensory processing differences mean I am very sensitive to light, sound, smell, touch, taste, my own sense of my body in space and balance (which are the vestibular and proprioceptor senses) as many neurodivergent people are. I find crowds difficult - visually a crowd of people is very overwhelming.

I find people are loud and when they are in a crowd this is amplified, the sound of all these people walking, talking, and coughing can be paralyzing for me. With numerous people close together, there are so many smells: aftershave, perfume, hairs spray, body odour, etc. I can smell it all and sometimes feel physically sick. My sense of touch is very sensitive, strangers standing or walking close to me is very unsettling, and I know I have had panic attacks in crowded settings as a result of being overwhelmed by my sensory experience (See Box 5).

Box 5 Autiethnography elements from AA3 (2017)

So many faces, clothes,
all different colours and textures,
and limbs coming at me.

My sense of being overwhelmed led me to develop the *Overwhelm Avoidance Device (OWAD)* which became another performance piece, and the video documentation of this was eventually featured as part of my Solo performance piece *Adventurers of Super Aspie Grrl (2017)* (see Appendix 5). *OWAD* was performed in

March 2017, where I performed in the city centre to demonstrate my sensory differences and my need to escape from these situations due to overwhelm.

The *OWAD* was a device I envisaged as a backpack that could be deployed so that when I started to feel overwhelmed in a crowded environment I would be able to hide inside until I felt less overcome. I modified a tall, thin pop-up tent to create my prototype *OWAD*, and could carry this around with me on my back. In my third piece of action art, I walked around a city centre wearing the *OWAD*. Under my normal clothes, I had on a super-hero costume I created as 'Super Aspie Grrl' (see Figures 8 and 9).



Figure 6 Autistic Action 3 (AA3) (2017) Canterbury. Partial deployment of OWAD.

When I started to feel overwhelmed, I deployed the *OWAD*, and took refuge inside (Figures 6 and 7).



Figure 7 AA3 (2017) Canterbury OWAD completely deployed with Super Aspie Grrl inside.

As I calmed down inside the OWAD, I would feel brave enough to show my inner 'super-hero' self. I would remove my outer layer of clothes and, like Wonder Woman, emerged out of the tent as 'Super Aspie Grrl' and would then run off down the street (Figures 8 and 9).



Figure 8 AA3 (2017) Canterbury, Emergence of Super Aspie Grrl from OWAD.



Figure 9 AA3 (2017) Canterbury, Super Aspie Grrl running down the street

All three of the action art pieces were video recorded ([REDACTED]). These pieces of video art are metaphors for many things that affect me personally as a late diagnosed autistic queer person. I deal with sensory overload daily, which I have had to learn to manage. I initially thought this was something everyone encountered, and I was baffled by the ease at which most people could move through this often toxic, debilitating, and annoyingly irritating world. My everyday experience is expressed in Box 6 below.

Box 6 Autiethnography element for AA3 (2017)

an onslaught of sounds
images, people, body parts
facial expressions
intense smells

and the intensely disturbing sensation of everyday textures

including the clothes I wear

crowd of people

I dread the proprioceptive and vestibular experience of being in their

closeness it can cause an internal pressure or uneasiness

in extreme cases

I can become motion sick

The sound of a crowd

I hear as one noise

as well as overlapping individual voices

at the same time

I can hear an individual conversation on the other side of the street

along with the overwhelming noise of the whole crowd

ultimately

I cannot really hear anything at all

When people walk or stand too close to me

I feel as if they have entered an invisible boundary that projects

outside my body

My 'internal motion sensor alarm' goes off in my head

when this threshold is crossed the sensor is tripped

This can occur with a stranger bumping or brushing me and feels almost painful

I physically jump at all surprises especially loud noises

this causes me to become very stressed and angry

making it difficult to calm down,

especially after 2, 5 or 10 people have set this alarm off

Even the brightness of the sunlight and most fluorescent lighting can overwhelm me

These three videos also act as a commentary on the isolating aspect of my sensorial netherworld, as was my pre-diagnosis reality. I felt that I was the only person who cannot cope with these everyday sensations; everyone else just seems to get on with it. Other people just do not understand why you are so anxious, exhausted, irritated, stressed by things that do not seem to bother allistic or neurotypical people.

Before my performance, there were other published works that have tried to illustrate this experience of autistic overwhelm. *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), which became an award winning play (Haddon, Stephens & Elliot, 2012), tells the story of Christopher, an autistic child. In one scene, Christopher goes to London and becomes very overwhelmed by people and things within the train station. This depiction is well loved by the public but is also problematic as it was written by an allistic author who presents Christopher as "... a conglomeration of stereotypes, presenting autism as the public eye would imagine it

to be: his character is more consistent in sticking to general perceptions of the spectrum than any real individual person could be, resulting in a figure who is overdrawn to the point of caricature” (Loftis, 2015, pp.124–125). In 2017, the Indiana Repertory Theatre production of this play chose to employ an autistic actor, Mickey Rowe, to play Christopher. Another curious incident about this is that the author admits, “I know very little about the subject [Asperger’s and autism]. I did no research for curious incident...” and goes on to say “...curious incident is not a book about Asperger’s. It’s a novel whose central character describes himself as ‘a mathematician with some behavioural difficulties’. Indeed he never uses the words ‘Asperger’s’ or ‘autism.’” (Olear, 2011).

The National Autistic Society (NAS) also put out a video as part of the Too Much Information project (2017) which portrayed a, once again, stereotypical young, white autistic boy walking through a shopping mall experiencing overwhelm and having a meltdown. This was created in consultation with autistic people for a neurotypical audience to spread awareness of autistic experience. However, both these are examples autistic awareness, the roles of which are portrayed autistic people in situations that are perceived as tragic and that demand the general public be aware of and tolerate; my work, however, moves beyond general awareness - autistic acceptance is about celebrating differences.

Super Aspie Grrl portrays my acceptance of my autistic world and is primarily made for, and presented to, an autistic audience to celebrate our diversity from the norm. The *OWAD* is a metaphor of acceptance: I made this for myself and I place myself in

it and then, at my choosing, break free from *OWAD* as Super Aspie Grrl³³ as a happy autistic person revelling in my autistic-ness and difference³⁴.

My idea for Super Aspie/Autie Girl/Grrl was a reaction to the stereotype that if you are autistic, you have some kind of super savant ability; what if you are just autistic and average? I wanted to say that all autistic people whether they have savant abilities or not, are super and amazing individuals. Although I was not aware of it at the time, my super-hero depiction appears to parallel Andrew Tunney's parodic comic book covers, 'Super Crip' (2012)³⁵. Tunney uses the term 'Super Crip' to parody the stereotypical representation of disabled people overcoming their disability to become an inspiration (Tunney, 2012). Schalk states "these narratives almost always look at ...concepts of overcoming, inspiration, and exceptionality...[and] scholars tend to agree that 'Super Crip' narratives emphasize [over] compensation for the perceived 'lack' created by disability" (Schalk, 2016, p.74). Tunney's 'Super Crip' lampooned the view of the disabled hero who could overcome and interchange the loss of one sense to gain another super sense. Super Autie Grrl was designed and depicted with absolutely no superpowers at all; Super Autie Grrl is plainly and

³³ I also used Grrl instead of Girl to reference the underground feminist punk movement 'Riot Grrrrl' that originated in my home state Washington USA. It is a subgroup movement that joins feminist awareness with punk music, fashion and principles. It often is connected with third wave feminism, and by many it is referenced as the jump start or beginning of this wave of feminism. "Riot Grrrrls rebelled not only against the dominant ideological frameworks of capitalism and consumer culture, but also against the patriarchy that dominated American society" (Wright, 2016, p.53).

³⁴ Please note that in 2017 I took the decision to change my super-hero name from 'Super Aspie' to 'Super Autie'; the reasons for this are found in appendix 6. As the term Asperger's (Aspie for short) is named after the Austrian paediatrician who discovered, and there are associations between Asperger and the Nazi party.

³⁵ Andrew Tunney's 'Supercrip' (2012) comic book covers can be found here: (<https://andrewtunney.tumblr.com/post/29219973921/super-crip-for-dadafest>) Andrew Tunney's SuperCrip character's "...power is that he can switch impairments at will". He can give up one sense, such as sight, for super hearing, depending on the circumstances.

simply ordinary! Other authors have also criticised the notion of the autistic savant stereotype, including (Draaisma, 2009; Loftis, 2015; Murray, 2008; Arnold, 2013b).

As an aside, several academics (Schalk, 2016; Silva & Howe, 2012; Hardin & Hardin, 2004) observe that 'supercrip narratives' tend to establish artificial expectations for disabled people to 'overcome' the consequences of their disabilities, "through sheer force of will, but also, simultaneously, these representations depend upon our ableist culture's low standards for the lives of disabled people" (Schalk, 2016, p.74).

I designed and created the costume for Super Aspie Girl (Figure 9) which consisted of a turquoise unitard and a homemade, two-tone, satin cape; both had handmade, multi-coloured, appliqué patches on them. The appliqué patch placed over my chest region, mimicking a superhero's symbol, read 'Super Aspie Girl' (Figure 10), and the patch on the cape which stated, 'Autism is Awesome' (Figure 11), attached to the costume with safety pins (Figure 9).



Figure 10 Super Aspie Autie Girl Applique (2017) Chest piece of Costume

It was important for me to make the costume myself, and create the appliqués, as this was not only part of my aesthetic as an artist but also, I believe, part of my ‘autistic aesthetic’ which I had been working with throughout my career as an artist. I felt that the letters should all be different colours and patterns to show the complexity of autistic individuals and the autistic community. I made the letters with brightly coloured and wildly patterned fabrics of different textures as I also wanted to make the words difficult to read, paralleling the difficulty I have with reading words as a dyslexic person³⁶.

³⁶I (and some autistic people) have visuospatial cognition differences and tend to focus more on the detail than deciphering details into a whole or the gestalt. (Bogdashina, 2003; 2016) As an artist who trained as a painter, I have always had a fascination with negative and positive space and how it can fool your eyes. I found it amazing that you can see one shape and then an entirely other one in the same visual field. This reminded me of my experiences of reading and writing as a dyslexic person, where letters seemed to move the wrong way around while I read and write them, and I wanted my audience to have some notion of what this is like. To highlight this, I created appliqués which were challenging for people to interpret, as many autistic people find different things in the neurotypical



Figure 11 Autism is Awesome (2016) Super Aspie/Autie Grrl cape applique

Most of the books and information I read online were coming from the biomedical paradigm which I found very disconcerting. Appliqué was one of my passions (described by biomedical paradigm an autistic person's 'special interest'). Appliqué also helped me to deal with the uneasiness I felt whilst researching my thesis and encountered this type of language; words and phrases that neurotypical 'autistic experts' and/or neuropsychologists were using to label and describe my personal experience of living as an autistic person. Subsequently I have continued to make appliques related to my experience of researching the biomedical view of 'autism', which contrasted with the autistic self-advocate community's paradigm of neurodiversity, and I used these in my final work as part of this PhD³⁷.

world hard to decode. Creating the patches became a way for me to deal with researching myself as the subject matter of autism researchers and understanding who I was as a late discovered autistic person.

³⁷ Appendix 7: [Video documentation of Applique used in Super Autie Grrl Performance](#) and for Video Documentation of Applique used in Adventures of Super Autie Gang and Autistic Applique Photos by Annette Foster [REDACTED].

Craft has always been an easy way to channel my need for self-soothing, which the autistic community refer to as 'stimming'. Stimming helps an autistic person self-regulate their feelings of over- or under- stimulation, which will vary at any given moment. My stimming takes the form of a repetitive physical action that makes appliqué ideal as a source of pleasure, calmness and happiness - appliqué occupies my mind with the type of stimulation it needs.³⁸ As autistic author and self-advocate Julia Bascom puts it, "Sometimes being autistic means that you get to be incredibly happy. And then you get to flap.... I pity anyone who cannot feel the way that flapping your hands just so amplifies everything you feel and thrusts it up into the air" (Bascom, 2011) (Please see Appendix 8 for a more detailed description of Stimming).

The Performance of Neurotypicality/ Masking

Emerging from the *OWAD* in my super-hero costume also embodies my experience being late-discovered as autistic. I was a person who was an expert at '*Pretending to be normal*'³⁹ (Willey, 1999) or, more accurately, 'pretending to be neurotypical', and my diagnosis allowed me to shed my disguise and show my true nature, my authentic colourful, appliquéd self. I find I have several identities that I 'wear' or 'perform' daily. Judith Butler (2006) explains the performance of gender and I see

³⁸ Perry (2018) interviews Julia Bascom via email and quotes her as saying, "Stimming is a way that we can help ourselves feel calm, soothed, or focused, but it can also be a huge source of joy and beauty". "I don't know how to explain what that joy feels like to neurotypical people", she writes, "I think it might be a little like dancing, or seeing a beautiful piece of art, or becoming totally engrossed in a piece of music, times ten. But we can get it just from flapping our hands" (Perry, 2018).

³⁹ *Pretending to Be Normal* is the title of an autie-biography by Liane Holliday Willey (1999). I read this very early on after I was diagnosed and I identified with the phrase, 'pretending to be normal' as I had realised that I had spent the first 40 years of my life doing this.

echoes of this in my performance of being neurotypical. “If gender attributes, however, are not expressive but performative then these attributes effectively constitute the identity they are said to express or reveal” (Butler, 2006, p.23).

I ‘perform’ as a neurotypical in the same way. I learned, by careful observation, what characteristics and traits were expressed by non-autistic women. I realised these did not come naturally to me and I had to learn to ‘perform’ these to the best of my ability in order to successfully pass off as a non-autistic woman in a neurotypical world.

I am aware now, ten years after discovering that I was autistic, that I also unconsciously suppress characteristics of my identity to fit into society and avoid stigma. I feel that my identity is very complicated and delicate, and I went through a period of not really knowing who I was, and this related to all aspects of my personality. Once I started to identify where I was masking my autistic characteristics that I had consciously and unconsciously suppressed, I also began to understand my gender identity. I now identify as non-binary and use the pronouns she/they. This was something else that I had unconsciously masked in my attempts to fit into a neurotypical society.

The autistic community uses the word masking (Milton & Sims, 2016a) to describe their experience of ‘pretending to be normal’ (Willey, 1992) by consciously or unconsciously suppressing characteristics of your identity, and this is a fairly new area of research within autism research. (Miller, Rees & Pearson, 2021).

This ‘pretending to be normal’ or, as the autistic prefers to call it, masking, has been acknowledged by autistic people for years, however science is just catching up to this idea in the last five years. To mask is to “...invest considerable effort daily in monitoring and modifying their behaviour to conform to conventions of non-autistic

social behaviour” (Mandy, 2019). It has been termed ‘social camouflaging’ (Hull et al., 2017a; Mandy & Lai, 2017) or ‘compensation strategies’ (Livingston, Happé & Shah, 2019) by most non-autistic autism researchers in the past, which suggest it as a ‘social strategy’.

Masking is not a new concept especially in social science where Erving Goffman (1959; 1963), a prominent sociologist and social psychologist from Canada, proposed in his book, *A presentation of Self in everyday Life* (1959) that the social life of society was similar to that of theatre (Goffman, 1959). That all humans that took part in face-to-face interaction were like actors on the stage, playing parts (Goffman, 1959). Once a person enters a social space, they will try to influence, “...through setting, appearance, and manner the impression (usually an idealised one) they form of [them]” (Javier, 2003, 49). Also, the other person will try to deduct understanding about that person so that they know what to expect from them (Javier, 2003), so that all humans are constantly trying to control the ‘impression’ they give off to others. As Damian Milton (2014) proposes, this is relevant to autistic experience, and he states “[f]or Goffman the ability to manage such impressions is fundamental for an individual to be considered normal by others. Hence, those that exhibit autism whether diagnosed or not, are likely to be considered abnormal and subsequently stigmatised” (Milton, 2013, p.5). Goffman also spoke of mask as a means to hide part of yourself. This does not mean that the person masking become someone else but that the mask worn, and the person hidden behind it, are characteristics of the same person (Bullingham & Vasconcelos, 2013).

Up to 70%, of autistic people participating in an online study in 2019 reported that they consistently camouflage (Cage & Troxell-Whitman, 2019). Pearson and Rose⁴⁰ (2021) argue that masking is much more complicated than the current researcher suggests - that masking is at many times subconscious and not always something autistic people elect to do or use as a 'social strategy'. They also argue that masking "is an unsurprising response to the deficit narrative and accompanying stigma that has developed around autism...[and] it is important that we do not impose gender norms and stereotypes by associating masking with a 'female phenotype'" (Pearson & Rose, 2020). This last argument is in line with the thinking behind Farahar's and my reconceptualization of autistic experience (appendix 2).

I performed this role with varying degrees of success but on many occasions was 'found out'. When this happened, I felt I was treated as an imposter or labelled as 'weird', and often ridiculed or subjected to neurotypical teasing and bullying. However, I was usually much harder on myself and felt like I continuously apologised for my existence (please see appendix 9 for Apologising for my Existence about this). This internalised oppression or ableism was expressed in the solo performance *Adventures of Super Aspie/Autie Grrl* (2017) (appendix 5 and 10 links to documentation of the performances). Before the performance begins, in my attempt to 'challenge the negative construction' of my identity as Autistic and promote 'equality without sameness' (Bumiller, 2008, p.980), I carry out a private performance alone: I painstakingly write words in black marker pen all over my body (this usually takes about four to five hours), words used to describe me over the years preceding

⁴⁰ This article is written by Amy Person PhD from the School of Psychology, Sunderland, UK and Keiran Rose, *The Autistic Advocate* and set up *Infinite Autism* a social enterprise from County Durham, UK <https://theautisticadvocate.com/>; <https://theautisticadvocate.com/2019/03/infinite-autism/>.

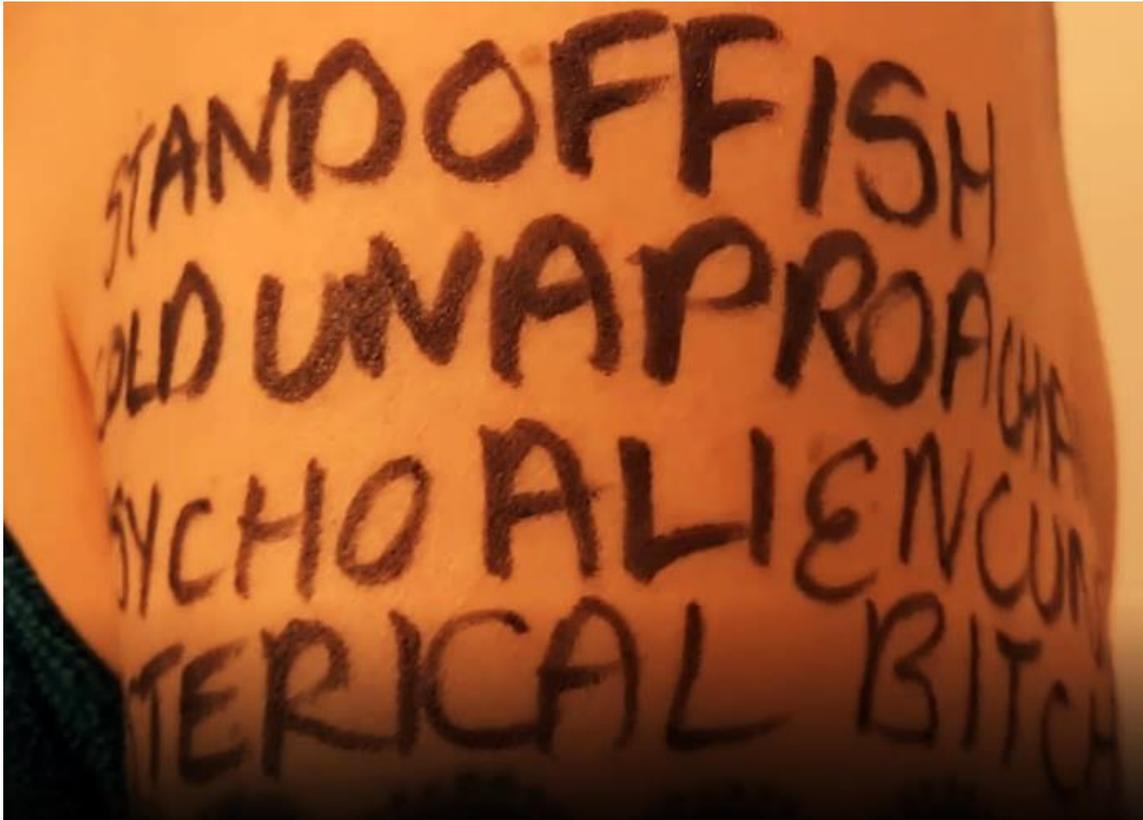


Figure 13 Sharpie marker on my body of stigmatised words for ASAG (2017) Canterbury

I then cover my body in clothes and perform *Adventures of Super Autie Grrl* (2017) and *Gang* (2019) covered in these words without the audience's knowledge. However just like masking my autisticness, these stigmatised words show through, and you can see the Sharpie marker on my stomach, feet, and hands; words peeking out of my shirt and trousers while I perform (see Figure 1). As part of the performance piece, I then reveal this writing to the audience by coming on stage toward the end of the piece nude, with my body covered in words in permanent marker⁴¹ (Figures 14 and 15).

⁴¹ I want to note a connection between this act and that of Carrie Sandahl in her piece *The Reciprocal Gaze*. As Eisenhauer explains, "In this performance, Sandahl walks outside while wearing a lab coat and white pants completely covered in red text as well as drawings of a spinal cord and hipbones (Thomson, 2005). As she encounters people's stares, she hands them a piece of paper that details her medical history. The text on her clothing includes common comments and questions that she experiences in her everyday life, such as. Are you contagious? I bet the Easter Seals could help you. Do you ever dream that you're normal? Along with these questions, she includes drawings of her

INVISIBLE Weird
vulnerable naïve
friendly **too-sensi**
deranged manic
simple sick mania
scatterbrain airhe
delirious irrational
handicapped too e
bother **CRAZY** trou
gay tedious absu
emotional tense
intense finicky th
uneasy irritable d
wreck nervy on-ed
state shaky strung
distraught Weird
out of place self d
reject unsocial wit
cynical **Hysterical**
defective whore sl



NGE stand-offish
trick unusual too-
insane depressed
ic ignorant **Rude**
sessed demented
ced psycho daft
Atypical delayed
loner annoying a-
dyke lesbian cunt
sensitive **nervous**
d impressionable
I uptight anxious
ve antsy hyper a-
case bugged in a
s distracted **CRAP**
hesitant insecure
e solitary out cast
noody pessimistic
uliar queer dumb
Retard dyspraxic

Figure 14 'Membrane' Performance photography for Adventurers of Super Autie Grrl (2017)

scars drawn to size and in the exact location of the scars on her body. Adjacent to the scars, are the names of the doctors that performed the surgeries" (Eisenhauer, 2007, p.13).



Figure 15 'Membrane 2' performance photography for Adventures of Super Autie Grrl (2017)

I also ask audience members to come on stage and write some of these oppressive words on my body to illustrate that we are all complicit in negative stereotypes. This stigma for being different seeps into our skin, like Sharpie drawn tattoos, with all the negative words used against us for being different to the neuro-majority. Other people tattoo stigmatising words onto each other: society and even those close to us stigmatise us, using negative and hurtful words to describe our behaviours (Figure 16).



Figure 16 Adventures of Super Autie Gang (2019) Audience member writing 'Hysterical' on my back.

“...words can seep out of you like inky, angry stigmas, like shadows, words can be a beast on your back.” a line from Super Autie Grrl, 2017 and Gang, 2019.

I then scrub away these words off my body (see Figure 17). Although I was not a discovered autistic, I was still given negative labels; I was treated differently, negatively, for not hiding my autistic nature. My very autistic behaviour makes me stand out, and this makes autistic people vulnerable to bullying, ostracism and isolation from those who can perform neuro-normativity (see Appendix 11 for a piece of writing about this performance).



Figure 17 Adventures of Super Autie Gang (2019), scrubbing off the stigmatized words.

There are several studies that suggest that autistic children and adults are much more likely to be vulnerable to bullying and ostracised, or isolated due to not fitting in (Cappadocia et al., 2012; Schroeder et al., 2014; Weiss & Fardella, 2018).

In reality, pretending to be normal, apologising for my existence, and masking that my sensorial world did not overwhelm me was a fulltime job, and utterly exhausting. The world seems a very complicated thing to me - I observe minute detail and am aware of the ever-changing shifting and overlapping of these minutiae. I appear to see how everything inter-relates, my sense of 'reality' is multisensorial, overlapping waves of experience on top of, around, and underneath each other. I have the

impression that one thing affects another, that affects another, and so on and so forth. The Dawn Meson painting, *Exclusion Principle*, on Karen Barad's book cover really resonates with my experiences (Barad, 2007) (see Figure 18).

[REDACTED]

Figure 18 Exclusion Principle by Dawn Meson. The cover of Barad's book 'Meeting the universe halfway' (2007).

In her book, Barad offers "...some sense of this complex and lively manifold of entangled and changing practices and possibilities... for the reader who shares my yearnings and struggles to see, feel, touch, taste, smell, hear, and otherwise sense phenomena with the mind's eye" (Barad, 2007, p.389). I think this is a neurodivergent way of thinking, however I note that Barad does not identify as such.

Barad believes when we intra-act (Barad, 2007) with another entity, human or non-human, we become intertwined, rather how a conversation becomes entangled.

Barad (2007) skilfully explains intra-action as “the complex manifold of connections in question is an ever-changing, multi-dimensional topological manifold of space-time matter, not a three-dimensional object (assuming you'll grant that) located in space with the barest of hint of time thrown in for good measure” (Barad, 2007, p.388).

As an artist, I explain this to myself that since on a subatomic particular level we are predominantly space, our atomic and molecular clouds will drift, cross and mingle with any others' cloud. Essentially if I accept Barad's notion of intra-action, I think we are no longer separate, and in fact cannot exist without co-existing with others. In part I think we also exist because of the millions of intra-actions we have had before, each of which have left us with a residue of prior mingles, shifts and drifts of our clouds and particles.

Throughout my project I aimed to use Barad's concept of intra-action to understand my world and how I intra-act with specific epistemological constructs (devices) such as theory, culture and science. I hope this will elucidate the evolution of how we have come to 'see' concepts such as 'autism' or 'autistic people'. Definitions and concepts do evolve and, as Hacking (2006) suggests, they become somewhat of a moving target.

Hacking (2006) suggests that any investigation that uses the scientific method will interact with the groups of people being studied and, in turn, modify them. Hacking's

(2006) argument is the presence of 'looping effects', or feedback between external systems of classifications/ theories, and self-conceptualisation of those subjects being classified and theorised about.

Overview of the historic approaches to research on autism that impacted on me personally⁴²

For a comprehensive overview of Baradian analysis applied to the historic attempts to generate a 'general theory' of autism, I would refer the reader to Hollin (2017), an excellent paper that describes the effect of the traditional cognitive psychological hegemony on autism.

Since starting my thesis, I have noted that the contemporary understanding of the experience of 'autism' is ever changing like 'a throw of the dice'. Stephen Shore (2018), an autistic advocate, pragmatically says, "If you've met one person with autism, you've met one person with autism" (Shore, 2018; Flannery & Wisner-Carlson, 2020).

The second Baradian concept that I have adopted is that of 'agential cuts' (2007, p.147). My understanding of this is that 'agential cuts' recognise that when a decision has been made to look or define a particular 'object'. This artificial act of bounding or describing entangled and indivisible intra-acting particles in order to learn about it, is

⁴² For a historical review of the history of autism from a biomedical perspective please see *How autism became autism: The radical transformation of a central concept of child development in Britain* (Evans, 2013) and for a blended sociocultural history of Autism please see *Autism: A Social and Medical History* (Waltz, 2013). For a historical overview of the autism rights division of the neurodiversity movement from the main autistic advocates and organisers themselves, please see; *Autistic Community and the Neurodiversity Movement: Stories from the Frontline* (Kapp, 2020)

a crucial time. The point at which you define or describe an object and attempt to isolate it from the entangled reality, by necessity you will instantaneously include certain properties that are observable, but simultaneously exclude all other feasible explanations. For example, choosing to observe the properties of light acting as particle (a photon) immediately excludes observing the wave-like properties of light; the act of choosing to observe a particular property of light cuts the agency of other feasible properties.

Within my own work, I was really struck by the responsibility of being aware of the ethics of making 'agential cuts' and I became extremely conscious that if I chose to include some expression of method of articulating an autistic person's experiences, I will always be excluding other possibilities for creatively expressing and articulation these experiences, and this was a weighty responsibility for me.

I recognise that for this project I have chosen to learn about the impact of gender on the autistic experience, (by looking solely at women (cis-/trans-) and non-binary people) and in so doing I excluded the experiences of cis- male autistic people. I keep in mind that this agential cut ruled out the exploration that autistic cis- males have similar experiences of the world, and this weighs heavily on me.

I am using an interdisciplinary approach for this project and looking to feminist science studies⁴³ as one of my underpinning theories. I feel the agential cuts brought

⁴³ Feminist science studies or Feminist technoscience studies came out of years of feminist critique of the bias that exist in science and technology, and the entanglement of identity markers such as gender, sexuality, race, socio economic status which are intertwined with science and technology. This transdisciplinary critique of science has moved away from the social and personal relations of men and women and concentrates more on wider concerns such as the construction of knowledge of how groups are discerned and recognised in culture. This critique holds into account science with the

about by the early research that resulted in the so-called 'extreme male brain' model, necessitated the exclusion of women and people with complex gender identities. Barad states, "indeed, as Butler and Bohr emphasis, that which is excluded in the enactment of knowledge-discourse-power practices play a constitutive role in the production of phenomena - exclusions matter both to bodies that come to matter and those excluded from mattering" (Barad, 2008, p.56).

I feel that my own history has been shaped by this agential cut, I felt my experiences of being autistic were excluded based solely on the fact that I was not male and therefore could not be considered as autistic. I was diagnosed as 'depressed', 'anxious', 'bipolar', and managed both medically and psychologically as possessing some form of mental health issues.

I wondered what the phenomena of being autistic would look like when we included the entangled 'others' - women (cis-/trans-) and non-binary people of colour, and other cultures. Do the 'other' excluded autistic humans influence the making of knowledge, discourse, or power? I remain convinced that 'agential cut' had created a different kind of world perception of autism and autistic people. As Barad states, "Rather, the point is that these entangled practices are productive, and who and what are excluded through these entangled practices matter: different intra-actions produce different phenomena" (Barad, 2007, p.58). Therefore, throughout my research, I aimed to acknowledge the entangled processes and where 'agential cuts'

same ethical and political answerability as the technologies that are created from these disciplines (Åsberg & Lykke, 2010).

in my research were made. I was mindful of the ethical responsibility I have to not ignore the exclusion as well as the included issues in my research.

Barad goes on to state: “*The point is this: one can't simply bracket (or ignore) certain issues without taking responsibility and being accountable for the constitutive effects of these exclusions*” (Barad, 2007:58).

The secondary issue that arises from acknowledging that research creates agential cuts is not simply a matter of inclusion. There is an underlying point related to power. How is power understood? How are the social and the political theorised in relation to power? I would refer readers to Halperin (1997) for a clear articulation of Foucault's strategies of resistance one can find within queer praxis.

This was an introduction into my personal perspective and how this might intra-act with the research and the research participants.

The Problem:

In this introduction I have used my personal experience as a late diagnosed queer autistic person to sketch out one of the crucial problems this thesis speaks to: the marginalisation of AWCTN+ people in autism studies. Many AWCTN+ people (and I would also add cis--men who slip through the diagnosis net), are misdiagnosed, or diagnosed later in life with mental health issues, or other less negatively stigmatised neurodivergences, which may or may not be co-occurring conditions in relation to an autism diagnosis (Au-Yeung et al., 2019; Lai, Kasseh, et al., 2019; Zener, 2019).

Many of these undiscovered autistic people therefore remain invisible to the medical profession and the general public, or even the autistic community itself. Within the scope of my PhD research starting in 2016, I have seen a large shift in the research looking at women in autism studies, and a development of a 'female phenotype'.

However, I have three main reservations about this way of understanding the topic:

- The idea of female phenotype is essentialist, and retains the theoretical framework developed by Baron-Cohen in his book *The Essential Difference* (2004)⁴⁴
- It may still exclude a large population of autistic people that identify as trans- or non-binary.
- There is increasing evidence that autistic people may experience gender differently, which would impact on their self-conception and subsequent gender expression (Davidson & Tamas, 2016; Kallitsounaki & Williams, 2020). There has been more research looking at the prevalence of trans- and non-binary people and they have started to be included in some of the research alongside females (Cooper, Smith & Russell, 2018; Dewinter, De Graaf & Begeer, 2017; Kourti & MacLeod, 2019).

The biomedical paradigm dominates most of research into autism, although currently this is challenged by autistic and disability studies (Woods et al., 2018; Milton, Mills & Pellicano, 2014; McWade, Milton & Beresford, 2015; Milton, 2012; Walker, 2012; Walker, 2014b; Woods, 2017b; Friedner & Block, 2017; Runswick-Cole, Mallett & Timimi, 2016; Brownlow, 2010).

⁴⁴ See Cordelia Fine's book, *Delusions of Gender* (2011) for a critique of this essentialism

Autistic researchers have advocated for the involvement of autistic academics, autistic researchers and the use of meaningful participatory research in autism studies with autistic people for years. An example of this is *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* (2012- present) started by Dr Laurence Arnold, who is a well-known autistic self-advocate and academic. *Autonomy* publishes well-known autistic scholars alongside autistic researchers who have had little experience with academic publishing (Arnold, 2020). Another example is the *Theorising Autism Project* (2014) which was a series of one day seminars that aimed to bring together autism researchers, autistic academics, and self-advocates to discuss how autistic people are being portrayed and theorised in autism research. This event focused on autistic academics presenting their theories and research, whereas in the past their work might have been outside academia or marginalised. The seminar also stressed the need for meaningful autism research that is developed for and with autistic people, that values autistic experience and gives autistic people more prominent roles in the research process (Greenstein, 2014).

The Participatory Autism Research Collective (PARC), chaired by Damian Milton, was influenced by these autistic-led projects and continues to support the involvement of autistic people in autism research. This includes valuing and supporting autistic academics and researchers to carry out research that will better the lives of autistic people. Over the period of my PhD, many autism researchers have adopted the neurodiversity paradigm and parallel calls for researchers to actively involve autistic people in a meaningful way in their research (Fletcher-Watson et al., 2019). I felt it was important to develop a research project that was

autistic-led and involved autistic people in a significant way, and I adopted this perspective as my project was in line with the autistic-led Participatory Autism Research Collectives (PARC) already. Their aim was to foster relationships between the autistic community, including academics and activists, with researchers early in their careers, as well as specialists who work with autistic people. Their goal was to create a network and a community for people who desire to realise more important involvement of autists in autism research (PARC, 2020).

I became a member of the participatory autism community including partaking in, and presenting papers at, the PARC conference in 2019, attending the branch of PARC at the University of Kent meetings, and also running events such as a workshop on Subtyping Autism with colleagues Chloe Farahar and Sam Fellows in November 2019. Farahar and I presented as part of the workshop by arguing against autism subtyping and presented our reconceptualisation of the autistic spectrum to a more nuanced *3-dimensional Internal external Autistic space* that I mentioned earlier.

My personal experiences highlighted that there is important work to be done to capture, articulate and understand this lost sector of autistic people; people who suffered the agential cut brought about by early research that strived to create diagnostic criteria for the biomedical professions. I am not alone with this view, and many authors are contributing to this interesting area of autistic research (Bargiela et al., 2016; Zener, 2019; Milner et al., 2019; Carpenter et al., 2019; Au-Yeung et al., 2019; Hull et al., 2017). I see this in the work of autistic scholars, activists and allies such as Jim Sinclair, Ari Ne'eman, Damien Milton, M. Remi Yergeau, Nick Walker, Julia Bascom, Amy Sequenzia, and Dinah Murray; the rallying cry of 'Nothing about

us without us' inspired a whole new generation of autistic scholars and advocates, including myself.

This PaR thesis blends academic research with creative methods, extracting from my knowledge as a multidisciplinary performance artist and working with AWCTN+ people to describe the embodied entangled experiences of being autistic. In part, I hope this will drive the need for the creation of a language to describe autistic experiences. I think the neurodiversity paradigm is a model within which this language began. The more autistic voices are added, the more sophisticated the language will become. I am minded to add that this language would include non-verbal language, and to explore the importance of stimming as a language that communicates that which cannot be expressed in words.

In my previous work as an artist, I uncovered novel ways to encourage communication through sensorial, kinaesthetic, creative actions that include performance movement, video, visual art, and sound art. I believe these modes communicate parts of autistic identity and culture that to date have not been articulated in words - perhaps because words are too limiting? With that limitation in mind, I wish now to discuss the concept of Autistic Space.

The Concept of Autistic Space

I think it is important to define the concept of autistic space, which was espoused by the Autistic Rights and Neurodiversity movements and influenced my PhD journey. To say that autistic space was an important part of the ethos of this project is an

understatement. I discovered along my messy PaR PhD journey that without autistic space this project would not be successful. From my experience with the autistic community, most autistic people went about their lives surrounded by neurotypicals and had to get by in neurotypical spaces, except for the huge networks of autistic spaces online such as autistic blogs, websites, YouTube videos and on social media such as Tumblr, Twitter, Facebook, Instagram, Reddit (Kim & Bottema-Beutel, 2019; Seidmann, 2020; Davidson, 2008; Russell, Steer & Golding, 2011; Ringland, 2019). I did not have much experience with autistic space, what it was and how it was achieved, although I knew that it needed to be created by and for autistic people. I was aware of online spaces and blogs but wanted to create physical space for the workshop. When developing the workshops, I was aware of the need to create a space for AWCTN+ people to communicate autistic experience - this was apparent in the research questions - however I was not aware from the beginning that it actually needed to be an autistic space. This space could not be a neurotypical space created to be 'autistic accessible'⁴⁵ which at its core was still grounded in the pathological paradigm. However, I became aware that true autistic space had to be a part of autistic culture and be grounded in the neurodiversity paradigm, where people feel safe to be their authentic selves, not some self they have created via unconscious masking to fit into a neurotypical world.

The first known actual physical autistic Space is mentioned by Sinclair (2005) but happened in 1992 when Autism Network International (ANI) was set up, the first

⁴⁵ An example of this was the Tuesday group that I attended as a University of Kent's student in 2016 that was run by the student support and well-being disability advisor who was very much an autistic ally but not autistic herself. This was set up more like a support group for AWCTN+ people than an autistic social space. In the summer of 2018, the disability advisor asked Chloe Farahar and me to run the group as she was made aware of the concept of autistic space from the participants in the group and felt that the group should be run by autistic people.

autistic-lead social group. This was the first time that this type of group met, and Sinclair found that in this new, total 'autistic space' they understood each other, they spoke the same language, and found acceptance for who they were. Sinclair describes a feeling of 'home coming' when meeting for the first time, and that it was a relief not to worry about conforming to neurotypical values and customs. This was the beginning of the discovery of an autistic ethos and culture (Sinclair, 2005).

In 1996, ANI's dream of a 'autistic space' came true, the first Autreat was held - a two-day conference by and for autistic people. This was a cordial environment where autistic people were in the majority; something most had never experienced before. Autreat's central value is 'opportunity but not pressure', so attendance at all functions was optional as this was about spending time with other autistic people on their terms. Autreat was run yearly until 2013 (Sinclair, 2005, p.31). This inspired UK's Autscape⁴⁶ events which have run since 2005 to this day (Dekker, 1999). Sinclair defines autistic space more comprehensively in his article titled *Being Autistic together* (2010): "In a shared autistic space, autistic people are in charge. Autistic people determine what our needs are, and autistic people make the decisions about how to go about getting our needs met" (Sinclair, 2010). There is very little academic writing about autistic space or the formation of autistic space (Fletcher-Watson & May, 2018a; Bertilsdotter Rosqvist & Kourti et al, 2019; Buckle, 2020; Mattaini, 2020). Owren (2013), in an unpublished master's thesis, writes about these two autistic retreat/conferences and defines autistic space to be:

⁴⁶ If you are interested in the development of Autscape, please refer to this article titled *Autscape*, by Leneh Buckle (https://link.springer.com/chapter/10.1007/978-981-13-8437-0_8).

1. "...accommodating sensory issues through general adaptations plus enabling individual self-regulation.
2. ...facilitating an autistic style sociality by establishing autistic social rules.
3. ...protecting the boundaries of the space itself. Autistic people will be in the majority, and conditions adapt to autistic needs and preferences" (Owren, 2013 p.1).

My first experience of autistic space was from my involvement of the Autism Arts Festival (2017) at the University of Kent as an artist performing my solo piece *Adventure of Super Autie Grrl* (2017), and as an audience member in Spring 2017. The things that I observed from this event that I felt were in keeping with this idea of autistic space were as simple as supplying a self-regulation⁴⁷ kits with ear plugs, stim toys and interaction badges⁴⁸, and providing a chillout room equipped with changeable lighting and various forms of stim tools. These two things actively encouraged people to stim and feel as if they could be their authentic autistic selves. There were other things that helped to make the festival an autistic space such as turning off all the hand driers in the bathrooms and having a simple line painted on the campus walkways directing people where to go. The performances were also open, so if you were overwhelmed or running late you could leave and re-enter the space whenever you needed to. One of the major factors that made this an 'autistic space' was that the majority of the people at the festival were autistic or autistic

⁴⁷ Self-regulation refers to the idea that some autistic people's stims might be overwhelming to other autistic people, encouraging people to stim but also giving people an option to wear ear plugs. They also provided many ear defenders for people to borrow at invigilator stations if someone's stimming, or anything else, was sensorially overwhelming.

⁴⁸ Interaction badges were created at Autreat and Autescape originally to help autistic people feel more comfortable communicating, and to encourage autistic sociality. It had three choices: **green** if you were ok for people to come up to you and engage with you. This was also good for people that found it hard to initiate conversation but wanted to socialise; **yellow** was for people that did not want to talk to people that they did not know or recognise (such as people they had only met online); and a **red** badge meant that the person wearing it did not want to talk to anyone, or a very few amount of people (Fletcher-Watson & May, 2018a).

allies, including much of the staff helping to run it. Autistic people were in the majority, and this was something that you could feel - that our values and culture as autistic people were appreciated and respected. This was apparent when I performed *Adventures of Super Autie Grrl* (2017), I felt as if the audience were accepting of my neurodivergent aesthetic as a dyslexic, dyspraxic, autistic performer and they believed in what I was trying to say as an autistic person and self-advocate. I also attended *Autscape* in the summer of 2017 and 2018. These events and my knowledge of 'autistic space' were influential to how I set up the Super Autie Gang workshops and performance.

Moving from Auto to Autie Ethnography

This thesis develops a new form which I have entitled 'embodied autieethnography performance'. As a multidisciplinary autistic artist, I use this approach to analytically reflect upon my own lived experience and to document my transformation as a researcher through the practice based investigations undertaken for this project. This was influenced by M. Remi Yergeau's use of written autie-ethnography in their article, *Clinical Significant Disturbance: On Theorists Who Theorize Theory of Mind* (Yergeau, 2013) which I read during the first year of my PhD. This article inspired my use of autieethnography as a method, as I was surprised and excited by this unusual form of writing used in an academic paper. This form of writing was more closely aligned with my natural affinity as a creative and autistic person to include elements of microscopic, disjointed descriptions of my experience in my creative work⁴⁹.

⁴⁹ Yergeau's (2013) article also taught me the value of autieethnography to illustrate how autistic people have been portrayed by the biomedical model and by society as disordered and less human. It

Yergeau (2013) refers to the essay as both auto-ethnography and autie-ethnography, giving credit to Irene Rose (2005) who first coined the term to describe the tradition of life writing of autistic self-advocates and activists going back more than 30 years. Rose (2008) sees them as more than autie/auto biographies rather, important in “facilitating attitudinal change” (Rose, 2008, p1). She speaks of the common practice within Autistic autobiographical narrative to reference other autistic biographers about autistic experience that they have in common, and Rose proposes that this has transformed these autistic biographies into ‘testimonio’ as an act of reclaiming our stories and telling them from an Autistic perspective. This term inspired by Couser’s (2008) work related to ‘Disability life narratives’ which asked disabled auto biographers to challenge the ‘poor me’ stories, to challenge the ‘I was better when I was normal’ stories. To write life narratives that oppose these types of stories that Stella Young (2012), the late disabled activist and comedian, describes as ‘inspirational porn’ (Yergeau 2013).

Rose (2008) feels that this collective response, via the echo of parallel experience, transforms autistic life narratives beyond the individual to a communal autistic community. By defining autistic experience from the ‘inside looking out’ instead of the biomedical model of nonautistic researchers describing autistic behaviour from the outside looking in⁵⁰, Rose states,

taught me that autieethnography, coupled with analysis, was able to inspire new more positive autistic identities.

⁵⁰ Donna Williams and autistic author and self-advocate stated in her book, *Nobody Nowhere*, “...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced” (Williams, 2002, p.14).

“The proliferation of autistic life narratives [or what she also referred to as autie-ethnography] and the content of the lives they recount vividly flesh out and validate the lives of autistic people. In the space of ‘otherness’ that a diagnosis of autism can represent, these narratives work at a connective emotional level to resist the pathologisation of difference” (Rose, 2008, p.46).

In doing this over an extended period of time, with the help of publishers like Jessica Kingsley⁵¹ and Autonomous Press⁵², these authors have moved on to write other books which portray them as ‘experts’ in autistic lived experience and helps to reverse power relationships when collectively redefining the stereotypical views about autistic people. Ordinary autistic people speaking about ‘normal autistic experience’ as simply ‘different’ instead of seeing themselves through the pathologized lens as disordered, wrong, atypical, etc. (Rose, 2008).

Robert Rourke (2016) described autieethnography (this is the spelling I use in this thesis) in his blog where he references Yergeau’s 2013 article. Rourke states, autieethnography uses,

“Poetry, disjointed narrative and other forms of expressive writing [which] may be more akin to autistic empirical experience... This threatens the sanctity of academic, non-disabled ways of writing, presenting a normative academic persona that privileges a neurotypical, or normal cognitive functioning”
(Rourke, 2016).

⁵¹ Jessica Kingsley publishers <https://uk.jkp.com/>

⁵² Autonomous press <http://autpress.com/>

I was intrigued by these definitions of autieethnography and realised that I had been using this form of expression as an artist for years to describe my feeling of otherness as an undiagnosed autistic person to my audience. As a performance artist I use creative writing, employed disjointed narratives that were poetic and expressive, that did not follow any rules or conventions of grammar or punctuation. I also adapted these poetic disjointed narratives to portray my autistic experience via an all-encompassing visual and sensorial experience for an audience member.

I had been creating autobiographical performance for 20 years before I encountered the fact that I was autistic, at the age of 39, and my PhD three years later in 2016.

I was committed to articulate my experience of being autistic in the way I knew best, performance art, however this soon became much more than just performance due to my research into autistic culture and community, as well as my involvement with other Autistic women (cis- and trans-) and non-binary people. This was the beginning of my journey, alongside other autistic people, to building a positive Autistic identity. The performances evolved as the research evolved, articulating the transformative journey that I took as 'a person with autism', defined by the pathological paradigm, to an autistic person, with a culture and community that is defined by the neurodiversity paradigm.

Autieethnography a Form of Autoethnography

Autieethnography is a form of autoethnography and Carolyn Ellis, a communication scholar from America who has written extensively on autoethnography, defines it as

“an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis, Adams & Bochner, 2011, p.2). Autoethnography is telling a story concerning the self that is articulated “through the lens of culture” (Adams, Holman, Jones, Ellis 2015, p.2)

Autoethnographers use self-reflective analysis on their position as a researcher and encourage the reader to critically reflect on their personal lived experience, their understanding of themselves, and their relations with others within social and historical factors (Ellis, Adams & Bochner, 2011; Spry, 2001). Ellis et al (2011) claim that Autoethnography acknowledges the many ways that the research process can be affected or changed by personal experience. Researchers control many factors of the research including who, what, when, where and how the research is carried out, as well as choices that are made institutionally, and this is one of the many things autoethnography can reflect on and analyse (Ellis, Adams & Bochner, 2011). I originally had thought I would look at investigating women’s experience of being autistic but quite quickly realised, at the start of my PhD, that I had made an agential cut (Barad, 2007). Or to put it more simply, I had made a decision that was going to exclude a large number of people and change the outcome of my research. As soon as I joined the Tuesday university support group for Autistic women, nonbinary and trans people, I realised that I needed to expand my research questions to include nonbinary and trans people, as the last thing I wanted to do was exclude another marginalised group.

My research process is similar to what Ellis (1999; 2011) describes as ‘layered accounts’, which centres on the personal experience of the researcher alongside data. This is also related to Grounded Theory which looks at “data collection and the analysis process simultaneously”, (Charmaz, 1983, p 110). This project concentrated on my personal experience as a late diagnosed Autistic person alongside the rich data from the Super Autie Gang (SAG) workshops and, most importantly, the workshop participants, as well as theoretical analysis and relevant literature. Although similar to Grounded Theory (Glaser & Strauss, 1967), it uses ‘layered accounts’ to question my own practices, judgements, and principles and uses short descriptions or accounts from many voices and self-examination (Ellis et al., 2011). This was to make the reader aware of the evolving progression of my process as an autobiographical performance artist and researcher, and to make the reader aware of my emerging identity throughout the process of the research project. This is most apparent in the personal reflections and analysis on *The Adventurers of Super Autie Gang (ASAG)*.⁵³

At the beginning of my PhD, I became part of my research project by creating a piece of autobiographical performance, entitled *Adventures of Super Autie Grrl* (2017), and then adapted to *Adventures of Super Autie Grrl* (2017) eight months later, based on the knowledge I gained from the research and emersion in the Autistic Community, which told my story as a late diagnosed Autistic person⁵⁴. I would claim that this is an example of what Ellis (2004) and Fielding and Van

⁵³ Please see a written piece later in this thesis about the collaborative performance of ASAG, describing vignettes of the performance and the collaborative creative process, alongside analysis of the process and how this changed over time titled; *Personal Reflections and Analysis on The Adventurers of Super Autie Gang (SAG)* (p. 225-270).

⁵⁴ For more information on this see Appendix 6: Name Change from Super Aspie to Super Autie

Maanen (1989) call 'reflexive/ narrative autoethnography' (Ellis, 2004, p. 47). I argue this autobiographical performance was the start of my use of autieethnography, the autistic tradition of autoethnography I described above, and that this method of autoethnography developed and changed as the research project progressed. This is due to my belief that it was incredibly important to work with other autistic people and build a community that I hoped would create chances for social justice and cultural change (Adams, Holman Jones and Ellis 2015). This research evolved into something Ellis calls 'community autoethnography', however I would title it 'community autieethnography', which uses the personal experience of the researcher in conjunction with the community (Ellis, Adams & Bochner, 2011, p.9), where the stories and the research are co-constructed and co-authored. This is the case with the ASAG (2019) performances which were co-created and co-performed with five of the workshop participants, embodying our previous exploration about our experiences of being Autistic. The performance was about disseminating our discoveries with the wider world with the hope to develop cultural change.

Damian Milton also spoke about a concept he titled aut-ethnography⁵⁵ at an interdisciplinary symposium⁵⁶, in the talk titled: *Autism, Aut-ethnography, Interactional Expertise, Cultural Imperialism* (Milton, 2018). I observe that this aligns very closely with the other definitions of Autie-ethnography by Yergeau (2013), Rose (2008) and Rourke (2016). Milton states, "Unlike auto-ethnography which often

⁵⁵ Milton makes it clear that this type of ethnography has links to sociological and ethnographic field studies, such as anthropological studies (Grinker, 2010), qualitative and action theory used in the field of education (Greenstein, 2014; Greenstein, 2015; Blackburn & Smith, 2010), the work of the Autism Education trust, Building Collaborative communities (Wenger, 1998). This also links well to the representation of autism in media studies, and many forms of autoethnography which have been used by autistic scholars and activists such as Larry Arnold, Steve Graby, Remi M. Yergeau, and Hanna Ebben within the field of Critical Autism Studies (e.g., Runswick-Cole et al., 2016), Critical disability studies and Mad studies (see McWade et al., 2015).

⁵⁶ The symposium was titled: Autism, Anthropology and Lived Experience: An interdisciplinary symposium and held in Edinburgh, March 26, 2018.

seeks to construct a coherent narrative of self over time, to me an aut-ethnography (at least my experience/version) is a fragmented one, where snippets of information are formed into ‘rhizomatic’ patterns of shifting meanings” (Milton, 2018, p.11). Milton looked to the philosopher Deligny (2015) who worked with Autistic people whom were non-verbal or, at least, did not use mouth words⁵⁷.

I find an affinity with Milton’s interpretation of Deligny’s (2015) work in relation to my own experience as an autistic person, an artist and a researcher. My mode of *being* is a constant work in progress that is fragmented but also interconnected with other autistic people’s experiences. This was an important factor in relation to the use of Autieethnography to try and portray my experience as an autistic researcher in relation to autistic culture and people. It was important for me to build a collaborative community of practice with the workshop participants to ensure that autistic voices were at the centre of this project. That meant I needed to include my own experience as an autistic person throughout the research process in relation to culture at large and to the autistic community. My personal journey of discovery began with me as a ‘culture of one’ (Prince-Hughes, 2005), as I did not know many autistic people nor did I know of the similarities of autistic experience and culture. When I began this project, I was, for the most part, ‘a person with autism’ whose identity was defined by the biomedical model of autism, as I saw myself through the pathologizing lens as

⁵⁷ Firstly I want to acknowledge the complexity of Deligny’s work. Milton has some interesting ideas about his work in relation to the Autistic experience and ways of being that I find thought provoking in relation to his concept aut-ethnography. Milton explains that Deligny (2015) felt that autistic people had a connection to a very fundamental way of connecting to humanity and of being within the world through a ‘network’ which was outside of symbolism and language. Deligny interpreted the autistic people he was working with as an experience of the world that was outside of the idealised form of typical humanity, which he called “Humans-that-we-are” (Deligny, 2015; Milton 2016). Deligny traced the nomadic movements and walks of the autistic people he worked and lived with over time as a method to analyse their experience of the world. Deligny saw this way of being to be more like ‘maps’, where the process was wholly more important than the products, which were seen as continuously changing works-in-progress (Milton, 2016).

'disordered'. However, I did not identify with the cultural stereotypes of autism, so I went in search of other autistic people like me to try to create my own more positive autistic identity and a connection to autistic culture and community. I became quickly aware of the Neurodiversity movement and paradigm when I started my research, however the co-participants and co-performers that were involved in the research process for this PhD project from the beginning via the autistic social group, and the SAG workshops, helped me to embody this paradigm and to start viewing myself, and the autistic community, wholly through a neurodiversity lens.

The Beginnings of Embodied Autieethnography Performance: My Own Ethnographic Material as a Performance Maker

I have been a performance artist for 23 years and, looking back on it now, it was clear that I was articulating my autistic experience (that of an undiscovered autistic person) via my performance work. I also dealt with my own struggle with my gender identity that I now know was due to the entangled nature of my experience as an autistic person and my autistic interpretation of gender. I was influenced by early feminist performance art such as the work of Carolee Schneeman, Hannah Wilke, Valie Export as well as more current live artists working with one-to-one performance like Fiona Wright and Kira O'Reilley as they explore the 'scribed' body. I will discuss this further in the section titled 'Autobiographical Performance, Feminism, Queer Theory and the 'Scribed Body'' below.

My performances were always intimate in the way I interacted with the audience but, when I moved to the United Kingdom in 2002 to carry out a three-year artist

fellowship at the Bonington Gallery, I was introduced to one-to-one performance as a lone audience member in Fiona Wright's, *Stolen Dreams of Two Bodies (2003)* at the Bonington Gallery in Nottingham. As Rachel Zerihan (2009) defines these types of performances:

“One to One’ or ‘One on One’ or ‘Audience of One’ are all terms used to describe a performance that invites one audience member to experience the piece on their own. Such performance interactions generally last for around five or ten minutes, though they have been known to take anytime from one minute to one hour. Generally, they are site specific/based performances that can be described as drawing on live art aesthetics”.

This performance began (for me) with the artist opening the door naked and progressively putting on clothing that was strewn across the floor until they were fully clothed at the end of the performance⁵⁸. I also remember, distinctly, the performer looking at me through a small compact mirror and just making out her eye in the small round mirror as the performer had her back to me. This performance had a profound effect on me. I was really excited about the possibilities within this to create new relationships between audience and performer. One-to-one was interesting to me as it brought the audience from spectator to participant to collaborator - which I found exciting, that anything could happen in a one-to-one context, that you could create something new with audience members each time you interacted. I was also inspired by Fiona Wright's use of nonverbal communication, movement, dance and

⁵⁸ I later realised, after talking to other audience members, that half of the lone audience members experienced the opposite to me, where she began the performance fully clothed in the middle of the installation and opened the door fully naked at the end of the performance for the audience members to leave.

her use of a compact mirror to look at, perhaps 'stare back' at, the performance participants as it made me feel like I was a voyeur. This encouraged me to research Michael Foucault's (1977) theories on discipline and surveillance and the idea that people within institutions such as prisons, mental institutions and schools started policing themselves because they were either constantly watched or believed this to be so. This made sure that people were internalising the values and beliefs of dominant society and made it easier to see the 'deviants' of society. I also became concerned with the 'male gaze' (Mulvey, 1975). Garland Thompson in their article, *Dares to Stare* states, "Feminist gaze theory has articulated not only the normative heterosexual male gaze, but examines the complex identificatory tangle of how the female, Black and lesbian gaze operate in patriarchal society" (Thomson, 2005, p.32). I will discuss this further in the next sections, Autobiographical Performance, Feminism, Queer Theory and the 'Scribed Body' and Returning the Gaze. I began to make one-to-one performance (nine performances now in total since 2003) and continue to make them alongside more traditional, larger audience performances on stage or site specific.

I come from a fine art background and have always thought of my performances as moving, living paintings. My performance personas are live moving images; visual metaphors that question cultural norms and identities. These highly stylized personas are created by combining costumes, make-up, installation, dance, and text, with popular culture and/or historical content. The result is a series of strikingly bizarre personae, which the audience encounter, many times on a one-to-one basis. Within these intimate performances I want people to feel off guard, a sense of the uncanny, the surreal, where an individual does not know what is coming next. Royle

(2003) states that, “[t]he uncanny involves feelings of uncertainty, in particular regarding the reality of who one is and what is being experienced. Suddenly one’s sense of oneself (of one’s so called ‘personality’ or ‘sexuality’ for example) seems strangely questionable” (Royle, 2003, p.1). I would view my interest into the uncanny now as related to a constant feeling of being with liminal space, always in the in-between space, as an undiscovered Autistic and nonbinary person that there was some unconscious knowledge of my experience that I was not fully aware of consciously that ‘came out’ or emerged in my performance art making.

I wanted the audience to question reality, to know that their ‘qualia’⁵⁹ is not the only human experience there is. I wanted them to experience my existence, to feel confused and frustrated and struggle to ‘feel’ through our interaction or silent conversation. I wanted them to encounter the constant questioning of self (undiscovered Autistic self) that I knew, and to be constantly thinking about what I wanted from them, what they needed to do next and if what they were doing was ‘right’ or ‘wrong’. I propose that this experience within my one-to-one performance is an example of the ‘contact zone’ and shows the clash within social interaction between Autistic and non-Autistic people. In the *Arts of the Contact Zone* by Mary Louise (1991), the term ‘contact zone’ “... refer[s] to social spaces where cultures meet, clash and grapple with each other, often in contexts of highly asymmetrical relations of power, such as colonialism, slavery, or their aftermaths as they lived out in many parts of the world today” (Louise, 1991). I was concerned with the ‘asymmetrical relations of power’ that neurotypical people have when relating to

⁵⁹ Qualia, “the ways things look, sound and smell, the way it feels to have a pain; more generally, what it’s like to have mental states. Qualia are experiential properties of sensations, feelings, perceptions...” (Block, 2004, p.1).

Autistic people in social interactions. In *When Species Meet* (2008), Donna Haraway uses the idea of 'the contact zone' to suggest "how subjects are constituted in and by their relations to each other [...] It treats the relations [...] in terms of co-presence, interaction, interlocking understandings and practices, often within radically asymmetrical relations of power" (Haraway, 2008, p.216).

I did not know it at the time, but I was trying to express my own experience as an undiscovered Autistic person. The feedback I received from the audience was that I was captivating, mesmerising, and intimidating. I was unaware at the time that I was Autistic and was unsure why I wanted people to be intimidated. I know now that that was the way I felt most of the time around neurotypical people. I was confused by social interaction and never knew what to expect, and I wanted my audience to know what that was like, even just for five minutes. This powerplay between Autistic and non-Autistic people was my way to acknowledge that it existed. This unease and miscommunication could also be seen to relate to Damien Milton's (2012) 'double empathy problem'⁶⁰ and that I was looking at the problems of cross neurotype communication. My performances focused on nonverbal, or very minimally verbal, exchanges that worked with dance and intense eye contact to communicate with the audience. I often used intense eye contact for long periods with audience members. I now interpret this as my autistic nature seeping through, how long is eye contact acceptable before it becomes a stare, can you communicate through eye contact - would more intense eye contact not be beneficial to communicate to reach into someone's soul and imprint an understanding, or to communicate a way of being

⁶⁰ Please see a definition of Double Empathy problem on page 184 or more in depth discussion of research around the double empathy problem in footnote 66.

that is 'other'? Do we not need intensity to discover, to find out who we really are, to communicate with each other, is that not what really matters? Not some small talk understanding of a person.

I would describe this as now as 'neuroqueering' or performance. Nick Walker describes neuroqueer as "a verb: Neuroqueering as the practice of queering (subverting, defying, disrupting, liberating oneself from) neuronormativity and heteronormativity simultaneously" (Walker, 2021, p.160).

Neuroqueer (Walker, 2015; Yergeau, 2018; Walker, 2021) is inspired by queer theory (Foucault, 1980; Butler, 1990; Halperin, 1995) and I also notice many overlaps with the tradition of crip theory (Sandahl, 2003; Ramlow, 2009)⁶¹ to adopt the idea of queering (disrupting, challenging, disturbing, freeing yourself from societal norms). I would describe my performance work as neuroqueer performance which took inspiration from Carrie Sandahl's (2003) idea of *Queering the Crip or Crippling the Queer in solo autobiographical performance*. Sandahl states, "Queering and crippling are both theatrical and everyday practices deployed to challenge oppressive norms, build community, and maintain the practitioners' self-worth" (Sandahl, 2003, p.25).

My third one-to-one performance work was titled *Desire* (2005) (please see Figure 19)⁶² and was presented among other pieces at the National Review of Live Art,

⁶¹ However, Nick Walker does not take inspiration from Crip theory.

⁶² Please see <http://nettypage.com/> (go to live art and click on *Desire*) for more images of *Desire*(2005) also see <https://youtu.be/Beju5NfVZXI> to view *Desire (2005) at the Nottingham Castle, Nottingham* for the *In-between and Off-Site Future Factory*

Glasgow in 2005. This piece, in particular, looked at the medicalised body in performance. Fiona Wright was my mentor while I was creating this piece and introduced me to the photographs of hysterics in Salpêtrière asylum (please see Figures 20 And 21), her work was also influential in relation to her use of dance, movement and nonverbal communication.



Figure 19 Foster, A. (2005) Desire note the performance of the swoon (National Review of Live Art, Glasgow, Scotland)

A solo performance for an audience of one exploring the history of the performance of hysteria, sexuality, voyeurism and the hidden tensions of social interactions.

Desire muses about the swoon, or fainting, as one of the symptoms of hysteria and the lives of the 'hysterical women' in the black and white photographic

iconography of Salpêtrière asylum (see Figures 20 and 21). Hysteria was first spoken of in the fifth century and was an illness of women that were uncontrollably emotional or distressed to the point of irrationality and was, at its core, an excuse to pathologise the feminine and female sexuality. This was considered to be a common and chronic condition in women (Maines, 1998).

[REDACTED]

Figure 20 Photograph from Invention of Hysteria: Charcot and the photographic Iconography of Salpetriere (Didi-Huberman, 2003)

[REDACTED]

Figure 21 Photograph from Invention of Hysteria: Charcot and the Photographic Iconography of Salpêtrière (Didi-Huberman, 2003)

Many females diagnosed with Hysteria underwent various unusual ‘treatments’ at the hands of male doctors that would be seen as exploitative and unethical today. This included the common medical practice in western doctors of manual stimulation of the vulva through various methods to give the patient an orgasm (Maines, 1998). Another example of the unusual and unethical treatment of hysterics was Jean-Martin Charcot’s work with hysterics in the late nineteenth-century. He was a neurologist and anatomical pathologist. He held weekly lectures at a clinic in the Salpêtrière asylum in Paris which he titled, ‘Theatre of Hysteria’, where he asked hysterics to perform their ‘female malady’ for an audience of male physicians and often times non-clinical spectators (Justice-Malloy, 1995, p.136). Charcot would use hypnosis and pressure on parts of the body (including sexual anatomy) to help the women repeat their ‘spells’ of hysteria (Justice-Malloy, 1995), (please see Figure 22).

[REDACTED]

Figure 22 by Lurat, A. A depiction of Jean-Martin Charcot demonstrating hysteria in a hypnotised patient at the Salpêtrière. (Etching, 1888) view image here: <https://wellcomecollection.org/works/qrk3myu/items>

I performed the 'sexualised medicalised' body in a black and white Victorian dress to represent the black and white photos taken at Salpêtrière asylum of the supposable hysteric women and I performed a combination of a swoon, a symptom of hysteria, in conjunction with one of the main 'treatments' for hysteria at the time, an orgasm. I tap danced as part of this performance to portray the absurdity and obvious sexualised exploitation of vulnerable female patients that occurred within Charcot's 'theatre of hysteria' classes. I performed in a spotlight while the audience member stood in their own spotlight which was symbolic of the clinician role as complicit within these 'theatre of hysteria'. I tap danced towards the audience member (please see figure 23) and, as I got closer, I revealed a small pearl on my tongue.



Figure 23 Foster, A. Desire, performer tap dancing towards audience member (National Review of Live Art, Glasgow, Scotland, 2005)

I took a small box out of my handbag and placed the pearl in it and gave it to the audience member (please see Figure 24). This was symbolic of what I can only imagine to be the emotional and psychological trauma of the women who were subjected this 'treatment'. To complete the performance, I showed the audience member out of the dark room.



Figure 24 Foster, A. *Desire*, performer holds up pearl to audience member, (*National Review of Live Art*, Glasgow, Scotland, 2005)

On reflection, this was me trying to make sense of my “different”, I had been diagnosed with several mental health issues and struggled most of my life with depression and anxiety, alongside the fact I was undiagnosed autistic. I knew I was different in other ways. In relation to my sexuality, I identified as pansexual and was in a civil partnership with a woman between 2003-2013 at the time I was creating *Desire*(2005) and future work *Transgressions trilogy* (2007-9) that I write about next. I was fascinated with queering this performance of a historical figure in relation to hysteria as much as crippling it from the perspective of a person who identified at the time as having mental health issues.

I was interested in the ‘performance of hysteria’ and Foucault’s (1976; 1973; 1977) ideas about the categorisation of people into ‘normal’ and ‘deviant’, and the way this affects how people experience themselves. This is also related to Hacking’s (1985) ‘looping affect’⁶³

I relate very strongly to Goffman’s idea that people carry around ‘spoiled identities’, and at that time I felt I was broken, damaged and needed to be ‘fixed.’ But also, the feeling of ‘*otherness*’ that was so strongly in my experience that I could not identify with those around me. I was aware of my difference, but I did not know *how* I was different. Damian Milton makes reference to Goffman (1963; 2016) who Milton states “... [he] regards stigma as the disjuncture between the way someone acts and the way others would wish them to” (Milton, 2018, p.8). Milton discusses Goffman’s ideas about how people manage social communications by carrying a ‘spoiled identity’ that may be observable or unobservable (D. Milton 2018). Autistic people end up carrying a stigmatised identity, one that is coloured by our experience of internalised oppression and self-policing of the experience of not only our autisticness but also our gender, to try and fit into society’s idea of neuronormativity and heteronormality (Milton, 2018). Milton (2018) is careful to say this assumes a ‘self-awareness’ that is created by discourse, not a lived experience.

I rebelled against this stigmatised ‘spoiled identity’ in my performance work, looking to queer the interpretation of the hysterical women in Salpêtrière asylum. I had been called ‘crazy’ and ‘hysterical’ many times in my life and I identified with these women. I realised that had I been born in a different time, I could have been one of them.

⁶³ I discussed the ‘looping affect’ on pages 75-76. The looping affect is where certain types of people are categorised as ‘objects of scientific inquiry’ and this affects how these people then act. This creates a feedback loop where the categorisation changes due to the change in behaviour of the objects of study and vice versa (Hacking 1985).

I continued to make one-to-one performance in conjunction with stage performances and public workshops dealing with issues of my own transient gender identity and sexuality. I had always identified as queer, bisexual and then pansexual, but I also had an uncomfortable feeling of my gender identity that I could not put my finger on at that time (2000-2010). I was unaware there was a word for my experience and the closest expression of this at the time was trans. I now identify as non-binary and Autigender⁶⁴, as I feel I do not see myself as part of the gender binary system and I also feel my experience of gender is intrinsically linked with my experience of being autistic. I have discovered this over the process of the five years of my PhD, especially through my experience with the workshop participants, many of whom were trans and helped me to see, or to understand, that the unmasking of my autisticness also revealed that I was additionally masking my experience of gender.

Despite not knowing that I was Autistic and non-binary, I was part of the LGBTQAI+ community as a Bi/Pansexual woman in a civil partnership with another woman who was struggling with their gender identity. I felt affinity with the trans community and was extremely inspired by Judith Butler (1990; 2004) and Queer theory and, in 2006-2009, I developed a trilogy of work related to this topic titled, *Transgressions*. I created three characters that illustrated my experience of gender but also the queering of gender in relation to the heteronormative, gendernormative gaze and my return of that gaze as a queer (not yet discovered) non-binary person. I was inspired

⁶⁴ Autigender is under the umbrella of neurogender to describe how someone's gender could be affected by their neurotype, neurological differences and mental health issues (LGBTQA Wiki n.d.). There are numerous neurogenders connected to many neurodivergences including Autigender which is the description of a gender that is deeply influenced by the experience of being autistic. Autigender individuals feel that their identity and their experience of being autistic are interlinked, and that their experience of gender can only be comprehended from the perspective of being autistic (Munday, 2021).

by Butler's idea that 'gender' is a performance. In their book *Gender Trouble* (1990), Butler proposed that gender roles such as 'masculine' and 'feminine' are socially constructed, not biologically set. I was really interested in Butler's (1990) idea, that one performs gender, it is an act, it is something that you do, the expression of gender is not something that you are (Butler, 1990). I wanted to portray through these characters that the performance of gender can also be ambiguous, that my experience of gender was transient and that much of the time I felt in-between the gender expression of masculine and feminine.

I understand now I was creating agency for myself in confronting that heteronormative, gender normative gaze and queering the audience's experience of this non-normative depiction of gender. The performance trilogy I created, *Trangressions* (2006-2009), adopted three different personas which question our cultural ideologies of sexuality and gender construction. Each character makes explicit the performativity of gender, challenging audience perceptions of gender-bending and sexual attraction by fusing androgynous 1930s Hollywood icons such as Marlene Dietrich and Fred Astaire with historical drag queens, drag kings and trans-gender identities. This triptych includes stage performances with accompanying one-to-one encounters where the audience member can go 'backstage' to meet the performer.



Figure 25 Foster, A. *Trangressa* from the *Trangressions Trilogy*, (*Transcabaret*, Nottingham, 2007)

The first character, *Trangressa*, (2006-2007) (please see Figure 25)⁶⁵ who I identified at the time as a queer drag queen or bio queen⁶⁶, was tribute to Judith Butler's theories of the performativity of gender (Butler, 1990; 2004). The uncannily glamorous *Trangressa* performed a disturbing, absurd, yet seductive performance to *My Heart Belongs to Daddy*, merging elements of drag, burlesque, cabaret, contortionism, and contemporary dance. *Trangressa* begins to deconstruct drag and transgress away from gender. During this time, I also developed and facilitated drag workshops titled "*Drag it Up, Drag it Down*", with another queer performance

⁶⁵ Please see <http://nettypage.com/> go to Live Art, *Trangressa* for more images of this performance

⁶⁶There are many words for this type of dragqueen, and I would see it now as a queer nonbinary 'hyper'queen or a female impersonator, impersonator.

artist, Tom Marshman, as a part of our mini festival of trilogy works at the Arnolfini, Bristol, titled *'Hello My Name is Sue, How Do you Do?'*(2009), (please see Figure 26).



Figure 26, Foster A. & Marshman, T. Drag it Up, Drag it Down Workshop (Arnolfini, Bristol, 2009)

These workshops were for people to explore drag - I made it clear to the participants that they could play with the expression of gender however they liked, all genders had the option to explore dressing in drag as hyper 'masculine' or 'feminine' characters or somewhere in between. There were no rules, I wanted people to know that that they could express themselves via 'queer drag', 'dragging' however they wanted to that day and that this might change in the future. I felt it was important to work with people in the community and share my joy of 'playing around' with gender and drag. I also wanted to encourage people to explore their own drag characters to

allow people to express their gender in different ways that did not conform with the mainstream heteronormative culture (please see Figure 26). I wanted to show that drag did not have to be about just hyper 'masculine' and 'feminine' but about the in-between experiences of gender like my own experience of gender, as androgynous, that I had not fully grasped yet.



Figure 27 Foster, A. *Marlene Dandy one to one*, (Greenroom, Manchester, 2009)

The second character, *Marlene Dandy* (2007- 2009), (please see Figure 27)⁶⁷, is a bearded ballerina and burlesque dancer, another non-binary expression of gender: a

⁶⁷ Please see <http://nettypage.com/> click on Live Art then Marlene Dandy for more images of this one-to-one piece and the stage performance of *Marlene Dandy* (Greenroom, Manchester 2009) You can view the video documentation of this one to one here https://youtu.be/K8Srw_4ybMQ

combination of hyper femininity with an element of a drag, and performance of nonconforming gender⁶⁸. The final character was a tap-dancing drag king called Daddy Long Leggs (2008-2009), (Please see Figure 28)⁶⁹ .



Figure 28 Foster, A. *Daddy Long Leggs*, (Arnolfini, Bristol, 2009)

The description I wrote of the piece in 2009 seems very telling, looking back from my perspective of someone who was unaware of being autistic and nonbinary, how I was unintentionally masking these parts of myself. The description of this

⁶⁸ This refers back to my MFA final performance, *Nobody Loves a Bearded Lady* (1997), which looked at my experience of gender, or more my difficulty with performing femininity, my experience of having polycystic ovarian syndrome, where I had excessive hair growth on my face and chin, and the family connections with the circus.

⁶⁹ Please see <http://nettypage.com/> click on Live Art then Daddy Long Leggs for more images of this one-to-one piece and the stage performance of *Daddy Long Leggs* (Arnolfini, Bristol 2009)

performance states, “the impossible task of trying to become someone else. A piece about trying to be someone else, trying to be yourself, and where the two meet. This piece aims to explore the possibility and impossibility of becoming the 'other' and the un-realness of binary opposition” (Foster, 2009). Daddy Long Leggs is a tap-dancing drag king obsessed with the impossible task of trying to become Fred Astaire. Daddy Long Leggs creates a magical alternative reality in her studio, she dances obsessively until he becomes their idol. This speaks so much of my struggle to understand my identity as an undiscovered Autistic non-binary (Autigender) person.

This tryptic of performance works and workshops was inspired by performance artists working with drag. Such as Diane Torr⁷⁰ (UK) who was an interdisciplinary performance artist and held drag king workshops and the artist Vaginal Davis's⁷¹ (US) performance, experimental film and video practice. Dominic Johnson (2017) is quoted as saying she is a “homo-core punk movement and a gender-queer art-music icon... [and] the key proponent of the disruptive performance aesthetic known as terrorist drag” (Vaginaldavis, 2017). My multidisciplinary performance work for Transgressions (2007-2009) was also inspired by the photography of Del LaGrace Volcano⁷² and their books *Drag Kings* (1999) and *Sublime Mutations* (2000).

These performances are examples of precursors to my discovery of embodied autieethnographical performance. I was describing and documenting my experience of being autistic, pansexual, nonbinary and autigender, *my difference*, without my full, conscious knowledge. My work made apparent that I was strongly aware of my

⁷⁰ <http://dianetorr.com/>

⁷¹ <http://www.vaginaldavis.com/>

⁷² <https://www.dellagracevolcano.se/>

alignment with feminism and queer theory and the idea of 'the performance of gender' (Butler, 1990), however I was not fully aware of how I was portraying my own experience of gender as a nonbinary autistic queer person. This was an intuitive knowledge about my 'difference' or 'otherness' that I could not express in words at the time, but clearly expressed as visual and embodied performance art.

Autobiographical Performance, Feminism, Queer Theory and the 'Scribed Body'

Linda Park-Fuller (2000) sees autobiographical performance as often a voicing of acts of societal transgression and, in this action, the telling of these accounts can be transgressive in itself (Park-Fuller, 2000). Park-Fuller (2000) states autobiographical narrative performance is "a revealing of what has been kept hidden, a speaking of what has been silenced - an act of reverse discourse that struggles with the preconceptions borne in the air of dominant politics" (Park-Fuller, 2000, p. 26).

Although the author is talking about staged personal narrative performance specifically, I feel that this applies to feminist and queer artists' works and my own work in relation to this PhD. This use of reverse discourse directly relates to feminist and queer theory and practices. This kind of performance usually involves the performer who is acting as the 'subject' and 'object', is usually situated as a member of a group, or could be a representative for an invisible, or marginalised group (Park-Fuller, 2000, p.22).

I was influenced by feminist artists from the 1970's such as Carolee Schneeman, Hannah Wilke and Valie Export and their use of the female body in performance. In particular, the early performative and photographic images of their portrayal of the sexualised female body and of the idea of the male gaze (Mulvey, 1975). The male gaze is an act of portraying women in visual culture from a heteronormative masculine perspective, "...whose desiring gaze takes the female as its object, she [Mulvey] emphasized the way that sexual difference is articulated in structures of looking..." (Chaudhuri, 2006, p.121).

These artists reappropriated the male gaze and objectified themselves and their body as a way of forcing the viewer to investigate their own involvement in the subjugation of women (Forte, 1988). In doing so, these artists also disassemble the patriarchal fabrication of 'woman as object' (Forte, 1988; Wentrack, 2014). These artists offered novel representations in art of the female body and sexuality (Wentrack, 2014).

As an example of this work, I was inspired particularly by Carolee Schneemann's *Interior Scroll* (1975), which was a reaction to sexist comments filmmakers had made about her work⁷³. The performance concluded with Schneemann extracting from her vagina a scroll that she proceeded to read aloud to the audience (Horne, 2020) including text about the interaction she had had with a sexist filmmaker and his refusal to look at her work as it was, filled with "the personal clutter, the persistence

⁷³ The first performance of this work was at an exhibition where the artist started by undressing and then wrapped in a sheet reading aloud from her own book, *Cezanne, She Was a Great Painter* (Schneemann, 1975). She then applied paint on various parts of her body and held a series of life modeling poses one after the other (Horne, 2020). Please see an image of this work here <https://www.tate.org.uk/art/artworks/schneemann-interior-scroll-p13282> and <https://fineartmultiple.com/blog/carolee-schneemann-interior-scroll-masterpiece/>

of feeling, the hand touched sensibility, the diaristic indulgence, the painterly mess..." (Schneemann & McPherson, 1997, p.238)⁷⁴ This piece inspired me, due to its relation to writing the body. Ann Rosalind Jones (1981) writes about how Schneemann's work appeared around the same time as French Feminists were writing about this extensively in the theories of e'criture fe'minine (Cixous, Cohen & Cohen, 1976) where they theorized 'feminine' writing and sexuality had a revolutionary possibility to deconstruct patriarchal heteronormative culture. As Jones (1981) points out, although Schneemann was not directly inspired by French Feminists it is hard to not draw parallels with this work and the idea of 'writing herself' (Cixous, Cohen & Cohen 1976). Cixous states in *Laugh of the Medusa* (1976), "Women must write herself, must write about women and bring women to writing, for which they have been driven away violently from their bodies...Women must put herself into the text- as into the world and into history- by her own movement" (Cixous, Cohen & Cohen 1976)⁷⁵. Schneemann did this by literally pulling a written scroll out of her body and reading it, by documenting these performances and placing herself as subject and object and author in the art history books.

As a queer feminist, I was inspired by this work and by other artists such as Gillian Wearing, specifically her work titled: *Signs that Say What You Want Them To Say*

⁷⁴ This performance was shown again in 1977 at the Telluride Film Festival in Colorado, because she had just found out that her film was going to be screened under the demeaning label, '*The Erotic Woman*' (Horne, 2020).

⁷⁵ The work from the French feminists and e'criture fe'minine has been in many ways seen as essentialist in its idea that only 'the feminine' was silenced by patriarchal society. However, many people were not included as equals in hegemonic society, anyone seen as 'other' or not adhering to the white heteronormative, neuronormative societal norms such as LGBTQAI+ people, as well as Black, Indigenous, and People of Color (BIPOC), and disable people. I see this second wave of feminist work, the reassessment of women's role in society as a necessary step, to the better understanding of the intersectionality of the human race and the importance of inclusion and representation of all people.

and Not Signs that Say What Someone Else Wants You To Say (Wearing, 1992-1993)⁷⁶ where she goes a step further and asks the public to become active and willing participants in the art making (this being very similar to how I described elements of one to one performance and bringing the audience from spectator to participant to collaborator). Wearing (1992-1993) asked strangers on the street to write with black marker on a piece of paper their thoughts and feelings and hold it up for her to photograph. This form of public performance and the act of witnessing, and making visible, stranger's invisible truths influenced the creation of my own 'signs', applied signs and art pieces that I used to create a dialogue with the public in my performance *Autistic Action* series (2015-2017). In these series, I wanted to include the public as witnesses and observers in my invisible reality as an Autistic person, and my experience of having an invisible disability by holding a sign up in public that stated the simple word, 'Autistic' and taking photographic and video documentation of this. This also commented on the heteronormative male gender bias in Autism research and the invisibility of women (cis- and trans-) and non-binary people in this research.

⁷⁶ To see images of this work please go to this website: <https://publicdelivery.org/gillian-wearing-signs/>



Figure 29 Foster, A. *Theory of Mind*, (Applique, 2015)



Figure 30 Foster, A. *Autistic Sign* worn in *Autistic Action 3* and in *Adventures of Super Autie Grrl* (2017), (Applique, 2015)

The applique works, such as *Theory of Mind* (Foster, 2015) (please see figure 29), *My brain and its Reticular Formation* (2015) and the simple appliqued sign *Autistic* that was used in an Autistic Action (Foster, 2015)⁷⁷ (please see figure 30) were also

⁷⁷ Please see pages 41-67 of this thesis for more information about this performance.

influenced by Tracey Emin's applique autobiographical works such as: *Everyone I Have Ever Slept With 1963-1995* (Tent, mixed media, 1995-1996)⁷⁸. This piece of work is a tent that is covered in appliques made out of her own used clothing and textiles which spell out the names of one hundred previous lovers and friends she had slept in a bed with (Jefferies, 1997). This and other works by Tracey Emin, including her autobiographical quilt work series including *Psycho Slut* (Applique blanket, 1995)⁷⁹, used a very traditional form of textiles that represented stereotypical norms of femininity, such as the embroidery sampler and quilting (Hemmings, 2002). Janis Jefferies in her article *Autobiographical Patterns* (1997) points out that Emin's work shattered the oral and visual stories of stereotypical representation of the 'feminine'. Tracey Emin defied stereotypes and portrayed her own darkness, her own truth, that did not fit into stereotypical binary oppositions for masculine and feminine sexuality. She spoke of stories filled with chaos, danger sexual energy and anger, of self-destruction, abortion, and debt (Jefferies, 1997).

Tracey Emin is quoted in an interview by Anita Chaudhuri saying, "It's boring to say that confronting these experiences and making beautiful things out of them is something of a therapy for me... it's something much darker than that," (Jefferies, 1997; Hemmings, 2002). Emin is pointing here to transgression of traditional stereotypes of the feminine within her work and patriarchal societies' fear of the 'monstrous feminine' that still lurks below the surface and which threatens the sanctity of patriarchal heteronormative society (Jefferies, 1997, p.18).

⁷⁸ To view photographs of this artwork *Everyone I Have Ever Slept With 1963-1995* (Tent, mixed media, 1995-1996) by Tracey Emin go to this link <https://www.widewalls.ch/magazine/tracey-emin-everyone-i-have-ever-slept-with>

⁷⁹To view a photograph of this work *Psycho Slut* (1995) by Tracey Emin please go to <https://www.sfmoma.org/artwork/99.490/>

As part of my performance in *Adventures of Super Autie Grrl* (2017; 2018), I physically scribed on the body a representation of the internalised ableism I experienced at the time as a late diagnosed Autistic queer person. I tried to write the language of ableism and my experience of invisible disability on my body with Sharpie marker. I wore this like a skin of internalised ableism throughout the performance with bits of this 'spoiled identity' (Goffman, 1963; 2016) showing through where it was not covered by my clothing which was also two layers thick; the outer layer of clothing representing my 'masked' or shielded self that tried to appear 'normal'. Under this layer my Super Autie Grrl Costume was a representation of my positive, more authentic autistic identity.

The performance artist Kira O'Reilly⁸⁰ also created work that scribed on the body with wounds in a very different way from my work. My experience of attending her one-to-one piece titled: *Untitled Action* (2005) at the National Review of Live Art in the Glasgow Arches (2005) influenced my work. I was a performer at this event and performed my one-to-one piece, *Desire* (2005), next door to Kira O'Reilly's performance. Her one-to-one piece, where she asked people to either use a plaster on one of her cuts or create one small cut into her skin with a scalpel, was very influential as she invited people to be complicit in this act of cutting or not cutting, soothing. It was incredibly powerful to be a part of this time that was so incredibly personal, private and 'real', and it made me think about responsibility, I was

⁸⁰ For more information about Kira O'Reilly's please see her website <http://www.kiraoreilly.com/>

responsible for cutting her⁸¹. I was also fascinated to discover that her work was also inspired by the 'presenting, performing treatments for hysteria' (Zerihan, 2010, p.36), no wonder our two one-to-one pieces were set next to each other.

In Zerihan's (2010) article about this work, she states that O'Reilly acknowledged that her work⁸², was;

"...a visceral critique by how women had been 'treated' as hysterics... In displacing the acts of treatments from the private, sterile medical environment and resituating them into performance spaces of ritual, O'Reilly exposes traditional structures of patriarchal power, reclaiming her body from the pain historically inflicted upon it at the hands of (male) doctors of hysteria..." (Zerihan, 2010, p.36).

This was a modern portrayal of the 'treatments' of hysteria and the medicalised body. Kira O'Reilly's portrayal of the medicalised body and her performance of scribing the body with an actual physical 'cut' as a subversive act, is a restatement of the power structures that stain the feminine body as 'other', 'hysterical' and destructive. I feel the inclusion of one-to-one performance participants in this act

⁸¹ My memories of the piece were of signing a waiver form and being handed a sealed envelope that had an invitation that stated, if I desired to, I could make a 'cut' on her body⁸¹. I remember being asked to put on surgical gloves before I entered the white space where O'Reilly sat with her slightly bloodied, scarred and naked legs stretched out on what looked like a doctor's table. In front of us was a large television screen on which the live video feed of the performance played. She asked me to sit down next to her, I was excited and nervous as I had heard about, and I was intrigued by, the visceral nature of her work. I stared at all the scars on her legs from the other 'skin' live art performances. She then said something like, 'Some people want to make a mark, others use plasters' (Zerihan, 2010, p.38). I chose to cut her skin, as I wanted to experience the performance fully. I remember being incredibly shaky and wanting to be so careful. She then said after I cut into the skin on her thigh something like, 'oh that was a deep one, but don't worry'. I felt so incredibly bad that I had cut her, that I had caused her pain and immediately wished that I had chosen a plaster instead. She then asked me if I could hold her while she sat on my lap in a 'pieta pose'. We did this and sat in silence for what seemed like forever. I felt how strong and fragile humans are. Rachel Zerihan (2010) also describes this piece in her article, *Revisiting Cathartis in Contemporary Live Art Practice: Kira O'Reilly's Evocative Skin Works* (2010).

⁸² Seven works that concerned the marking of her skin between 1998 and 2005.

further illuminates the complicit nature society holds in perpetrating this hegemonic patriarchal mindset about 'difference', different minds, different bodies.

This piece and the other works I have mentioned are hugely influential to the embodied autieethnography performance piece created for this PhD *The Adventures of Super Autie Grrl* (2017;2018), especially the section which I title *Membrane*⁸³. In this piece, I marked my body with sharpie marker attempting to show the internalised ableism I felt, and to confront the negative language used to describe autistic people within the pathological paradigm, which affected my self-esteem and identity as an autistic person.

Returning the Gaze

My work was not one-to one, however I did also ask people to volunteer to come on stage one at a time and write words of my choosing related to things that people called me, and things I learned to call myself, such as: stupid, crazy, too sensitive, weird, loner, strange, hysterical, touchy. In doing so, I also made the audience members aware of the complicit nature of these words and when we used them to describe other people. I then asked people to help me wash off these words, to try to free my body from the internalised ableism that these negative words perpetuated. This was not an easy process, and my skin became red and raw from the scrubbing off of permanent marker.

⁸³ this is written about in greater detail on pages 67- 73 and in Appendix 11

I also want to note a connection between this act and that of Carrie Sandahl in her piece *The Reciprocal Gaze* (Sandahl, 1999, p. 25). I was not aware of this piece before I created *Membrane*, however there is clearly a connection between our work and the idea of the ableist gaze, as Eisenhauer explains,

“In this performance, Sandahl walks outside while wearing a lab coat and white pants completely covered in red text as well as drawings of a spinal cord and hipbones (Thomson, 2005). As she encounters people's stares, she hands them a piece of paper that details her medical history. The text on her clothing includes common comments and questions that she experiences in her everyday life, such as. Are you contagious? I bet the Easter Seals could help you. Do you ever dream that you're normal? Along with these questions, she includes drawings of her scars drawn to size and in the exact location of the scars on her body. Adjacent to the scars, are the names of the doctors that performed the surgeries” (Eisenhauer, 2007, p.13).

This work also looks at returning the ableist stare, which is directly related to the male gaze and society's reaction to nonnormal bodies or brains. However, my work was making visible something that is invisible to the naked eye: my own internalised ableism and the affect that had on my self-esteem and identity as a disabled autistic person. Sandahl's (1999) work was a reaction to the ableist stares related to her physical disability.

The aim of my performances of the *Autistic Actions* (2015-2017)⁸⁴ and *Adventures of Super Aspie/Autie Grrl* (2017) was to make visible the invisible starting with myself, to hopefully create a dialogue with the public. To make people stare at me, to stare at the physical label autistic around my neck, to stare at the words of internal ableism written on my naked body. In my past work I invited people to stare at a nonbinary representation of gender expression and I stared back. I feel that I have shown how all of my examples of performance artwork as a multiply neurodivergent queer artist is in line with other Disabled artists that forced the audience to stare. As Rosemarie Garland Thomson analyses in her 2005 article about three artists Cheryle Marie Wade, Mary Duffy and Carrie Sandahl, these artists “purposively enlist and manipulate the staring dynamic to mount a critique of dominant cultural narratives about disability” (Thomson, 2005, p.32). I propose that my work is in line with these traditions. Thomson proposes that “Staring is thus a kind of potent social choreography that marks bodies by enacting a dynamic visual exchange between spectator and a spectacle. Staring, then, enacts a drama about the people involved” (Thomson, 2005, p.32). This includes the people who are different and the audience, or *the starers*.

Other artists that influenced my performance work for this PhD include *the Vacuum cleaner projects* such as *Madlove* (2013-16)⁸⁵ where the artist carried out seventeen workshops in England and Europe and worked with people who experienced mental health issues, and psychiatric ward patients, to redesign mental health wards in

⁸⁴ Please see pages 41-67 for more information about this performance.

⁸⁵ For more information about this artist see, <http://www.thevacuumcleaner.co.uk/madlove-a-designer-asylum/>

hospitals. This series of workshops and artworks is important as the artists had had their own experiences of mental health and wanted to collaborate with neurodivergent people, specifically those who have experienced mental health issues, to try to invoke real physical change within the hospital. I can see parallels between this piece and the articulation and creation of autistic spaces like Autreat and Autscape and the sensory experience of neurodivergent people in a world that does not understand their experience of neurotypical society⁸⁶.

Embodied Autie ethnography Performance

Once I decided to carry out this PhD, I understood that I had always been researching and exploring theories that interested me through performance and live art. I wanted to use this in a more formal way through practice as research to explore my experience of being autistic. However, these practice as research performances needed to be more rigorous, portraying my personal experience as a queer late diagnosed autistic, dyslexic, person with attention differences but also convey the knowledge I was acquiring as a researcher looking at autism research and autistic culture in a much more conscious way. I also wanted this embodied performance research to show the changes that I went through in relation to what I learned from academic research and practical research via the SAG workshops that immersed me in a community of autistic people for the first extended period of time. The term

⁸⁶ Other works that influenced the participatory nature of the work feminist work of Nicola Caravan a project titled *Raising the Skirt* (2014) and Nic Green's participatory project *Trilogy* (2007-09).

'autieethnography' described this process to me, however this was only referred to as non-neuronormative writing. I felt that I have always expressed myself better and more wholly via visual art and performance, and that I should extend autieethnography to an embodied performance that changed over time, that was embodied by the researcher. The practice as research embodied autieethnography performances of *Adventures of Super Aspie Girl* (2017); *Adventure of Super Autie Girl* (2017; 2018) and the collaborative performance, *Adventures of Super Autie Gang* (2019) portrayed the knowledge that was gained through the research and how I, as a researcher, changed in response to this new knowledge.

As an artist, I was using autobiographical performance to describe and communicate my experience without total conscious knowledge of the origins of that experience. Within my academic research, I was aware of the depth of unconscious knowledge in my creative work that could inform the research, however I wanted to untangle this to be more conscious and thorough by researching autism research and embedding myself within autistic scholarship, culture, and community. I was aware that this immersion of myself in an autistic community and embodying my identity as an autistic person in a more positive and informed way via self-advocacy and academia would change my perception of myself. I aimed for this to be documented via embodied autieethnography performance for the length of my PhD.

The only scholar that I found who wrote specifically about Autoethnography performance was Tami Spry (2001) in her article; *Performing Autoethnography: An Embodied Methodological Praxis*, especially in the importance of the body and embodiment. She states that,

“Autoethnographic performance is the convergence of the ‘autobiographic impulse’ and the ‘ethnographic moment’ represented through movement and critical self-reflexive discourse in performance, articulating the intersections of peoples and culture through the innersanctions of the always migratory identity.... [and]...calling on the body as a site of scholarly awareness and corporeal literacy” (Spry, 2001, p.711).

I agree with this definition and see the body as site of academic awareness and visceral learning and knowledge very important to Autieethnography, specifically due to Autistic mind and bodies, and our fundamentally different experience of the sensorial world. Autistic mind/bodies experience the sensory world differently, especially in relation to differences in how we receive, filter and understand sensory information that affect communication, thinking, socialising and moving (ASAN, 2020). Spry (2001) also writes about how autoethnography stories are written on and come out of the body in a continual cycle of observations, insight and analysis of the residual marks of culture inscribed on us and through connections with others in various environments. These visceral embodied texts reject the idea that the only way to represent lived experience is through references to quotes from fieldnotes, observations or interviews (Spry, 2001). Without this embodiment through ‘doing things’ physically, such as creative workshops and performances, I feel that embodied autieethnography performance would not be fully realised.

The practice-as-research performances *Autistic Actions* (2015-2017), *Adventures of Super Autie Girl* (2017; 2018) and the collaborative *Adventures of Super Autie Gang* (2019) are examples of embodied autieethnography performance. A form of autobiographical performance that is akin to autoethnography or ‘autie’ethnography

in my case incorporating my lived experience as a late diagnosed autistic person. Autieethnography in the past has been referred to as the use of 'lived experience' of the researcher within research described with the inclusion of creative writing and photographs in academic text (Yergeau, 2013; Rourke, 2016; Milton, 2018). I feel that embodied autieethnography performance has taken this form one extra step to articulate autistic sensibility that cannot always be articulated in words, those words have not been invented yet. Autistic Culture and Community via the Neurodiversity paradigm are just starting to create words to describe our experiences, words like stimmy, flappause, neurotypical, neurominority, neuroqueer and autie gender, are the tip of the iceberg when it comes having words to describe the experiences of autistic people. I would also state that words cannot describe everything and this form of autieethnography acknowledges that we can start to learn to create and articulate our experience as autistic people in nonverbal more embodied forms with the uses of multidisciplinary methods of communication that incorporate more sensorial forms of experience. Borrowing from Queer theory and neuroqueering the way we communicate and identify as people. Examples of these other forms of communications via multidisciplinary performance art in The Super Autie Grrl and Gang Performance's (2017-2019) include visual elements created for the performance: Super Autie Grrl appliques and costume; the specially designed ear defenders covered in flowers, feathers and pompoms created for the co-performers to model; the objects and visual imagery we chose to present on stage, such as a large map of my Autistic brain drawn on the stage with different colored electrical tape to demonstrate with 13 audience members (as sensory information) how an autistic brain feels in overwhelm; video art of Autistic Actions; PowerPoints created by co-performers articulating their version of autopia; and five autistic people dancing

in their own personal Overwhelm Avoidance Devices (pop up tents). I also feel that the Inclusion of (autistic) movements on stage, such as stimming, toe walking and autistic mannerism and cultural use of the deaf clap, flappause, allowed for an expression of a more embodied experience of autistic culture.

I am a multidisciplinary autiegender queer performance artist who uses embodied autieethnography performance to communicate and articulate my ever changing 'lived experience' of this PhD. I hope that the community of practice that was created via the project of *Neuroqueer Pioneers* and the articulation of Autieethnography performance will give autistic people more forms to express and communicate autistic experience and help to allow other autistic voices to express themselves in alternative forms that work more naturally for them.

Section 2

Underpinning Methodology and Methods

The questions I asked were:

- 1.) What does it mean to be AWCTN+?
 - a. What does it mean to be AWCTN+ from a neurodiversity paradigm perspective and from the traditional psychological/biomedical perspectives?
- 2.) How can live art and performance provide a space to articulate the lived experience of AWCTN+ people?

Methodology and underpinning philosophy

It is important to state that first and foremost I am an artist - my world view and work is messy, chaotic, creative, and challenges bounds. Readers need to remember this whilst reading my thesis. My approach to this thesis is also unashamedly messy, chaotic, and creative. Nelson (2013) who is the seminal writer on practice as research in the arts refers to the importance of this messiness, by describing it as akin to the difficulty of containing a form of knowing that is in liquid form;

“ the importance of close-up, tacit, haptic know-how, seeks a means to establish as fully as possible an articulation of ‘liquid knowing’, and a shift through intersubjectivity into the know-what of shared and corroborated soft

knowledge, in turn resonating with the harder know-that of established conceptual frameworks” (Nelson, 2013, p.60).

I return to the concept of academic messiness (Campbell & Farrier, 2015) in my discussion at the end of this section 2. Overall, I use a phenomenological approach as I am interested in exploring the lived experience of the participants of this project, or what an individual instantaneously experiences for oneself (Burch, 1990). I would like to explore and somehow capture a little bit of the ‘qualia’ of my participants. Qualia meaning “to refer to the introspectively accessible, phenomenal aspects of our mental lives... [and] the intrinsic qualities of its bearers” (Tye, 2018). I am interested in the participants unique sensorial experiences, how they relate to their environment or physical world, and to each other. Within this project I incorporated the ethics of new materialism (Barad, 2007), which melds elements of realism and relativism⁸⁷. I have also borrowed concepts described within queer and crip theory (Giffney & Hird, 2009; Sandahl, 2003) feminist science studies (Barad, 2007). From this point of view, I ask whether the dominant biomedical and heteronormative paradigms traditionally underpinning autistic research are sufficient.

My research is emic in nature as I am interested in capturing the experiences of AWCTN+ people, as I am a part of this group myself. I immersed myself within this community who are both ‘discovered’ (biomedical diagnosed) or self-discovered. This allowed us (the participants and I) to explore, describe and perform the experiences of AWCTN+ people. I recognised that a component of my participants’

⁸⁷ Please see pages 10-15 of the introduction.

qualia were nonverbal, which I address by incorporating practical creative approaches within this project. I recognise the subsequent paradox that using the written words to describe these events will reduce and lose aspects of these non-verbal and kinaesthetic experiences. I also remain aware of my need to bracket my experiences, to the extent that is possible (Spinelli, 2005), but recognise that the knowledge is co-created with my participants (Charmaz, 1990). I acknowledge that human experience is intricate and multifaceted, is based in the world, and has meaning, and which the participants and I experience intersubjectively (Bevan, 2014).

This thesis also adopts the neurodiversity paradigm in order to represent the diffractive view of the entangled nature of my participants, who are simultaneously within and between the neurodiversity and biomedical paradigms. My hope is that my findings will contribute to the iterative and evolving knowledge about what it is to be late-discovered autistic people who identify as a woman (either cis-- or trans-) or non-binary people. I recognise that the concept of autism within the biomedical model appears in tension with the lived experiences of autistic people - with this project I aimed to add new insights to both paradigms.

Queer PaR Neurodiversity and the Queer movement

In finding the gap and the relationship between my research and theory, I have struggled to define AWCTN+ people experiences and by what -ism to articulate their experience theoretically. After the SAG workshops, feminism felt essentialist and not inclusive enough to include all autistic people that present in a non-stereotypical

way. I also was looking for something that encapsulated the two very important elements of my PhD; firstly, the idea of taking the word 'autistic' back, or re-appropriation and making it our own as a culture and secondly, recognising that gender identity has also been an enormously important issue in relation to this project and should be recognised.⁸⁸ After the workshops and making these realisations, my journey led me to discover Queer and Crip theory. This influenced the creation of the final performance of the Adventures of Super Autie Gang. Crip and Queer theory captures the ethos of the SAG workshops and performances especially in relation to criping and queering the stereotypical hegemonic representation of autism. I wanted the SAG workshops to focus on the phenomenological experiences of participants without the value judgements of neurotypical society, for participants to see the value in their view of the world and that they should be proud of being autistic and their uniqueness as individuals.

Queer as a Theory

When it comes to defining and explaining Queer theory, it is challenging as it seems there is not one definition of queer. The idea's of Queer theory are entangled within culture and the political climate of each person, each generation using it. Queer Theory is ever changing and aligned only with the idea that it is an analytical theory

⁸⁸ I have always identified as bisexual/pansexual and then as queer, however I have discovered through this project that my need to identify as queer was not only due to the prejudice that bisexual people receive from both the gay and straight community. Moreover, I have never felt I was a woman or a man and that if I had had the option when I was a teenager or young adult to identify as non-binary, I would have. This discovery and my identification as she/they is due to me being immersed in an autistic and queer environment throughout this project, as ten out of the seventeen autistic people in the group identify as LGBTQIA+, and six out of the seventeen participants identified as non-binary or trans-. I have learned so much from being a part of this community that was accepting of my own pansexuality, where LGBTQIA+ groups in the past have been judgemental of this identity.

to confront and breakdown established classifications and "... is continually renewing and reinventing itself in response to changing social and political climates" (Ramlow, 2009, p.131).

As David Halperin (1995) states in one of the seminal texts for queer theory, *Saint Foucault: Towards a Gay Hagiography* (1995), "... 'queer' does not name some natural kind or refer to some determinate object; it acquires its meaning from its oppositional relation to the norm. Queer is whatever is at odds with the normal, the legitimate, the dominant" (Halperin, 1995, p.62).

Another reason I am interested in queer theory is its messiness (as I stated earlier, life as an autistic person is chaotic and unruly), its resistance to definition, the fact that it is constantly challenging, the inflexibility and stiffness of identity categories and their imposition (Giffney & Hird 2009). As a queer autistic person, I have rallied against my own categorisation as; stupid (dyslexic), clumsy and disorganised (dyspraxic), crazy (autist and reacting to ableism), difficult (autistic), militant feminist (queer feminist autist who believes in equal rights vehemently), lesbian or straight (bi/pansexual/ non-binary) my whole life. It could be said that Queer theory is for PaR practitioners that see their field work like 'liquid bodies of knowledge' (Nelson, 2013) sloshing around, spilling information, revealing here, coming out there, for some practitioners that feel they can, and they must, take radical pride in their difference so that they can help make the world a better place (Campbell & Farrier, 2015).

I am also interested in the idea that as a discourse analysis, Queer theory "...takes very seriously the significance of words and the power of language" (Giffney & Hird, 2009, p.7). Language is very important to the key early authors of queer theory such as Judith Butler (1990) and David Halperin (1995). As I stated earlier, for any kind of paradigm shift there needs to be close attention paid to the language used to discriminate against non-normative identities, such as queer and autistic, and to the creation of new language, to give back power to the disenfranchised. It could be said that queer theory and queer activists caused a paradigm shift in many ways. I see it in the students that I teach; their ideas about gender and sexuality are much more fluid and open. This process helped me to discover that I am non-binary and, if I wish, I can identify with the pronouns of she/they (and that there is room for this description of she/they instead of original non-binary pronouns: they/them). It shows this shift in reference to the lack of vocabulary for many to even describe their experience as young people even 30 years ago.

The definition of Crip in relation to Queer as a word, an identity, a theory

Crip theory is developed by Sandahl and McRuer from the outset with the analogy with queerness in mind (Sandahl, 2003; McRuer, 2006). 'Crip' is seen in many ways like the word 'queer' - both of these words have been reclaimed by the actual community that they were intended to oppress. Hutcheon and Wolbring (2013) state that,

"...by using the terms 'cripping' and 'crip,' instead of 'cripple' or 'crippling,' one may claim, strategically, that a host of well-meaning diagnoses, labels, treatments, options for intervention, and medical cures have the potential to be unwelcomed by

— *if not harmful to — the individuals they are designed to ‘help’* (Hutcheon & Wolbring, 2013).

As Sandahl states, similarly to queer, the word cripple is, “..fluid and ever changing, claimed by those whom it did not define” (Sandahl, 2003, p.27). The term ‘queer’ was an insult directed at the homosexual community however, it has become as an expression of pride for the queer LGBTQIA+ community, which is much more inclusive of people of different sexualities, relationships, sexual practices and genders. The term ‘crip’ since early twenty first century has also expanded to include “...those with sensory or mental impairment” (Sandahl, 2003, p.27).

Ramlow (2009) states that both Queer and Crip theory were influenced by Foucault, specifically in his work *Madness and Civilisation* (1965); *The Birth of the Clinic: Archaeology of Medical Perception* (1973) and *Discipline and Punish: The Birth of the Prison* (1977). Where ‘bodies’ were constructed as a kind of ‘objects’ which were categorised and organised into the ‘normal’ and the ‘deviant’, which were liable to penal controls that permeated civilization. Bio-, sexual-, gender- and neuro- diversity of human being do not exist as differences without the normative categories that are, “... socially constructed norms and values that uphold existing ideological practices, extend the grasp of normativity and organise (heteronormative and compulsorily able-bodied) societies” (Ramlow, 2009, pp.133–34). I suggest this could mirror concepts in relation to autism – compulsory sociality and neuronormativity.

Ramlow (2009) speaks about the influence of Foucault and Constructivism, and how it unlocks the reading of disability, which was “ ...previously the exclusive domain of

the biological, medical, and rehabilitative professions, as a new field of cultural studies". She believes that constructivism creates the potential case that disability is a not always "a pathological or even biological condition as it is a cultural condition, a marginalized group identity..." (Ramlow, 2009, pp.133–34) that has a past story of injustice and marginalization, a branded classification produced for the benefit of the overriding belief system (Ramlow, 2009). It could be said that autistic community and culture is just as, or more, important than the prominence of the pathological condition for autistics people's quality of life.

Neuroqueer

I also want to introduce the idea of neuroqueer - a word coined by several autistic academics as the neurodivergent or autistic experience of crippling or queering.

Neuroqueer was somewhat concurrently created by Nick Walker, Athena Lynn Michaels-Dillon and M. Remi Yergeau, and these authors agreed on a definition written in 2015 by Nick Walker in a blog post (Walker, 2015). Neuroqueer is similar to queer and crip in its use as a verb and an adjective.

"And as an adjective, neuroqueer can also serve as a label of social identity, just like such labels as queer, gay, lesbian, straight, black, white, hapa, Deaf, or Autistic (to name just a small sampling)" (Walker, 2015).

As they put it, "you are neuroqueer if you are neuroqueer" (Walker, 2015). However, they also set out other definitions of types of neuroqueers, neuroqueerings and neuroqueerness (Walker, 2015).

Walker's (2015) definition of neuroqueer is very wide and includes many variations to identify a person who is neuroqueer including:

You are neuroqueer:

- if you are neurodivergent and your attitude about your neurodivergence is understood as a practice of queerness, in which you see neurodivergence in a way that is comparable to the way the word queer or crip is comprehended in Queer, Crip and Gender studies and queer or crip self-advocacy (Walker, 2015).
- if you are queer and neurodivergent and consciously approach how these two facets of your identity interconnect (Walker, 2015).
- if you are out as neurodivergent and intent on conveying or rejecting pressure to suppress your neurodivergence in similar ways to the idea of queering one's performance of gender, sexuality, ethnicity, disability or other facets of an individual's identity (Walker, 2015).

I was not wholly aware of these definitions when this project began however I believe that this PhD project is an example of neuroqueer practices, and the aim of the project was to speak to the heart of Walkers (2015) definition of neuroqueer to engage *"... in practices intended to 'undo' one's cultural conditioning toward conformity and compliance with dominant norms, with the aim of reclaiming one's capacity to give more full expression to one's neurodivergence and/or one's uniquely weird personal potentials and inclinations..."* and *"...Working to transform social and cultural environments in order to create spaces and communities – and ultimately a society – in which engagement in any or all of the above practices is permitted, accepted, supported, and encouraged"* (Walker, 2015).

Section 3

Methods

I used a PaR approach to explore the lived experiences of adult AWCTN+ people who were all late-discovered autistic University of Kent students.

As explained in the introduction, my solo performances have driven the design of nine creative workshops that provided opportunities to uncover new insights into the lived experiences of AWCTN+ participants. I then conducted a series of one-to-one interviews with eight of the workshop participants and, using elements of grounded theory (Glaser & Strauss, 1967) blended with thematic analysis, analysed the transcriptions and generated a number of themes. Grounded theory "...emerges from rigorous data analysis, not from adopting preconceived theories" (Charmaz & Belgrave, 2015, p.2). Thematic analysis is an iterative method of coding and pinpointing themes from rich data (Hewitt & Cramer, 2011). Furthermore,

"Thematic analysis is a method for systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set. Through focusing on meaning across a data set, TA allows the researcher to see and make sense of collective or shared meanings and experiences. Identifying unique and idiosyncratic meanings and experiences found only within a single data item is not the focus of TA. This method, then, is a way of identifying what is common to the way a topic is talked or written about and of making sense of those commonalities" (Braun & Clarke, 2012, p.57).

These emergent themes were used to evolve my original solo performance of *Adventures of Supe Autie-Grrl* into a co-created final performative piece entitled *Adventure of Super-Autie Gang*. This final performance included five of the workshop participants, which provided the audience with a wider representation of our lived experiences than my original solo performance. *Adventures of Super Autie Gang* (2019) was also designed to involve the audience; we provided an innovative and unique experience by inviting the public to literally step on to the stage and walk with us in our AWCTN+ autistic world.

I will also analyse the final performance of *Adventures of Super Autie Gang* (2019) by using the same phenomenological methods as the one-to-one interviews. The data I will use will be derived from: focus group with co-performers; feedback via Facebook messenger from co-performers; and my own self-reflection on significant moments from watching the videoed performance. This will be situated at the end of the discussion.

The one-to-one interviews and focus groups are "...a way of collecting qualitative data, which – essentially - involves engaging a small number of people in an informal group discussion (or discussions), 'focused' around a particular topic or set of issues" (Wilkinson, 2004, p.177).

In addition, I will watch the video recording of the performance to reflect on, and analyse, the performance using antiethnography and Crip- and Queer- theory as the

analytical frame. I will present these results, including my reflections and analysis, along with illustrative quotes where appropriate.

As mentioned previously, as part of my PhD I created *Adventures of Super Aspie Grrl* (2017) (Appendix 5)⁸⁹: a one-hour solo performance articulating my experience of being autistic over the first year of my PhD 2016-17 and premiered this solo performance at the *Autism Arts Festival* April 30, 2017. The solo performance of *Adventures of Super Aspie Grrl* (2017) included the video pieces *Autism Action 2*, *OWAD*, applique pieces and *the Letter to Simon Baron-Cohen* performance piece discussed in this introduction. Throughout my PhD, this solo piece has been an evolving practice research project continuously adding, deleting and refining as a response to my own academic and self-advocacy research. This was as I began to be a part of an autistic community via the University of Kent Tuesday Group and as I learnt about autistic community and culture at other events such as *Autism Arts Festival* (2017), *Autescape* (2017), and the *Participatory Autism Research Collective Conference* (2018).

The solo performance further developed from feedback from audience members, especially from the autistic community, and continued to evolve into *Adventures of Super Autie Grrl*⁹⁰ in November 2017 where I performed a revised version for *Disability History Month* at the University of Kent. I also performed a shorter 30-

⁸⁹ Please see photographic documentation of *The Adventures of Super Aspie Grrl* (April 2017) for *Adventures of Super Aspie Grrl* Photo Documentation [REDACTED] and Appendix 5 for the script of this performance.

⁹⁰ Please see video documentation of *Adventures of Super Autie Grrl* (Nov. 2017) here: [Adventures of Super Autie Grrl performance](#) and photographic documentation of this performance [REDACTED] and Appendix 10 for the script for this performance.

minute version of the *Adventures of Super Autie Grrl* at the *Invisible Festival* at Rich Mix, London, April 2018. This script became the beginning material for the final rendition of the collaborative *Adventures of Super Autie Gang (ASAG)* created and performed with workshop participants for *Autism Art Festival* in April 2019.

My own artistic creations and performances, including applique pieces, Autistic Actions 1, 2, OWAD performances and video, *Adventures of Super Aspie* (April 2017) and *Autie Grrl* (November 2017), were keys to developing the subjects of the participatory workshops used in my PhD. The final participatory reinvention of my original solo performance (*The Adventures of Super Autie Grrl*⁹¹) where I collaborated with five of the workshop participants to incorporate the key findings from the workshops which celebrated the breadth of their experiences in *ASAG (2019)*⁹².

I carried out nine two-hour workshops with late diagnosed AWCTN+ people (see Table 2 below). In order to make sense of the rich data collected via the workshops, I interviewed eight participants about their experience of the workshops (listed as participants 1-8 in Table 1 below).

Workshops

I recruited⁹³ all participants via a number of channels: social media, University of Kent (UoK) postgraduate email newsletters, student support and wellbeing groups,

⁹¹ Please see the script of *Adventures of Super Autie Grrl* in Appendix 10

⁹² Please see video documentation and script of *Adventures of Super Autie Gang Performance* in Appendix 12 or for Photographic documentation: [REDACTED]

⁹³ Please see recruitment poster in Appendix 13.

autistic support groups, mailing lists and Kent County Council autistic support group for women. I also invited participants from the Tuesday Group, a support group for AWCTN+ people that I had been attending for the past year and a half before I started the workshops. Initially, I had aimed to recruit ten AWCTN+ people but I anticipated that some would not be able to attend every session. I therefore recruited a total of seventeen participants.

At the outset, I asked participants to attend at least five out of nine sessions. However, I soon realised that this was ambitious due to the nature of ongoing participatory studies and the needs of autistic attendees with co-occurring conditions such as depression and anxiety. Additionally, autistic sensory overwhelm on a regular basis in their everyday lives made it difficult for students to attend every session as shown in table 1 below.

Table 1 Participant Demographics and Workshop attendance

Demographic					Workshops Attended									
No.	Age	Gender Identity	Sexual Identity	Ethnicity	W1	W2	W3	W4	W5	W6	W7	W8	W9	Total
P1†^	21	non-binary	LGBTQ+	Irish/ Saudi	X		X	X	X	X	X		X	7
P2†^	19	cis- female	straight	Asian Hong Kong	X		X	X	X	X	X			6
P3†	21	cis- female	LGBTQ+	White British	X	X								2

P4†^	19	cis- female	ACE ⁹⁴	Asian Hong Kong				X	X	X	X			4
P5†^*	18	cis- female	straight	White Barbados	X	X	X	X	X	X	X	X		8
P6†^	20	cis- female	ACE	White German			X		X	X	X	X	X	6
P7†^	20	cis- female	LGBTQ+	White British		X		X	X		X		X	5
P8†^	19	non-binary	LGBTQ+	White British			X	X	X	X	X		X	6
P9 ^	34	cis- female	straight	White British	X	X	X	X	X	X	X	X		8
P10	21	cis- female	LGBTQ+	White British		X								1
P11^	20	trans- F-M	LGBTQ+	White British		X	X	X	X	X	X			6
P12	20	cis- female	straight	White British		X	X	X		X			X	5
P13	19	cis- female	straight	BAME British			X	X	X					3
P14^	20	trans- M-F	LGBTQ+	White British				X	X	X				3
P15^	19	trans- F-M	LGBTQ+	BME British				X	X	X			X	4
P16*	23	non-binary	LGBTQ+	White British	X	X	X	X		X		X		6
P17*	45	cis- female	straight	White British									X	1

* SYA participant

^ Tuesday (autistic) group/ UoKA participant

† One to one interview participants

⁹⁴ ACE stands for Asexual, a sexual orientation which is a broad spectrum of people that have different experiences of sexuality, where they have little or no sexual attraction or sexual desire (Catri, 2021)

Participant Characteristics

All participants were University of Kent undergraduate and postgraduate students with a median age range of 20-years-old. The cohort were mostly from the southeast and southwest of England, but several were international students from China, Germany, India, and Bermuda. One participant was Afro-Caribbean British, some other participants' parents came from Ireland and Saudi Arabia. All of the students were either late diagnosed or self-discovered autistics, some awaiting diagnosis and others not. Many of the participants identified as LGBTQIA+ (including sexual orientation and gender identities), nine out of 18 participants identified as LGBTQIA+, two participants identified as asexual (ACE), two participants identified as non-binary, and three participants identified as trans- (two participants were female to male trans- and one male to female trans-). Three participants changed their names to a gender-neutral name during the time period of the workshops and used these names in the sessions as a trial run before using that name more formally.

Data Collection

Workshops

I used a wide variety of materials and techniques to guide and facilitate the workshop sessions in a creative way. Participant information sheet, consent form, a detailed description of the workshop outlines and session guide can be found in Appendix 15, and a sample session guide is in Appendix 16.

Between February and June 2018, I ran nine workshops on a number of topics (see table 2 below); each workshop lasted two hours and were held in a studio at the School of Art, University of Kent.

Workshop number	Title	Aims	Attended	Date
W1	Appliqué 1	Three workshops looking at developing a positive word/s or slogan to describe their experience of being autistic and appliquéeing this onto a piece of clothing or fabric.	6	18/2/18
W2	Appliqué 2		8	20/2/18
W3	Appliqué 3		10	06/03/18
W4	Stimming 1	One of two workshop to explore the autistic experience of stimming and stigma of stimming. This workshop also explored the experience of visual/ light. Task: Documentation of stimming on video and audio and <i>Night Light Activity</i> .	13	13/03/18
W5	Sound	To explore autistic experience of sounds and music. Task: to explore and document liked sounds and autistic sounds including echolalia.	12	20/03/18

W6	Stimming 2	Second workshop to explore the autistic experience of stimming and stigma of stimming. To explore autistic experience of the happy stim, smell and masking. Main task: Stim Movement, Stim Circle and Pretending to be Neurotypical.	12	27/03/18
W7	Object Description 1	One of two workshops exploring the experiences of being autistic through objects. Task: To bring three objects to describe your experience of being autistic and describe this and any story of the object.	9	15/05/18
W8	Object Description and performance movement	Second workshops exploring the experiences of being autistic through objects. Task: To bring three objects to describe your experience of being autistic and describe this and any story of the object. Recreate your object story into performance.	4	22/05/18
W9	Fantasy Safe Space	One workshop exploring 'autistic space' and personal safe sensory spaces. Task: To identify your sensory preferences and create a representation of your fantasy safe space with electrical tape on the floor. Allowing participants to identify personal boundaries and sensory profile.	6	05/06/18

Table 2 Brief Description of Super Autie Gang Workshops

- W1-3 enabled participants to develop a positive label or slogan to describe their experience of being autistic.

- W4 and W6 focused on stimming and masking.
- W5 focused on sounds.
- W7 and W8 enabled participants to bring in objects that represented their experiences and to tell their story using these.
- W9 enabled participants to describe and design their individual ideal 'Safe Space'.

I recorded the workshops with video, audio and photographic documentation where appropriate; I remained sensitive to the vulnerability of the participants and the personal nature of the subject matter we were discussing.

In between workshops, I encouraged all participants to become more aware of their sensory experience; to creatively explore look/feel/smell/taste and listen to what to be an AWCTN+ person. I also encouraged them to keep a sketchbook, diary, voice- or video-diary throughout the process, which was designed to focus the participants attention on each of the different senses. These were to encourage participants' self-exploration and were not used in any part of this study.

I also setup and moderated a private Facebook group for Super Autie Gang participants to make it possible to communicate with attendees about homework or anything they wanted to share with the group outside of session time. The other aim of setting up the group was to provide a forum for the participants to connect and build a community online, which some autistic people might find easier to engage with.

In the first few workshop sessions, I concentrated on developing a rapport with all participants, creating a 'safe autistic space' so they would feel comfortable enough to share their personal experiences of being autistic with the rest of the group. This openness and 'safe autistic space' was essential to start building this community. All workshops had a designated 'chill out' room, which I provided for participants; somewhere they could access if they needed a quiet space to retreat to, outside of the workshop space.

The Overwhelm Avoidance Device (OWAD) developed as part of *Super Aspie Grrl* performances was present in every workshop for participants to use if they deemed it useful. I curated the workshops to be an 'autistic space', designed to ensure lighting, sound, and all other sensory stimulation remained at levels that did not overwhelm participants. The *OWAD* was used several times during the workshops.

Interviews

Following the workshops (between February 27, 2019 and March 28, 2019), I conducted eight one-to-one interviews with eight workshop participants, resulting in 378 minutes (6.5 hours) of interview data being recorded and transcribed. To ensure coding rigor I went through two coding processes: 1.) line by line coding of each participant's transcript. 2) line by line coding of transcripts that had been grouped by interview question resulting in a between-participant coding. An example of a within-transcript coding is found at appendix 17 and the question-by-question coding at appendix 18. Codes from both processes were conflated and axial codes derived from both processes, which then generated the final subthemes and main themes.

I will present the main themes and subthemes below, supported by illustrative quotes. All direct quotes are italicised and identified by a participant number at the end of each quote. To assist the reader, I have extracted extraneous material and signify this with ‘...’ and, in addition, may add contextual text within the comments, which will be non-italicised and contained within brackets.

Images and descriptions of all *Super Autie Gang* (SAG) Workshops activities can be seen in appendix 19, including the Appliqué workshops 1,2, 3 (Appendix 19.1).

Ethics

Ethical approval for this study was obtained from the Faculty of Humanities Research Ethics Advisory Group for Human Participants on 8th February 2018 - (ref 0271718). I worked to follow the University of Kent’s ‘Research integrity code of Ethics practice for research’ (Palmer, 2009) and I aimed to make sure my research was ‘honest’, and ‘rigorous’ in all aspects of research (Palmer, 2009). I worked to be ‘accountable’ for my actions and have ‘transparent and open communication’ in reporting of data and sharing research findings. I also worked to make sure that I had ‘training and skills’ to carry out my research which included training in programs like Mendeley for referencing, qualitative research and interview techniques to name a few (Palmer, 2009). Above all, I was concerned for ‘the care and respect’ of the participants that took part in SAG workshops (2018) and the SAG performance (2019) (Palmer, 2009).

All participants taking part in this research were fully informed via a participants' information sheet outlining who I am, the purpose of the research, what they were expected to do if they chose to participate, what data would be collected, and how data would be collected (please see Appendix 14). Participants gave informed, signed consent to take part in the research. Participants were made aware that their participation was voluntary and that they were free to withdraw at any time. Participants were also made aware that they did not have to take part in any aspects of the workshops, or answer any questions, that they did not feel comfortable with, and they did not have to give any reason for not doing so. Participants were also given instructions on whom to contact to ask for more information, including information about the complaint process.

Participants' confidentiality was respected within this project and, in written documentation, participants' identity was kept confidential by referring to them as a number e.g., Participant One.

Information collected during this study was held confidentially by the researcher in line with the UK Data Protection Act 1998. Only the researchers involved in the study will be authorized to access the data.

Participants also gave informed consent in the use of photographic and videoed documentation of the workshops to be used for research purposes and presentation of that research. Prior consent was obtained for access to identifiable personal information and before using any sensitive personal material in a presentation of that study.

One of the main ethical issues arising from the study was the possibility that by exploring and articulating autistic experience of AWCTNB+ people, this might, and sometimes did, bring up sensitive, personal, medical, and psychological material that participants might find distressing. Participants were informed of this risk in the participants' information sheet and I consulted with the University of Kent disability team about how to support participants as autistic people throughout this project.

As an autistic person myself, I also have insight into the needs of autistic people from my own lived experience and was keen to develop relationships with an autistic community to have a more well-rounded experience of autistic people. It became clear to me early in the PhD that the autistic community is highly diverse and as varied as any nonautistic community. I also made sure that in each session there was a discussion on how to make the environment of the workshops an autistic space for all and asked the participants themselves the best way to support them in the sessions. I joined the Autistic social group that many of the participants are a part of almost two years before the SAG workshops. This gave an opportunity for participants to get to know me as an autistic person and a researcher, and develop a trusted relationship. Due to this involvement in the autistic social group, participants could address any issues they had that came up during the workshop with me (which gave me useful feedback) but also under the supervision of the disability advisor and mentor running the autistic support group. I also supplied sign posting information and referral leaflet for disability and mental health issues which might arise as a result of exploring personal experiences via the workshops.

This project took inspiration from the position of the Participatory Autism Research Collective (PARC). Their main ethos was that they sought to create a community where autistic people could have meaningful involvement in autism research (Fletcher-Watson et al., 2019). This also meant that I wanted to respect the lived experience of all the participants and that I considered them researchers and experts via lived experience right alongside me.

Participants' involvement in the live performance and documentation work of Adventures of Super Autie Gang (2019) was consensual. All performance participants were asked to give consent for Adventures of Super Autie Gang performance as part of the Autism Arts Festival to be live streamed and documented.

During the Autistic Social Group meeting I attended outside of SAG workshops, one participant started to talk about their negative experience of stimming and the first stimming workshop I facilitated. The participant became upset as they felt that they did not have any positive stims to share with the group. I felt it was very important to have that space for participants to share their experiences of the workshops and their feelings about the issues in the Autistic Social group, which was facilitated by a Student Support and Wellbeing mentor and disability advisor on the Autism Support Team. I spoke to the participant and we talked about the possibility that they did have positive stims but that they were unaware that they were positive stims. We also spoke about the stereotype perpetuated by the DSM and the medical model that all autistic stims are 'symptoms' of Autistic Spectrum Disorder and seen negatively. I

suggested that at the next session we could reclaim and explore positive stims with the group. That we could all try to embody and share each other's stims in an attempt to recognise and remember our own positive stims that we had simply forgotten due to internalised ableism, or we were unaware they were actually stims. I changed my thinking about the importance of recognising and identifying positive stims as part of the workshops due to this interaction for the welfare of the autistic participants. This participant came to the next sessions and shared a positive stim they titled, 'the dad dance' (P1) and they admitted in the interview that, at the time, they did not know if this was a stim but they knew that they did do it when they were happy. The above example shows how I worked with the participants to find ways to carry out research that was respectful and genuinely concerned with the wellbeing of the participants in relation to the research. P1 stated this about their participation in the SAG workshops: *"...I really didn't have many or really any reservations about being safe or explaining things you wouldn't understand, or I didn't feel like a subject...In other studies, sometimes you feel like a test subject and you get that even when you talk to doctors and stuff...especially if you have a late diagnosis they say that is curious can you tell me about it because it is new and I like data. I don't care that you are a human being...but there wasn't, there didn't feel like there was any relation of authority, as like an unequal one, it didn't feel like there was an unequal relationship because you were taking part with us and you were leading them but you'd never force anyone to do something..."*. Above all I was very concerned with treating the participants with respect and honesty. However, I sometimes got it wrong and I was always willing to be honest with participants and try to rectify the issue as soon as possible via workshops design or ethos.

Section 4

Results

Themes emerging from the Super Autie Gang (SAG) Workshop

Theme 1: Autistic Connectivity/Autistic Space

1.1 Connecting with Self

Connection with self was important, P2 wanted to “*develop [their] understanding and my connection towards my autistic...background*” and felt it “*...was an opportunity to explore yourself and also explore anything related to autism*”; This was often the first time participants had thought about this “*cuz [they] didn't really know much about it [being autistic] at that point*” (P5).

1.2 Connecting with Others/Community

Participants had differing experiences of the autistic community. Some explained “[I did not spend time with autistic people] *before coming into the group, not that I know, I mean obviously now it turns out my family, but now that I know of that, like that they [the workshops] taught me they [my family members] are autistic!*” (P6). Some were already aware of liking community; “*I like being around other autistic people, it's kinda nice to socialise in [the workshop] setting*’ (P3), and for others it was relatively new, “*I was still integrating myself into the community and still learning about everything. And I think that [the workshops] really helped, just exploring things*”.(P6) One participant described their experience of the autistic community as: “*It's kind of like just letting a bunch of cats into a room or something and just let them do what*

they want, you know? Just like letting a bunch of autistics loose in a room, you know, having fun being autistic...it [the workshops] felt a bit like that" (P8).

Participants also explained that their experiences during workshops allowed them to feel more joined to the autistic community, *"I feel more connected to the people who are identified as autistic and I feel that yes I am definitely a part of this group"* (P2) and that this was related to communication styles, stating *"...it's just nice to, you know, communicate with autistic people, ...not really have that barrier of... neurotypical / autistic, trying to... It's not quite a language barrier, but it's that kind of, you know, communication differences at times"* (P8).

Inter-autistic socialising was seen to be unique, *"...our normal is kind of different. I mean, like say, eye contact in the group it's normal for us to not be able to make it but like, outside, it's kind of like... not. So... that's really nice that you kind of feel like there's a normal autistic kind of experience, like not doing eye-contact, and how that's accepted within the group and within the workshops. It's kind of like there's autistic normal and then neurotypical normal"* (P8). The freedom to not socially engage was valued, *"I like being able to sit in the back and just draw or something. Yeah, it's nice to be able to just sit in the back and not be pestered to be involved"* (P5). The ease of autistic friendships was noted *"...now we are all friends, kind of... or even if we aren't friends in whatever traditional sense it is, we all can like hook up and spend time together and have fun and still go our separate ways and there are no problems"* (P1). P3 described the autistic community as: *"mutual understanding and empathy instead of just knowledge [of autistic experience]"* (P3). This participant was comparing this experience of the autistic community with their

friendships with non-autistic people, in particular a friend who was neurodivergent but not autistic, and had some knowledge or their experience based on their own neurodivergence.

Subtheme 1.3: Heterogeneity, Textures of Autism

There was also recognition of the breadth and heterogeneity of the autistic community. It was found that this autistic community was also very diverse and intersectional, participants were struck by the sharing of similarities but also differences and the acceptance of difference within the autistic community.

P4 commented on how there is a whole spectrum of different autistic people, *"...it's called the spectrum. I love that. It's not just me, me, me, me, there's a whole spectrum and I might fit in like here and, I might fit in a little bit there"*.

P8 comments on the different types of expressions of autism among the community, *"...Yeah. I mean, I got to see more like different types of autism maybe, like different expressions, might be a better phrase. Yeah"*.

P6 found the fact that autistic people were different but also similar an important discovery for them during the workshops, *"Also the notion that we're all like, really different in the way that we, like, show our traits and like the traits we have, but we're still really, really similar. It's that finding, finding the differences and finding the similarities at the same time that was really cool"*.

Participants were struck by the importance of seeking commonalities in autistic experience in the workshops but also acknowledging and celebrating difference.

This appears to be perceived by participants as a theme of the workshops from the

beginning. P3 participant only attended the first three workshops however they felt that this was one of the central motifs, and they stated *“I think it was looking at the sort of shared experiences or ways we differ, I think it mostly focused on women but also non-binary folk. And kind of looking at the textures of autism”*. Participants learned from sharing with SAG participants and the sharing of the other members in the group. This allowed them to see similarities with other autistic people that they had not been aware of before. This sharing was helpful to validate their experiences as not just unique to them, but that they shared many commonalities with other AWCTN+ participants of SAG. P3 thought that they *“learned that [they] have a lot more in common [with other autistic people] than I thought I did which again was really validating. Especially when you notice your mannerisms [autistic traits] in other people that is cool. I don’t know about you, but I used to think I was a robot or an alien and no one told me that and I didn’t get what was different”*. P7 states when talking about the benefits of the SAG workshops in relation to finding shared experiences, *“there was stuff I did which I thought was literally just like a weird thing that I only did, and it turned out to be a very common thing [among SAG participants]”*.

Being in an autistic community allowed participant to learn about other autistic people and to recognise shared behaviours. For others it highlighted gaps in knowledge about being autistic, *“I didn’t even realize that you know, there’s a bunch of sensory issues, ...social communication things...it never occurred to me, I just assumed that they [autistic people] would just be really good at maths and really good at sciences. And okay, no, admittedly, a bit socially awkward”* (P4), or enlarged their view, *“so I gained a broader outlook to identify myself as autistic... doing the*

workshop it really made a much bigger connection [with other autistic people]" (P4). Participants felt they could get valid support from other autistic people: "...well, it's support from the community. It's about that. They know what I would be going through. And it would feel less like an invalidation, because they [autistic people] were like they will say, 'No, what you're feeling is completely valid'...I got advice from autistic people, how they had dealt with this, how they dealt with the stress, how they got around the stress, how they, you know, and it was really beneficial for me to hear about this" (P4). Participants felt that they could be themselves in the SAG workshops and be able to take off the shells or masks they usually wear, "Well, I didn't [spend time with other autistic people before the workshop], I think it's like we got a lot closer actually, for the most part, because like, we were able to sort of accept each other for who we are. Rather than just like, keeping our shells on, I suppose" (P7).

Subtheme 1.4: Future connections

Participants were anxious about not having an autistic community when leaving university, where there might not be an understanding of difference: "...I don't know how Autism is well received in the working society because if this classifies as one of the disabilities to yes technically it's not a disability and people aren't good at accepting of different people ... that makes me really anxious still" (P2). However, some recognised they could play a part by creating an autistic space at work, "My work do know I'm autistic, hence they wanted me to like, consider starting on a Tuesday like groupesque type thing" (P7). Others were fearful about the possible lack of autistic community outside the UoK, "...back home I tried looking up groups

and stuff that they may have, social ones, but it's like, 'parents with autistic children' and I'm like, 'I am the autistic children, that's me!'" (P8); "...I have no idea if the university I'm going to in Spain will have any kind of like support programs or ways to reach out to other autistic students...I just really hope there will be something similar or I will have to like do it myself" (P6).

Theme 2 Labels and Identities: Reappropriation

This theme arose throughout the interviews; however, participants found the applique workshop (Appendix 19.1) helped them to focus on the labels and identities they had adopted. The participants were asked to create a word or phrase that articulated their experience of being autistic that we would then applique onto a piece of clothing or fabric. I aimed for participants to perhaps wear/display their items to remind themselves of a new perspective, the more positive experience of being autistic, possibly reappropriating negative stereotypes. For an in-depth description of the Applique workshops and associated pictures (Table 5), please refer to appendix 19.1.

In the applique workshop, participants used the word 'weird' in several different appliqués; 'find your weird', 'I found my weird' and 'weird as heck!' (Figure 31). (See also table 5 in Appendix 19.1): *"I was diagnosed at 19, formerly I was heavily hinted at being on the spectrum from about 16...Yeah before that [my diagnosis] I just thought I was kinda weird and unlikeable... I still think I am weird but hopefully less unlikable".* They also reflected that *"...at the time [of making the appliqué] 'heck' was one of my echolalia words that I would say a lot, I still do, I kind of go through*

cycles of saying the same words um over and over especially depending what TV I have been watching. It's definitely a mirroring behaviour" (P3).



Figure 31 Weird as heck Applique in process

The participant also explained why they felt that they were 'weird' and why it was a positive autistic attribute or "not boring" (P3). P3 stated *"and because also I think that my personality and my interests are very shaped by being an autistic person. Um, I have like very obsessive niche interests, special interests and ahh I think they do make me weird but that is a good thing because I would be really boring otherwise ..."*

P5 used the words *"Alien Brain"* to describe their experience of being autistic in their applique created in the workshop (Figure 32).

"Alien Brain": "... Yeah, I'm really proud of the one I did... because it's really tidy. And the colours are good. [I]t's silly, but like I was trying to figure out like, an identity kind of label. And I settled on 'alien' for some reason because it just, it fit.... I like the way he [Spock from Star Trek] talks. I always really liked the way he talked..." (P5).



Figure 32 participants working on Alien Brain applique in workshop 2

In the applique workshop, participants created an applique with the positive label: P1 chose 'Wholesome Autistic' (Figure 33) and explains "*I go through verbal tics like, I use the same word over and over for a while and I think 'wholesome' was it. Yeah. I think it was inspired by Captain America, cuz he's very wholesome. I don't actually like him. I don't like him as a character. He's very wholesome. Yeah. Yeah. It is like um, it's like white bread. Do you know what I mean? It's not wholesome... Yeah... Because white bread like just plain slice of a buttered white bread feels like the typical nuclear American family. That's like Wonder Bread... I really like the way it sounds. It's a bit of a verb. It was a verbal stim as well*" (P1).



Figure 33 Wholesome Autistic applique

Another label that participants felt they reappropriated was the word 'Autistic', by pretending to be Neurotypical and realising that, despite pretending to be neurotypicals most of their lives, they didn't want to be neurotypical anymore.

Participants felt these creative exercises, such as Pretending to be Neurotypical (Please see Appendix 19.4 V), were empowering and changed the power dynamic.

P6 commented "...one time we, we pretended to be neurotypical and in a really exaggerated comic way. I just remember that was quite fun. And yeah, because I spent my entire life masking without even knowing what that is because there was just no alternative for me. And just trying really, really, really empowering because it was really changing that power dynamic. And oh, yeah, why would I want to be neurotypical?"

Subtheme 2.1: Intersectionality Labels and Identities

In total, eleven out of the eighteen SAG participants identified as LGBTQIA+ (including sexual orientation and gender identities).

[REDACTED]

Figure 34 AUTI-FEM applique

In the applique workshop, many participants created an applique with the positive label that referred to their intersectionality especially their autistic and LGBTQIA+ identities, such as P8 who developed “*Auti-Fem*” (Figure 34) to express their identification as a lesbian and autistic. P10 created “*Autistic Queer Pioneer*” and P11’s “*Autisti-Queer*” expressing their identity as queer and autistic. Also P6’s: “*Autistic Asexual Awesome*”. P6 describes this phrase as “*Empowering. It was still so much stigma around it [being autistic and asexual] and just taking that statement*

being like, 'no, that's BS'. It's something that's really awesome. We should be proud of it and just taking that and putting it into something creative was really cool".

Three participants changed their names to a gender-neutral name during the time period of the workshops and used these names in the sessions.

Participants felt it was easier for them to come out as non-binary and change their name to a more gender-neutral name in the workshops than come out to their neurotypical friends and family. P8 states *"I think with non-binary people and stuff in the group made it easier, you know, to explain that... I think it's nice in a way that I called myself [gender neutral name] in the workshops and stuff because it's kind of like a bit of a, not really a secret identity, but it's like the right one really, in a way. Yeah, it is the right name".*

One participant, P8, commented on how gender can be complicated as an autistic person; *"I mean, gender's funky and then, like, when you're autistic it can be even funkier. I mean, the closest term [to describe my gender identity] is like non-binary lesbian, yeah, it's difficult to explain but like my autism and lesbianism just complicates my gender and stuff".* P8 explains that they think autistic peoples' experience of gender can be *"complex"* based on several factors related to different communication styles of autistic people, the performance of gender in relation to sensory issues, and not adhering to gender norms. *"It's like communication like, you know, the social aspects, like your autism... not quite impairs but you know, changes and stuff compared to like maybe a neurotypical... And like socialisation. you know when you're younger and, like sometimes, you find hanging out with men easier because there's less drama and stuff".*

They explained how they struggled to identify their gender due to their autistic experience differing from a Neurotypical experience of the performance of gender. P8 states *“Then as you grow older, you kind of feel a bit like, I can't perform femininity as well, like wear make-up and stuff. Like the sensory aspects of it and stuff. So, I think that that plays a lot into it. A lot of it is to do with like performance and expression I think, yeah. Yeah, when I was younger, I was like, ‘am I a trans-guy? Am I this? Am I that? Am I gender fluid?’ And then I just kinda like... kind of gave up in the end. I was just kind of like, ‘I'm not cis-[gender]”*.

Many participants reported experiencing negative reactions from peers, parents, teachers and clinicians to stimming throughout their life, starting in childhood. Two participants who spoke about parents and friends asked *“what the hell are you doing?”* (P1 and P4), stimming was *“not welcome”* (P5) and *“weird”* (P6). From a young age, participants who stimed were labelled as *‘bad’* and *“bad things would happen to you if you did it”* (P6). *“So, um, so I kind of didn't really want to do anything that could, like, make people pay attention to me in a negative way. Just the entire stigma of seeming weird because I was always the weird kid in school. I mean, there's an explanation for that. But when people don't know what's, what's happening. It's just... oh, yeah... that's just weird...outcast”* (P6).

Another reflected, *“Yeah. I think it's [the workshop] made me aware of what I used to do when I was younger and stuff. I used to suck my thumb... that was a massive thing... Yeah!... much to my parents' hate”* (P8).

Theme 3: Stimming / Body Signs

For a week prior to this stimming workshop (Appendix 19.2 and 19.4), participants were encouraged to keep a ‘*stim diary*’ in which they would note when, how and what was involved in their stimming behaviours. Participants were encouraged to take pictures or videos if this was easier, or they could just write a collection of words as a response. It was emphasised that there was no right or wrong way of documenting a stim diary.

This workshop was developed to explore the pleasures and/or agony of stimming and the negative stereotypes of stimming for autistic people. Participants were asked to bring stimming objects to the workshop to share if they had any. Participants were given the opportunity to talk about stimming and what they discovered from the stimming diaries, we then worked with movement to explore happy stimming and stim dancing, and filmed participant’s stimming, which include some stim toys/tools (See Appendix 19.2, Table 6 to access links to video footage taken by participants; see the table below {Table 3} for a list of stim actions and objects by the workshop participants; see Appendix 19.2, Table 9 for descriptions of participants’ happy stims).

Many participants first awareness of their stims where when they were considered harmful by others: *“Oh so throughout High School I knew I was stimming. My biggest thing with my nails because I would [be] scratching at my skin a lot - I think technically dermatali thing...yeah, dermatillomania⁹⁵. I made myself bleed quite a lot.*

⁹⁵ Sometimes called ‘skin picking disorder’ <https://www.nhs.uk/conditions/skin-picking-disorder/>

I found myself putting my hand up in class I am like, ‘Ok I am bleeding can I have a plaster?’ ... My back is full of scars and my face was full of scars as a teenager, but I am glad that is gone” (P1). Another participant explained “...and I was so upset and frustrated that I wasn't being listened to, I started, I started stimming, what's it called unintentional, uncontrollably stimming. I was doing this [P4 demonstrates rubbing her fist into her other hand very strongly]. I was like, rubbing my, rubbing my fist into my other hand and because of that it rubbed this part [pointing to knuckles] raw. The GP was [not listening to me]” (P4).

Table 3: Selection of stimming actions, and which body part or objects used to stim, as described by participants.

Stimming Actions	Object/ Body part
Spinning	Body spinning by itself, on merry-go-round, or in office chairs
Rocking	Whole body on ground, or in a chair or sofa
Swaying back and forth	Whole body
Twirling	Rings
Flicking	Fingernails
Flapping	Hands
Picking	Fingernails, skin
Scratching	Skin

Stimming Actions	Object/ Body part
Pocket play	Keys, stones, toggles, USB sticks
Rubbing legs, hands, arms, face; participants liked the feel of soft fabrics against skin	Clothes linings, blankets, fabric, soft fuzzy objects, bed sheets, grandmother's cardigan, mother's scarf, plush toy octopus, in hands
Sucking	Thumbs
Smelling	Green tea lotion, lavender pillow
Noises/echolalia/counting	Mouth or in head
Drawing/writing with finger	Self or other body parts (hands, arms, legs)
Shaking legs, feet	Legs, feet
Fidgety hands	Tangles, balls, spinners, hair, fingernails, stretchy or squishy stim toys, bicycle chains, remote controls, fidget cubes
Watching	Moving patterns of light, cat lamp, light up wand, lava lamp, fairy lights, hourglass with sand or gel.

Participants' stimming shared a number of qualities; stim movements were predictable and repetitive in nature, often involved patterns, feelings, counting, and were associated with a calmness; *"Yeah, there's something soothing about spinning, spinning like I usually like at home I would stick some headphones in and then just*

sort of like, do it I guess and like, office chairs or like spinning office chairs are like the worst thing, invention in the world. For me, I feel like, because I am like hmmm cuz when I was younger, I was like, I loved like things like roundabouts and stuff a lot, the parks like to the point that it didn't even look like I was having fun. I was kind of just sitting there like zoning out on this, on this roundabout. and teacups and stuff. And it wasn't, it wasn't actually like fun per se I was just sort of like, ummm, it made my brain feel nice, I don't know”(P7).

One participant explained, *“I really like keeping the sense diary...The first thing was stimming and just keeping track of all the times I noticed I was stimming, which is really cool, because I noticed how much I'm actually doing it, and which stims are for which kind of feeling?”* (P6). They go on to describes the feelings and emotions behind several stims: *“like happy things for me it's like hand flapping...and when I'm like nervous but more in a good way, more like expecting something... [P6 does a modified hand flap] I take my hands like really close to my body...”* They described it as, *“a bit like Raptor hands but more moving”* and, *“... when I am nervous, but more like an anxious way. I will often like wrap my hands [similar to ringing hands]”* (P6). Developing on this, P1 explains *“It [stimming] creates a whole system it's like supplementary communication ... so it can convey an emotion that you know words doesn't, as words are very specific. So, things like air guitar it doesn't make a physical sound, but it makes.... Because if I ask you to describe a sound, you are like how? And if I asked you to describe an emotion you are like how? ...and that is why they are the same... you can only really remember the feeling, but you wouldn't be able translate that because it's... a feeling...”*. P4 also noticed that *“people always seem to know my stims...and my friends would say oh, '[P4]'s just happy!’, and they*

just instinctively knew that every time I did this [P4 demonstrates their stim, a modified hand flappy stim] it's usually because I'm excited or because I am happy".

Another participant reflecting about the workshop confessed that they started to stim in public for the first time after the stimming workshops, and P15 talks about the many positive aspects of stimming: *"Stimming feels good!! It soothes, distracts, focuses, stimulates, expresses feelings, etc. And can be great communication if you learn an individual's language. And there are SO many forms of communication!!"*

P4 comments on how they stim more openly in response to emotions since the workshops, *"Oh, yeah, definitely. In my, house now, if I'm really excited about something, I will FLAP, or I will like giggle like hysterically. Or if there is someone, I really don't like at all I [will actually] hide myself....to the extent where I cover my entire face and like cower behind the jumper. Or if I'm being frustrated, I do like end up hitting myself if I am really frustrated or... not even if I am just frustrated, but to say like 'no, really this is frustration!' Where I will just slap my leg [P4 just slaps her leg]. Or if I am really excited, I am like... Haa, haaa [P4 makes excited sounds] and I felt like hitting them, I feel like hitting them aggressively like, 'Hey, we want this thing, we want this thing, look at it.'"*

Subtheme 3.1: Masking - Sublimating Stims

Participants sublimate their stims due to pressure from family and peers in relation to cultural norms of appropriate behaviour and stigmatization of stimming. Participants explained that if they experienced negative responses to their stimming, they would modify these to be hidden from others, but continue in secret. P4 stated that their

mother has expressed disgust with P4's autistic expression including stimming – *“I don't stim as much in front of my parents because I get told off for that... they used to tell me off a lot about that... I used to bounce my legs [stim] and my mum would put her hand on my legs and say, ‘don't do that, it's disgusting’. She used a Cantonese phrase which basically translates to disgusting. So, because of that, I get really nervous stimming in front of them”*. This participant (P4) continued to be told not to do things; *“and dad said, ‘you're not autistic,’ [the participant went to her school nurse for help] I was stimming in her [school nurse's] office like this [P4 continuously rubs fist into other palm] for about fifteen minutes straight. And it was wearing it [the knuckle] raw... She had to stop me.... But at that point, I was like, I had the urge to do something even more like...aggressive”* (P4).

“So obviously, I didn't want to, I had to flap. but at the same time, I knew that it wasn't acceptable to flap but I did something else that would channel that energy. And that was [P4 does her stim where she rubs her fingers really quickly together]...”

Some participants only stimmed in private or late at night. P7 said *“...I knew as I got older, she [my mother] started stopping it [stimming]/ rocking and spinning], I think because like, I feel like rocking was one that only really occurred when I was in my room, only when I felt really, really stressed. And it was, it wasn't that obvious. So, but no one really paid much mind to it. Whereas, like, spinning was the one I like to do most. And I think she just, she's like, ‘what the hell are you doing?’ and it's like, really late at night. As I got older, so... I sort of did that more privately”*.

Participants found ways to stim around their parents that were physically hidden and more acceptable, or less annoying, neurotypical behaviour for their parents. *“I just*

like, you know, I just like just clicking it [a fidget cube] and everything, and rolling the rolling part around, because I always used to break off the backs of like remotes and stuff. And it used to frustrate my dad because, you know, just like clicking as I'm watching TV or whatever, it's always nice, I still do it now". Another participant, P2, uses their everyday objects as stim toys, *"these are the keys to my university accommodation like putting in a pocket and just stimming inside it..."* and they note that this is *"a safety mechanism to make sure I have not lost my keys! I just always seem to stim a lot in my pockets and... It's almost always a masking thing..."* and another participant, P4, states, *"that's why I really like the rocks [small smooth beach pebbles] and like, things I could put in my pocket because they [my parents] can't see that I'm doing it, but I'm still doing it..."*

Participants valued the SAG workshop's autistic space, *"Yeah, I think that's why, like, the [SAG] workshops were so good, cause it's kind of like, I guess like bringing that secretiveness into a more acceptable area...Yes, like safe space or nicer space?"* (P7).

Subtheme 3.2: Recalibrating Self Awareness and the Autistic Experience

Many participants commented on their new awareness of autistic sensory experience, including stimming, and how this recalibrated self-awareness. *"It made me feel really happy because I was like everyone else has these personal stims of theirs, they might be different than mine. Yeah. But I really appreciate the fact that we can all come together and agree on something that we all enjoy, stimming"* (P4).

Participants saw stimming as a secretive or hidden activity and that the SAG workshops brought this out into the open, “So, it was just fun to see, you know, everybody’s [stims]. It was kind of like a hidden move in a way” (P8). When talking about the *Night Light* activity (See Appendix 19.2 IV, Table 7 for video links to night light activity), P2 stated “...we played with different lights in the dark... it was just fun, and it was really seeing how people.... it was really just ah umm people’s moments of sensitivity or well enjoyment of sensitivity ahh amongst autistic people... I think I just got attracted to the lights, I think it was something about the objects we brought that day they were just fascinating?... The senses can be a bit [sucks teeth in], well really a bit too much, uncomfortable for some” (P2). “Yeah, I think I started noticing it [sensory experience] more. And just noticing the sensory differences I’m experiencing more in the good and in the bad ways” (P6); and “...there’s definitely stuff that we can’t really talk about with neurotypical people, because they just don’t understand it the same way... no one understands my absolute hatred of velvet, you know? But I feel like an autistic community does, because no one gets, like I am physically visibly, like cringing in shops, if I’ve accidentally touched a bit” (P7).

Many participants describe how they are more comfortable about stimming in public after the SAG workshops, especially happy stims in response to ‘joy’ (P5) and feel less guilt (and sometimes even pride) when doing more obvious autistic stims, like flapping their hands, after doing the SAG workshops (P4). “Being more proud of stimming and just...I’ve been more comfortable doing like happy or excited stims in public. Yeah, I mean stuff like that just like flapping my hands and stuff” (P6). “Flapping! When I am happy it’s, it feels less like a guilt thing now because I remember when I was younger...I wanted... I’m energetic but I don’t want to do

anything that could potentially be deemed bad. So, I manifested in different ways. I do it more opening now because I feel like now, I have an actual reason to.” Another participant, P7, felt comfortable enough to teach ‘flapclap’ after the SAG workshops to their little brother when they were watching a marathon live. *“They’ve been crying because like it was quite loud because everyone was obviously clapping as they’re running, as the runners are going by. And I actually was like, why don’t you like, why don’t we clap in sign⁹⁶ (see Figure 35) And we did. Because like, you taught us how to do that [in the SAG workshops]”* (P7).

Many of the participants expressed they felt more connection with the group and happiness when taking part in the Stim Circle (sharing of happy stims). P2 stated, *“It was fun... having other people to do the same stim, you know, to get a connection as well. It felt quite connected with people and it was nice listening to other people’s experiences... but it was nice to see that... [cough]... ah well... I am not the only one [that stims]... at least... and there is a lot of variance”*. P4 also expressed happiness to see people stimming without fear of stigmatisation: *“It made me happier to see everyone do that, completely without, you know, to not be judged for that [stimming]. And I was really happy [about] that and it made me jump with my stim”* (See Appendix 19.2, Table 9 for descriptions of participants’ happy stims).

The workshops encouraged participants to explore and enlarge their sensory world with stimming; *“I really liked the long one, completely dedicated to stimming and we bought cool stimming like props and stuff. which was cool. Yeah, it definitely was,*

⁹⁶ The autistic community adopted the D/deaf communities sign for clapping, to replace noisy clapping, which is the waving of hands held near your head back in forth in the air. The deaf clap originated in French Sign Language LSF to American Sign Language ASL in 1985. The autistic community calls it flapclap. (Harrington, 2007).

because I felt like it was stuff that I was like, 'Oh, okay. I might give that a try as well' and because it's really cool stuff. So, there was obviously there was the cat⁹⁷) that



Figure 35 Adventures of Super Autie Gang (2019), Canterbury. Co-performers demonstrating a flappause.

was like rainbows rituals really soothing, which I have my own version of now [that also has] ...an essential oil that sprays into the room" (P7). "I did buy some [stim toys] recently though [since the workshops] as presents as well...for other people and like I got from other people. I also got stim toys as presents I have like a rainbow-coloured tangle now. It's a nice big one and it's like really soft...a good texture" (P6).

⁹⁷ P5 brought in a soft-touch glowing lamp cat that cycled through a rainbow of colours.

One participant felt able to 'indulge' in buying more stim toys because they 'know it helps' and are 'more accepting of the fact that it helps'; *"...I definitely got some helpful new stimming tips, I would say. Yeah. So, like, one thing I've definitely done, is I've indulged much more in my love for fluffy things because I just like how they feel and like my life and stuff and just, yeah, because I know it helps, I guess more, and I am more accepting of the fact that it helps"* (P7).

Theme 4: Autistic Sensory Experience

During the workshops, participants became much more aware of the impact their sensory experiences were having on their day to day lives and found this particularly revealing. When asked 'is there anything you have taken away from the workshops?', a participant responded *"Yeah, I think I started noticing it [sensory experience] more. And just noticing the sensory differences I'm experiencing more in the good and in the bad ways"* (P6).

Participants noticed during the sound workshop (Appendix 19.3) how the impact of the senses differed within the group, but that sound and music played important roles. Participants reported being deeply moved by it; *"I could feel the music all the way down my spine and throughout my body as if I had a kinaesthetic reaction or bodily reaction to the music... sounds like that, [cello music]... it reverberates in my body"* (P13). *"Cello music is my thing. I think it's just, very harmonious. Like, it's sound, the tone of it. It's not too low, and it's not too high. It's right bang in the middle, which I really appreciate. It's like a very well-rounded sound"* (P4). Other participants enjoyed video game music and anime music, which is high pitched and frenetic (for an example of this <https://youtu.be/9FjAo1SjoQs>); *"... at work if I have to*

sort of like get my head in gear I'd usually play like video game music cuz you, usually it's like quite relaxing music, but it's also been designed to keep your brain focused" (P7). Another participant who was very musical, played the guitar and the piano said *"I am really inspired by the chord, 'major 7"*. They were *"interested in where mathematics and music meet"* and showed a video titled *What Tau Sounds Like*, where musicians apply numbers to all the notes in a major scale and calculate the mathematical constant Tau to 126 decimal places (P13). Another participant stated, *"the sound of silence is the only positive sound I could think of"* (P8).

Participants also enjoyed creating sounds themselves and saw this as a form of echolalia or verbal stimming (Please refer to Appendix 19.3 IV, Table 8 *'autistic (stimmy) sounds'* recorded in the Sound Workshop). One participant spoke about one of the sounds they made: *"a clicking sound with your mouth, I did this sound while I was in lectures, I wasn't aware I was doing it and you can just hear me [in the recording of the lecture] in the background clicking"*. (P4) Participants recorded and spoke of *"...words that sound nice and people like to repeat"* (P7) such as: 'nostalgia', 'pernickety', 'facetious' and a Chinese Mandarin phrase.

As part of Workshops 7-8 (for a description of these workshops go to Appendix 19.5), participants were asked to bring in three 'favourite' objects and to tell the story of that object and how it represented them as an autistic person. Please see Appendix 19.5, Table 9 for more detailed examples and quotes about the objects participants chose to bring to the workshops.

Commenting on one of their objects, a yellow purse, one participant said *“It’s not the purse that I want you to notice but the colour of the purse... I found that yellow actually kind of made my mood higher... I actually picked it because it actually did help my diagnosis of autism because when I was little, I was such Little Miss Stropky I would refuse to leave the house unless I was wearing an item of yellow. My parents would try to convince me otherwise I’m sure but like they had to buy a lot of yellow stuff... but like I think yellow was the only one that actually changes my emotion, so like ready for the day almost because it’s like a charging colour”* (P7). One participant explains why they always drew on one corner of a page: *“I’m left-handed so I can’t use the ring book the normal way around...So my hand will be like here, and then I like stop drawing here. And then when it comes to like the top...”* (P6). Even smells could have a profound effect, *“If someone’s wearing perfume, like too much in the street, it will cause me to like, kind of, stall and pause, and like kind of - not really recalibrate - but like get my gatherings together”* (P8).

Touch was also a powerful sense, with two participants referring to themselves as a *“Fabric Messer”* (P7) or *“Fabric molester”* (P1) when they visited certain shops: *“...especially clothing stores, Primark has so many soft things. The softness goes really quickly when you buy it... but in the store... it’s like perfectly... its heaven... soft”* (P1). In contrast, however, one participant notes *“...I bought stuff that the material triggers me so much I’ve actually thrown it at full force back at the bag... like... No get away from me!”* (P7). Another participant’s applique related to their aversion to touch by using a phrase, ‘Don’t Touch Me’ followed by a heart for their applique (P12). P12 did not like to be touched by anyone, especially people they didn’t know (Figure 36).

Taste was a strong stimulant for some: *“When I was younger where I had to have two of them, the same food when I would come home from school”* (P9). One participant brought in a Milk jug they used as a gravy jug as one of their objects to represent two things: their love of *“traditional British roast dinners”*, and gravy, *“I actually licked the plate inside the room... usually when I have had dinner, I just go back to my room, my bedroom and I have dinner there and I just lick the plate and I just chug [gravy out of the milk jug] on that”* (P2). They also stated that they *“...used it [milk jug] as a gravy jug instead, and then to say that ‘well I just don’t care about labels sometimes’”* (P2).



Figure 36 Don't touch Me Applique by P12

Participants felt that vision was a strong stimulant; one participant comments on the light night activity in the *Stimming 1 Workshop* (See Appendix 19.2 IV for description of night light activity, and Table C for video links), their fascination with the objects, and also sharing this very visual sensorial experience, *“... it was just fun, and it was*

really seeing how people.... it was really just ah umm people's moments of sensitivity or well enjoyment of sensitivity ahh amongst autistic people... I think I just got attracted to the lights, I think it was something about the objects we brought that day they were just fascinating?" One participant chose to sit in the OWAD during the light night activity workshop. This allowed them to still take part in the activity and remain involved in the enjoyment of the sensorial experiences of the group. I observed them stimming by rubbing the walls of the OWAD. At the end of this workshop a participant said, *"We turned on the lights and many of us realised that we were over stimulated/ overwhelmed and felt; dizziness, had a feeling that we need to eat- like low blood sugar, many people had a headache and a glazed overlook in their eyes, or looks of confusion and being 'out of it'"* (P12; See Appendix 19.2 IV, and Table 7 for video links to night light activity).

Many participants felt that sound could be very overwhelming. Volume played a key role in whether or not a sound was overwhelming, as one participant stated: *"loud noises are like a slap in the face"* (P1), as if they physically felt it (See Table 4 below for sounds that participants didn't like and had physical reactions to).

Table 4 Sounds participants disliked

List of sounds participants disliked and physically reacted to
<ul style="list-style-type: none"> • Sudden loud noises: car horns, sirens, alarms, dogs barking • Hook-and-loop fastenings ripping • Nails on a chalk board and white board

- Marker on paper
- Ripping paper
- High-pitched sound of fluorescent lights
- Electric buzzing
- Polystyrene braking or rubbing
- Scraping a bowl
- People eating, chewing, crunching (crisps)
- Murmurs through walls
- Wet, sticky sounds

Some participants who recognised this sensory overwhelming, came up with inventive solutions for these overwhelms; *“I’d like to invent noise-cancelling headphones with three different modes: 1) normal noise cancelling where it gets rid of most of the sounds but leaves some so you don’t accidentally get run over because you didn’t hear anything, 2) a white noise option for when you need some sound but music and surroundings are too much (different kinds of white noise available) and 3) complete noise cancelling where you hear nothing, not even your own heartbeat and breathing for when even that is too much”* (P6). Some participants wore ear defenders or noise cancelling headphones during the sessions. Another participant found it hard to hear people speaking, especially when there was other noise or sensory sensations happening at the same time, and wanted to invent *“...glasses I wear that show subtitles for people speaking in front of them like on a screen. I suppose they’d be like sunglasses. a bit like those sci-fi movie ones where they have a screen in front of them when they wear them, and they’d work just like*

*normal subtitles, so they pretty much just appear when sound is on*⁹⁸ (P8). Another participant wanted to design “*Meeting/social places where one sense is restricted i.e., in totally dark place or a place where all noises are silenced (/white noised) to better focus on the other senses/other forms of communication, when you’ve run out of one...*” This participant said they would also invent a “*Directional hearing device to isolate conversations and switch between them*” (P15).

Subtheme 4.1: Fascinations and Anthropomorphising Sensory Objects

In the Object Description workshop (Appendix 19.5 and for a description of all the objects see Table 10), participants explained how they became focussed or fascinated by certain things, and the underlying reasons were many and varied. Participants were given, or took, objects from people they loved, “*my grandma’s cardigan... it’s not very heavy, but it’s a really comforting thing to just, like, hold, like just to put near your face... it’s just something really comforting knowing that it’s my grandmother’s... it used to smell a lot like my grandma. I can’t really explain what the smell was but it’s like a really nice, warm, comforting smell that made me really want to hug her all the time*” (P4). This prompted another participant to admit, “*I just stole it [their mother’s scarf]. It was one of her best scarfs too and I forgot where I put it, I don’t know if I have left it back with her. I need to steal something else*” (P1).

⁹⁸ *The National Theatre*, London has previously trialled captioning glasses in performances. The idea is that it’s less intrusive than the usually captions, as it’s only visible to those that want it and it’s overlaid wherever you’re looking. <https://www.bailiwickexpress.com/jsy/life/technology/national-theatre-trialling-smart-glasses-display-subtitles-during-live-performances/>

Other participants described other objects that they were fascinated with due to the object being related to their passions, or what has been called 'special interests' by the medical profession. P5 had several plush toys that were very important to them and represented their passion and fascination with donkeys and sharks. P5 talks about their fascination with sharks: *"I just, I just, love them. There's so many of them and they're just they're really interesting... Yeah, I used to have this big... shark Almanac and it's just every shark that's been discovered so far. And it's just fantastic..."*. Several participants reported having more than one passion as P5 does and that these change over time. Another participant, P11, experiences temporary mutism often, so they asked P1 to read their response. They wrote about their skateboard, *"It's their first special interest since diagnosis... its super fun... it's probably going to take over their life a bit"*. Another participant, P6, speaks about several of their 'special interests'; history, languages, and drawing, and describes how these were *"...a long term passion of mine"*, and how one of their passions had a calming effect, *"...[it] really helps me to just calm down sometimes because if there's one thing I can completely focus on, [then] everything else ceases to exist..."* as well as one of their 'long term passions', languages, is what they are studying at university.

Some of the participants can also be described as anthropomorphising objects by giving them names and genders, such as P5 who had a plush toy Donkey named 'Corduroy', *"I took him literally everywhere. Like in every picture of me as a kid, he's just there... He is really important to me"*. Their plush toy was recreated by parents, *"I missed him so much that my mom just took him apart and got like a pattern and made him out of some material"* as they were loved so much. P5 also researched

and visited the store where their beloved 'Corduroy' was made. P6 still sleeps with their stuffed dog 'Honey' as an adult, and sometimes takes it on holiday with them, but only if it is not 'dangerous' to do so as, *"I don't want to, Honey to get lost and we also moved around in the country a lot. So, we spent nights in different places, and I was like, he can't get lost"*. It represents their love of Roman history and is named after a famous historical figure Hannibal Barca. P6 saved the first 'Honey by Barca' plush dog in a glass box *"So, it could still survive, and we didn't have to throw it away"*. As I stated earlier in the themes on stimulating, P9 had a *"...bit of satin that I had, originally it was like a whole blanket and I loved it so much that I wore it out"*. P9 also had empathy for their blanket when it was thrown away, *"and my granny cut off most of it and just let me have the side satin bit which actually devastated me, and I was only like four. And it devastated me because I imagined this big other bit of blanket waiting at the dump to be rescued because I had personified it and um anthropomorphised"*.

Theme 5: Articulating and Re-evaluating Autistic Needs

The theme of articulating autistic needs arose from the SAG workshops: Participants took their cue from me, and one commented that the creative space *"let us be like kind of silly but [the space] didn't feel patronising because you [the author] were also being silly... it felt a little bit like... this is a sand box play... in it"* (P1).

P4 states *"... it was, you know, it's nice hearing about what other [autistic] people thought, it was a very nice way to broaden horizons. So, it's not just me, me, me, me. It's more like, everyone and me... I've learned a lot of things about myself. Like,*

stims I like, stims I don't like, yeah. You know, myself as part of a community, like, in part like my sexual orientation”.

One participant felt the experience of the workshops has made them “*kinder to my younger self, especially. Like I say, I am good with setting more boundaries and stuff [and]... made me reflect a bit, I think in that sense, it helped me understand my own self a bit more... My family were always like, 'oh you potty trained late' and stuff like that, and now I'm just like, that's just autism. It's a developmental disability at the end of the day, so it makes total sense that I had developmental delays” (P8).*

P7 felt the workshops were about positive collective identity and self-worth, “*Or like we are all, 'super' in our own ways and collective ways. It's like, much more about self-worth rather than...the almost fictional side of autism, I suppose”.* P4 felt that the most impactful experience of SAG workshops was “*Validation... Yeah, it's validation in how I perceive myself. To see like, how I behave, how I act. And you know how I perceive the world”.* P1 reports the SAG workshops gave them confidence to be out and proud, to ‘own’ their autistic identity: “*So, I felt part of the workshop was me like exploring that [what it means to be autistic] and also like becoming comfortable in, owning It...I struggled quite significantly with like being, 'Out and Proud' sort of thing, like not over justifying every little action I had to outsiders. Especially because I received such negative feedback on my diagnosis from family members...”(P2).*

In the fantasy safe space workshop, participants thought about what their fantasy safe space would be (Please see Appendix 19.6 for a description of this workshop).

One participant realised to that a safe space for them was “[S]omewhere so I could cocoon myself away from the world... You have the control of it, and it can’t be entered by someone especially without permission... it’s dark and soft and like quiet and... it’s all a big cocoon from the senses” (P1). Another participant stated, “Somewhere you could say, ‘Please stop using so many bright lights’” (P2). A participant added, “... and people should say what you mean, rather than what you think you want to mean” (P15).

One of the safe spaces was designated by two lines that bounded the space; one participant commented on this, “the safe space and the space around it still had like another line and one of them, people could still cross with permission, and the other one ...Absolutely not” (P6). Being aware of needs, being able to articulate these and portraying boundaries were recognised as being quite normal in a neurotypical world, so why not in an autistic one? “... [These] are just our needs, just like your [neurotypical people] needs are your needs... Yes I am perfectly normal, I am very normal and very autistic!!” (P15). Another participant commented, “I’m also better at setting boundaries for myself, like socialising-wise. I mean, it’s easy to get overwhelmed when I like, socialise and stuff...”. When invited on a night out they knew would be overwhelming they stated “I really can’t, full stop’ and when out for drinks with friend now I will just state, ‘I can’t hear you because of my auditory processing issues’. So, I think it’s easier, you know, to express it in simpler terms now, that neurotypicals can understand” (P8).

Another participant stated, “I am generally engaged in the activity or conversation. Please don’t make me smile, nod, respond or look at you to prove this” (P15). Some

recognised that they felt unable to ask for their needs to be met, “*they [the landlord] have given me a spring mattress and I hate it, but I am too anxious to go over there and say ‘hello, this hurts me a lot’*” (P1).

Additional Commentary from Participants about the Personal Impact of the Workshops

These quotes are not part of a theme, but I felt it was important to note the impact the workshop had on participants.

Positive Autistic Identity

The impact of the SAG workshops was overall positive, and participants felt it “*fosters a really nurturing and positive space*” (P3). Largely, the participants felt they learned about themselves, increased their knowledge and understanding of their own autistic experience and the experience of other autistic people. P2 stated the workshops were an “*...opportunity to explore yourself and also explore anything related to autism... it was really the opportunity to share uh, each other’s autistic experience. I think the workshops was a more ah...a really extended opportunity to discuss about anything about autistic [experience]... and it was much more comprehensive, more structural way of discovering autism*”. Many participants had never had the opportunity to explore in this way with a group of autistic people before.

Many participants reported that they were more positive about being autistic after the workshops and, because of this, ‘came out’ to friends and roommates as autistic. P6

explained, "... then as soon as I got the diagnosis⁹⁹, I told all of my friends, like on a group chat. And I got really, really positive, like feedback and stuff. And that was really cool".

Since the workshops, P6 also has felt strong enough in their autistic identity to be a self-advocate in their daily life, "... now I just tell people when it comes up... and we're talking about like, ILP's¹⁰⁰ and stuff and she's asked me, 'Well, why do you have an ILP', I was like, 'yeah because I am autistic'. And then I used it as a chance to like educate her a bit because she was like, 'Okay, I must confess I don't really know anything about that', and then I just taught her some stuff and that was, felt good. Yes, it feels good".

P8 reports that they are more 'open' with their autistic identity: "... I'm more open to saying it in public. You know, 'oh I'm autistic' or like 'I do this because I'm autistic' ... you know, I'd say I'm more open to say I'm autistic to people... particularly neurotypicals because that's always a mixed bag of reactions at times... I think I feel it's more okay for, you know, for me to express myself as an autistic. With like, autistic ways".

Participants reported that although they still feel 'pessimistic' or felt 'down on themselves' sometimes, they found the workshops "... made it a bit nicer [to be autistic]" (P8). P1 commented, "I flip flap back and forth about being super

⁹⁹ P6 was self-diagnosed during the workshops as they awaited an Autism assessment through the University.

¹⁰⁰ At the University of Kent, ILP stands for Individual learning Plans, which are usually used to make staff aware of Neurodivergent and/or disabled students and the accommodations they might need to access learning.

pessimistic, like 'ahh I am completely non-functioning, I am never going to be able to do a PhD. I am never going to be able to get a job and I am just gonna never feed myself'. And just be like, 'screw that, I am just going to go for it!' And 'I am really good at my discipline because, I am autistic!' And I am like, 'okay, I am just going to go for it!'".

The workshops also had an impact on self-worth; P7 said *"Yeah... like overall very good, sort of more accepting of who I am and how to deal with the me I suppose. Ha, yeah, no, it's definitely, it's definitely a good experience... a step in the right direction I would say"*.

With one participant feeling sorry for non-autistic people; *"... when I'm around autistic people I'm like, 'oh yeah, isn't it fun, we do this because we're autistic' or whatever. Yeah. There was that sense of that in the workshop, you know, like, 'oh isn't it nice we do this just because we're autistic' and stuff. 'Shame [that] neurotypicals can't!'" (P8).*

Participants reported that Super Autie Gang workshops were a good way to help autistic people feel more positive or have pride in being autistic. Participants reported that they were especially relevant for people pre- (self-) diagnosed, recently diagnosed or people 'on the fence' about whether they are autistic or not. P1 said *"Especially if they were recently diagnosed like I was that would be great. Yes especially because everyone there was autistic, you don't feel like you are playing it up for a non-autistic audience - you just like, oh well everyone is doing this so I can do this, it's cool and I am just going to go for it!"*; P7 agreed *"I think it's really good as*

well for people who are on the fence of if they're autistic as well? Yeah, I think we mentioned last time like someone, like there is a quote that people would say, like, 'everyone is a bit autistic' but it's only people who are probably, actually autistic that say that [not knowing they are actually autistic]. Ha ha yeah. So, it's like 'are you sure you're not just autistic, mate?' ha ha".

Giving Definition to Autistic Experience

Participants reported that learning about themselves within an autistic community and about autistic culture, including learning new neurodiversity and autistic terminology from each other, gave participants the language to express their experience to others and also helped them learn about their own autistic experience. P1 was recently diagnosed before the workshops and felt the workshops helped give *"definition to an area that was only vaguely defined before... I see the workshops as part of that whole... It was new and I was coming to become more comfortable using the words and explaining things and sometimes especially because... my family are not very emotionally explicit. So, when people ask things like 'how do you feel?'... it's like... I just fucking feel, you know what I mean... there were certain commonly used terms like for chronic pain experiences they can call themselves, ah, 'spoony' people, that's a 'term' and that means something very specific but it's also exactly what it needs to mean. But this terminology, 'I don't have enough spoons'... So after the workshops and using commonly used terms that meant exactly what I needed them to mean and it's like giving definition to an area that was only vaguely defined before - you didn't have the terms for it. But it was also because I was using these*

terms, it seemed I had just gone full frontal [autistic] and like, 'I am going to play up this'. But no, I have just got words, I can use now".

P8 reported they had learned more autistic terminology at the workshop, and they feel better equipped to explain their experience. They thought it would be helpful to have an autistic dictionary for newly diagnosed people and their families, to be able to explain their experience to non-autistics: *"They should come up with like an autism dictionary. Maybe not more words, but I think it's easier, you know, to put it in a more succinct way... So I think it's easier now that I have more phrases and stuff".*

Participant's Comments on the Impact Creative Embodied Exploration and PaR.

Many participants stresses the importance of the combination of being a part of an autistic culture and community, and actively doing creative things. Many participants felt that it was important to actively do things with hands on experience, which was really empowering. *"I just want to emphasize once more again that I really like the movement part of it, because at first it kind of also made me a little anxious because that's just not a thing I was used to. I was never much of a like movement and like, person. Like, we've been expressing stuff through, though, like, movement and drama and that kind of stuff. But I think combining the talking about the experiences and exploring the experiences, but combining that with, with movement [Stim circle, stim choreography, pretending to be neurotypical exercises] or other kinds of artistic expression like that applique [applique workshops] or the, making the space with the tape [fantasy safe space workshop]. Was really helpful? Yeah, and you felt like, yeah, there wasn't any right or wrong way to do it. Yes, yeah, you wanted us to move*

'autistically', that was, that really took the pressure away and that really, that really added to the experience. Hmm, I guess it makes you embody the experience..."

(P6). P6 elaborates, *"Yeah, all that community feeling, integrating myself. Just learning more about autism, not from just sitting in front of a computer and researching stuff, but actually talking to people and actively doing things. Because in the group, we talk about things but in the workshops, we had hands on experience with, the with, the little space [fantasy safe space workshop]."*

Many participants reported they felt they could be autistic, revel in being autistic, and explore their autistic nature in an autistic space, where there would be no negative repercussion, and in contrast to the stigmatisation, policing and self-censoring of autistic nature in most neurotypical spaces, the workshops were a celebration of autistic experience and culture. P8 stated *"Yeah, I found that quite interesting and pretending to be like a neurotypical and stuff, you know, expressing our stims and stuff. I liked the movement ones. I just found it quite fun and like, quite funny to see who, are other autistics, you know, [pretending to be neurotypical] if neuro... neuro... neuro neurotypicals because I found it, you know, [they found it] entertaining themselves... and I could relate to that. It is something you can't really express as much in public because you got a lot more scars and stuff and like, even when you're younger, as a child, your parents will tell you [to mask], you know, and you'll learn that over time. So, it's nice to just be able to do it in an environment where, you know, just let a bunch of autistics loose in a room. Ha, ha, ha. It kind of felt a bit like that, you know, just go ahead and do what you want, do what you like"*.

Section 5

Discussion

In this study I used practice research methodology and performance and visual art to capture and articulate the experiences AWCTN+ peoples with a series of nine workshops and one-to-one interviews using a phenomenological approach. My approach to interviewing was influenced by Bevan (2014). In his approach, it is implicit to acknowledge that interviewee are regarded as "...real, active, and interpreting" and to aim to discover meaning in experience (Bevan, 2014, p.136). I also take influence from Giorgi's (1997) phenomenological approach in designing my interview, making sure the "...questions are generally broad and open ended so that the subject has sufficient opportunity to express [their] view point extensively" (Giorgi, 1997, p.245). I was also inspired by Bevan's (2014) structure of phenomenological interviewing, which comprising of three key areas: "...contextualization (natural attitude and lifeworld), apprehending the phenomenon (modes of appearing, natural attitude), and clarifying the phenomenon (imaginative variation and meaning)" (Bevan, 2014, p.138). To put it in another way, his method of interviewing engages with illustrative and structural questions, including original use of creative alternatives, to explore the participants lived experience. Bevan (2014) attempts to organise and make meaning from an individual's "conscious experience of phenomena" (Bevan, 2014, p.138).

I extracted six themes and seven subthemes by analysing the effect of the workshops on the lives of these AWNBT+ participants. Further analysis was obtained by findings from a focus group that was held with five workshop participants who took part in the co-creation and performance of Adventures of Super Autie Gang. Overall, there were 378 minutes of interview data and 61 minutes of focus group data. No new themes emerged from the focus group, as the Adventure of Super Autie Gang performance was based on the findings of the SAG workshops (Please go to Appendix 20 to see the results of this and some advice for practice).

This study used an intersection of Practice as Research (PaR), Participatory Autism Research, and Autie-ethnography to discover and describe the experiences of late diagnosed AWCTN+ people. That was facilitated by using a series of nine creative workshops. Additionally, using elements of Grounded Theory (Charmaz & Belgrave, 2015) and Thematic Analysis (Braun & Clarke, 2012), I analysed eight one-to-one semi-structured interviews with workshop participants. I found the following themes and subthemes within their experiences, summarised below.

Theme 1: Autistic Connectivity/Autistic Space

- 1.1 Connecting with Self
- 1.2 Connection with Others/Community
- 1.3 Future Connections
- 1.4 Heterogeneity, Textures of Autism

Theme 2: Labels and Identity: Reappropriation

- 2.1 Intersectionality Labels and Identities

Theme 3: Stimming / Body Signs

3.1 Masking - Sublimating Stims

3.2 Recalibrating Self-Awareness and the Autistic Experience

Theme 4: Autistic Sensory Experience

4.1 Fascination and Anthropomorphising Sensory Objects

Theme 5: Articulating and Re-Evaluating Autistic Needs

Theme 1: Autistic Connectivity/ Autistic Space

The theme of autistic connectivity encompassed three subthemes: connection with self, connection with others; and future connections. The first two subthemes articulated participants' desire, wants and needs to understand themselves and their 'autistic background' within the context of self and other. I see these desires have also been found within existing literature; the notion of 'self-discovery' was one of the themes Milton and Sims' (2016) mentioned in their article '*How is a sense of well-being and belonging constructed in the accounts of autistic adults?*'. It is interesting to note that Milton and Sims' sub-themes appear parallel to those of the SAG workshop findings. Milton and Sims (2016) applied thematic analysis to narratives that were published in 79 editions of Asperger's United (AU), a magazine for the autistic community. For obvious reasons, Milton and Sims were unable to comment on the demographics of the AU contributors, and the gender and sexual identities of these participants remains unknown.

There were also similarities between their study and the subthemes arising from the SAG workshops in the subtheme 'connection to others'. SAG participants explained feelings of connectiveness, autistic sociability, the ease of autistic friendship, and the sense of mutual understanding and empathy they had with other autistic people. This appears to have been very similar to Milton and Sims' (2016) theme of 'connection and recognition'. Milton and Sims describe this as autistic adults having "...found a sense of connection and recognition with/from others, a sense of well-being and belonging, and a better understanding of their subjective viewpoint from those around them" (Milton & Sims, 2016a, p.526). Whilst there was not a direct equivalent to the SAG theme of future connections, Milton and Sims noted the importance of connections with 'like-minded' people, and in this respect the recognition by SAG participants moving into the future meant a potential loss of this valuable connection with the SAG workshop group (P2, P6, P7, P8), and could therefore be argued to be a different side of the same coin. Indeed, some of the SAG group (P6, P7) stated that they would be motivated to set up and run a similar autistic space to ensure that they would have future connections with other autistic people.

A qualitative study by Seidmann (2020) on autistic blogs uncovered a theme of 'safety of autistic space' which they described as "The ability to be oneself and receive support from other members of the community is central to people in the autistic community" (Seidmann, 2020, p.5). This appears to support the findings of the SAG workshops. A SAG participant explained they received "support from the community" (P4) and "...advice from the autistic people..." in the workshops, and

found this validating and “beneficial”; stopped them from “keeping their shells on” and accepting each other “for who we are” (P7).

The SAG participants saw inter-autistic socialising as unique and different from socialising within a neurotypical setting, where they felt there were ‘barriers to communication’. Participants commented on the ease of autistic sociality and a sense of connection which allows for effective communication. This is similar to a study by Crompton et al (2020) entitled ‘Autistic peer to peer information is highly effective’. Crompton and their team found that autistic people are effective at communicating and feel a sense of rapport with other autistic people just as well as non-autistic people do with other non-autistic people. However, when there is a cross-neurotype of people, less information is shared and there is a less rapport among mixed groups (Crompton, Ropar et al., 2020).

Another thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family by Crompton (2020) also found that people of a similar neurotype (autistic) in an autistic space allows for authentic communication. However cross-neurotype spaces do not allow for effective communication and that they may be actively biased or partial towards the dominant neurotype (Crompton et al., 2020). This study and others (Milton & Sims, 2016b) have highlighted that the autistic space is important, that autistic people feel more at ease, have a sense of belonging and are more able to have compassion and understanding towards themselves, giving them a sense of agency. Crompton et al. (2020) found that “spending time with autistic family and friends gives autistic people the opportunity to extend that compassion, understanding and agency to the autistic people around them”

(Crompton et al., 2020, p.1446), which parallels the finding of the SAG group under the subtheme of 'connection with others'. SAG participants commented on the importance of accepting social difference, including the option to not engage in conversations or socializing at all.

Theme 2: Labels and Identity: Reappropriation

The themes of labels and identities appeared throughout the workshops, but the SAG participants found the applique workshop in particular helped them to concentrate on the labels and identities they had embraced. In SAG Applique Workshops 1-3, the participants were asked to create a word or phrase that articulated their experience of being autistic that they would then applique onto a piece of clothing or fabric. The idea being that the participant could wear this, or display this item in their home, to remind themselves of a new perspective based on the neurodiversity paradigm that was a positive experience of being autistic.

Some of the phrases that SAG participants invented for their appliques were words that previously might have been used to label or stereotype participants negatively, such as 'weird', 'alien', and 'nerd'. Treweek and their team (2019) interviewed twelve autistic people ranging from 20 to 63, eight of the participants were male and four of the participants were female. This study found that one of the three main themes that came out of the interviews with autistic people about stereotypes was that the "Primary stereotype is that autistic people are 'weird'" (Treweek et al., 2019, p.14). SAG workshop participant P3 used the phrase 'Weird as Heck' when creating their applique, which is echoed in the phrase 'obviously weird' as quoted in the interviews

by Treweek et al. (2019) study in reference to stereotypes about autistic people. This phrase 'obviously weird' (and I would argue 'weird as heck') Treweek et al. claims emphasise the stereotype that autistic people and their behaviours are odd or abnormal (Treweek *et al.* 2019, p.12). The participants of the 2019 study offered several examples of 'obviously weird' as; 'moving in a weird way', rocking, and drooling (Treweek *et al.* 2019b, p.13). Treweek (2019) found these stereotypes were perceived by their participants as having the power to "exclude and oppress autistic people" (Treweek et al., 2019, p.13). It is interesting to note that the late diagnosed AWCTN+ SAG participants had similar experiences with a more varied group of autists. However, the difference between Treweek et al.'s study and the SAG workshops is that the SAG participants were encouraged to reappropriate these negative stereotypes into positive labels and, in many cases, an expression of their pride in being autist.

There is a cultural association of 'autism' with the figure of the alien, which was found in P5's applique '*Alien Brain*'. Hacking (2009) cites several cultural instances that autists have been referred to as aliens, and autists themselves referred to themselves as aliens. Notably, Oliver Sacks wrote an article about autism, that later became a book '*An Anthropologist on Mars: Seven Paradoxical Tales*' (Sacks, 1995). It was named after something an early autistic author Temple Grandin stated while being interviewed by Sacks. She stated "Much of the time, I feel like an anthropologist on Mars" (Sacks 1993). This described her confusion when interacting with non-autistic people (Sacks, 1995). Hacking also points out an 'autism awareness' campaign run by CAN: Cure Autism in the early 1990's, now a parent run organization, which shows a father talking to the camera stating "Imagine that

Aliens are stealing one in every two hundred children... that is what is happening in America today. It is called Autism” (Hacking, 2009, p.44). Many autistic authors referred to themselves as ‘aliens’ using this in the titles of their books, and adopted this as a positive word, such as: *Through the eyes of Aliens* (O’Neill, 1998); and *Women from another Planet* (Miller, 2003). As Hacking (2009) states “An Alien is a second order metaphor... an alien is a foreigner... a rational and sentient being from outer space. At the second order, the word is used as a metaphor for the strangeness of autistic people” (Hacking, 2009, p.46). This shows a history of stigma and reappropriations in reference to the words ‘alien’ and ‘autistic people’. It appears that the SAG workshop participants are reappropriating or queering terms like Weird and Alien that were previously used in insulting ways.

Several SAG participants also commented on their experiences and enjoyment of echolalia and of ‘verbal stimming’ in reference to the words they chose for their applique. Please refer below to the discussion on Theme 5: Autistic Sensory Experience where I consider echolalia in more detail.

Subtheme 2.1 Intersectionality Labels and Identities

Some of the labels and phrases that SAG participants came up with were newly created words which expressed the intersectionality of their experience of being autistic and LGBTQIA+. Such as P8 who developed ‘*Auti-Fem*’ to express their identification as an autistic lesbian, P10’s identifying as autistic and queer with ‘*Autistic Queer Pioneer*’, or P6’s experience of being autistic and asexual, ‘*Autistic Asexual Awesome*’. Participants also felt empowered by the act of creating their applique around labels/identities. A theme of intersectionality has been found within

the existing literature in a study carried out by Hillier et al (2019), during which they held a focus group with four participants who were autistic and LGBTQ+. They used thematic analysis to identify four key themes, one of which was “Effects of dual identities: experiencing dual identities, autism spectrum and LGBTQ+” (Hillier et al., 2019, p.98). Intersectionality was a theme throughout Hilliers et al. (2019) focus group, and there were similarities between their study and the subthemes arising in the SAG workshops. In total, eleven out of the eighteen SAG participants identified as LGBTQIA+, and this was something that was expressed and discussed during the workshops. There were also similarities in the findings of Hillier et al. (2019) and the SAG workshop findings. One SAG participant, P8, spoke about their experience of gender being complex in relation to their sexuality and being autistic. This appears to be similar to what Hillier (2019) and their team reported that “one participant commented that while ASD had not affected their understanding of their gender identity, it may have affected their gender identity itself” (Hillier et al., 2019, p.103). However Hillier’s participants’ reasons for how being autistic affected their gender was explained differently: “ASD sort of separated me from a connection from my own body in some way” (Hillier et al., 2019, p.103). I feel that this is a subject that should be looked at in future studies.

There is a further study by Kourti and MacLeod (2019) looking at autistic perceptions of gender which found “Participants reported not identifying with typical presentations of the female gender for a variety of reasons, linked both to autism and to sociocultural expectations... Including participant having difficulties conforming to gender-based social expectations...” (Kourti & MacLeod, 2019, p.52), which appears to be in line with the insights of SAG participants.

Notes on Stigma

The interviews of SAG participants included a significant amount of data on their experiences of stigma, especially with peers, parents, siblings, teachers, and clinicians, however there was not enough space in my thesis to include all this data. If you are interested in this, please refer to Appendix 23 to view the most relevant quotes on this subject. I also wanted to note here that there are connections to the negative labels participants chose to reappropriate, such as the word 'weird' that connect with stigma, and how the biomedical model and society codify 'typical' and 'atypical'. Goffman (1963) suggests that stigma is a characteristic that makes a person different from others in a societal classification and this diminishes the person's status in society. He suggests that stigma is relational between the characteristic and the 'discrediting' of a person by other people without this trait. He suggests that a person with a stigma is not considered by society on some levels to be human, and built on this notion that non-stigmatised people discriminate against the stigmatised person, which greatly diminishes their life chances (Goffman, 2016).

Theme 3: Stimming/ Body Signs

Subtheme 3.1 Masking - Sublimating Stims

It is now starting to be established in literature that many autistic people report stigma around stimming behaviours (e.g., Kapp et al., 2019; Treweek et al., 2019). This experience was shared by many SAG participants who described examples of either being stopped and/or strongly discouraged from stimming by parents, teachers, clinicians, peers and neurotypical society. One of the main unforeseen

results was the suggested link between the stigmatisation of harmless stimming and the adoption of harmful stims. For example, hand flapping, rocking and leg jiggling, to name a few referenced in the interviews of the AWCTN+ people participants resulted in parents, teachers, psychologists and doctors stopping or discouraging participants from carrying out these harmless stims. This in turn resulted in participants adopting more neurotypically acceptable stims such as scratching, picking, harshly rubbing skin and nails, or nail biting that sometimes were harmful to that individual. Several participants came to the workshops with stims that they knew were harmful to themselves as they felt they had become obsessive, and they had a desire to stop carrying out this harmful activity. Prior to the workshops, many participants, including myself to a certain degree, did not have a positive view of stimming and saw it as a pathologised symptom of autism, something to hide and feel shameful about. During the workshops, participants and I discovered the joy of stimming together. However, we did not recognise at first that we could replace these obsessive stims with more healthier stimming. Once we explored what healthy stims we enjoyed, all of the participants adopted these beneficial stims most of the time and only went back to the more harmful stims when they were under extreme stress. Future studies could investigate the association between mental health and stimming, and the harm that the stigmatisation of stimming has done to autistic peoples in relation to the adoption of alternative stims to fit into a neurotypical society, which in turn affects the mental and physical health of autistic people. This provides a good starting point for discussion and further research. Recent psychological research that is in line with this thinking such as Jiujiang et al (2017) explains,

“... it appears as though insistence on sameness routines and restricted interest are more apt to calm anxiety rather than cause it. In fact, insistence on sameness behaviours and restricted interests may help to reduce anxiety in ASD... Although insistence on sameness behaviours and restricted interests may help to reduce existing anxiety in individuals with ASD, these behaviours may also be a source of anxiety if individuals are prohibited from engaging in these behaviours” (Jiujiias, Kelley & Hall 2017, p.950).

Participants described sublimating or masking their stims in response to this stigma. Participants' masked stims were adapted to smaller stims in pockets or with fingers that were easily hidden. Or they would 'temporarily hide' their stims and delay stimming to when they could do it in private, sometimes late at night in their room, where people could not see or notice. Pearson and Rose (2020) look at masking in relation to late/ missed diagnosed people. They found that many people in the autistic population have some form of alexithymia - it is said about 50%. This can cause regulation of emotions to be much more difficult and if there is additional “suppression of internal states and associated coping mechanisms (i.e. stimming) alongside an already present difficulty identifying one's own emotions could potentially be disastrous, leading to further long term difficulties in mental health and wellbeing (i.e. burnout, and suicidality)” (Pearson & Rose, 2020 p.11).

Many participants also adopted stims that looked more neurotypical, such as scratching, nail and cuticle biting, and skin picking, even though they sometimes developed into more extreme stimming that has often been diagnosed as a chronic skin picking disorder or dermatillomania. There have been some links to dermatillomania and autistic people as well as other neurodevelopmental differences

such as attention differences (ADD, ADHD) and that this is related to 'repetitive behaviours' or stimming.

There have not been very many qualitative studies on the lived experience of autistic people in relation to stimming. The most relevant is the article '*People should be allowed to do what they like: Autistic adults' views and experiences of stimming*', Kapp et al. (2019), which found that stimming is extremely stigmatised and misunderstood by neurotypical society. The article found that stimming had been reclaimed by the neurodiversity movement and autistic people. Autistic people, and a small but growing body of qualitative studies, claim that stimming is a "useful coping mechanism" to "...soothe or communicate intense emotions or thoughts and thus object[ed] to treatment that aims to eliminate the behaviour" (Kapp et al., 2019, p.1782). Many SAG workshop participants reported that their stimming shared a number of characteristics. Their stimming was repetitious and predictable, which involved counting, patterns, feelings, and was seen as calming or 'soothing', which might suggest a self-regulator function. This was also in line with Kapp's (2019) participants' description of stimming in response to positive and negative emotional states. SAG participants described different variations of hand flapping in response to different emotions, including happiness (portrayed by a more open hand flapping), an expression of excitement with hands closer to the body but moving, and nervousness as more hand wrapping which was interesting to note. Several SAG participants spoke of stimming as a form 'supplementary communication', that other of these stims were conveyed emotions, and in some instances could be read by people close to them in their lives. Kapp et al (2019) reports a similar relationship between stims and communication stating, "Although no scientific literature (to our knowledge) directly examines a reported communicative function of stimming, our

findings support accounts of autistic activists and authors such as Bascom (Bascom, 2011) which suggest that the language of stimming may assist with learning to recognise the inner emotional states of autistic adults” (Kapp et al., 2019). As well as the Canadian autistic semiotic academics Nolan and McBride (2015), who wrote a book chapter where they inspected the ways the biomedical model “...discursively constructs the autistic in a deficit-driven language of disease rather than difference” (Nolan & Mc Bride, 2015, p.1069). Importantly, they also discuss stimming as “...an expression of autistic embodied semiotics that communicates sensory signification otherwise pathologized within neurotypical semiotic domains” (Nolan & McBride, 2015, p.1070). They see stimming as “sensory utterances” that have the possibility to convey meaning in a variety of practical and expressive ways (Nolan & McBride, 2015, p.1075).

I propose that many autistic instances of harmful sublimated stims would diminish with less stigmatisation of stimming in society and that there should be more research into this topic in the future. This accords with Kapp et al (2019) who note that autistic advocates have appealed to the world to “accept non-harmful forms of stimming”. They cite self-advocate Julia Bascom’s writings and website ‘Just Stim...’¹⁰¹ (Bascom, 2012b). The article also found “potential evidence of the spread of the movement through the report of teaching oneself how to stim via online resources” (Kapp et al., 2019, p.1790).

¹⁰¹ juststimming.wordpress.com

3.2 Recalibrating Self Awareness and the Autistic Experience

SAG participants felt the workshops increased their understanding of their own sensory experiences, in relation to stimming, and the experiences of other autistic people in the group. It became clear that sensory experience and stimming were intrinsically linked and that the participants enjoyed sharing stimming. It was also evident that regular stimming could help participants combat sensory overwhelm. Participants also became more comfortable with stimming and expressing emotions through stimming in public and, for some, being proud of it. They felt more connected to the other SAG participants through their common experience of stimming.

Cooper et al (2017) found a relationship between mental health and autistic social identity, noting that a 'positive autism social identity' may offer a protected effect (Cooper et al., 2017). Arguably, the SAG workshops might provide a form of protection in that the participants indirectly suggested that their self-identity had improved when they had gone through the SAG workshops. In retrospect, it would have been useful to have captured data using a validated tool to determine participants mental health before and after the workshops to be able to quantify this effect. Nonetheless, there is early evidence from the qualitative data that SAG participants reported positive changes to their self-identity, in particular, following their recalibration to stimming and sensory experiences. Cooper's et al later qualitative study confirms that the more positive characteristics their autistic participants linked to being autistic, the higher the "collective self-esteem" (Cooper et al., 2020).

Theme 4: Autistic Sensory Experience

Sound

The senses were something that SAG participants were aware of and found they became even more aware of the impact that their sensory experience had on their day-to-day life during the workshops. Participants also noticed that the impact of the senses differed within the group, but sound and music were particularly impactful. Many participants expressed anxiety about the sound workshop and felt that “sound was a real trigger for [them]” (P12). SAG participants enjoyed engaging with music, whether that be listening, rehearsing, performing or composing; a phenomenon that has been described in modern theories of autism that were first introduced by Leo Kanner in 1943 (Kanner, 1943). Since then, much has been written about autistic peoples’ relationship with music, finding that autistic people may have higher levels of auditory awareness and musicality than non-autistic people. Autistic ‘pitch discrimination’ has been the subject of much research; nonverbal autistic individuals are known to be at least 100 times more likely to be pitch perfect compared to non-autistic individuals¹⁰² (Rimland & Fein, 1988). Autistic people have also been found to discriminate between pitch better than non-autistics (Bonnell et al., 2003; Heaton et al., 2008; Järvinen-Pasley et al., 2008).

None of the SAG participants identified as non-verbal, although six explained they did experience temporary mutism under stress and in certain social contexts. It is interesting to speculate whether this increased perception of pitch may underpin SAG participants comments about the profound impact music had on their mood and

¹⁰² There is a higher proportion, 5%, of autistic people that have flawless pitch than non-autistic people, which is comparably lower with only 0.01-0.05%.

how some explained they felt music in their whole body; the SAG participant relationship with music was obviously profound. This profound impact by either creating positive emotions, (i.e., improved, 'inspired', and 'deeply moved' them), the music '*focused*' their brain or, for some, the profound impact was quite negative; especially loud music and sounds were experienced by many as distressing physically, distracting, annoying and overwhelming.

Remington and Fairnie (2017) carried out several experiments on auditory perception which challenges the standard concepts about autism and sensory experience which found that "Autistic individuals have an increased auditory perceptual capacity" in relation to non-autistic people (Remington & Fairnie, 2017, p.459).

Essentially, they found that the capacity to perceive sound was increased in autistic people compared to non-autistic people, which broadly means autistic people had a greater capacity to perceive sound. These findings may explain the aforementioned enhanced pitch and tone recognition but may also explain the perceptual overload or amplified distraction that results in distress by what may be perceived as an offensive sound (Remington & Fairnie, 2017, p.459). Remington and Fairnie's theory also challenged the historic notion that autistic experiences of sound was explained by difficulties in sensory processing or filtering (Plaisted et al., 2003). Reframing what was traditionally a 'difficulty' as an increased capacity, is both value free and more accurately reflects the findings from the SAG workshops; participants relationship to sound was unique but profound.

Landon (2016) carried out a qualitative study of noise sensitivity in adults with autism spectrum disorder. They discovered four themes including: '*I feel it in my head*'; "several participants associated these sorts of sounds with a degree of physical discomfort or 'feeling' the sound, beyond simply hearing them"; and the comment, "the feeling is so intense it feels like pain" (Landon, Shepherd & Lodhia, 2016, p.46). SAG participants also felt noise like a feeling of pain. Landon and their team also found a theme of 'sounds that can make you fall apart'; they found that several emotive responses were reported in reaction to noise, with anxiety seeming to be the most usual: "Noise causes reactions and anxiety regularly in social settings" (Landon, Shepherd & Lodhia 2016, p.47). Several SAG participants were very anxious about even coming to the sound workshop for fear that they would be overwhelmed, stating "sound is a trigger for me" (P12). Landon's study looked at autistic adults aged 26 to 52, with six men and four women. It appears the SAG participants of late diagnosed AWCTN+ people had several similar experiences with sound to this more varied group of autists.

Echolalia

The basic definition of echolalia is the repetition of another person's spoken word. In many cases, echolalia was one of the many significant traits of the diagnosis of ASC and has been noted since the beginning of autism research with an initial description by Kanner (1943) of childhood autism. In the past, autism researchers have regularly labelled echolalia as "pathological, automatic, and non-intentional behaviour" (Grossi et al., 2013, p.903). However more recent research has looked at the language of autism as multidimensional, and show how echolalia could be

argued to “function as interactional accomplishment, social action and mode of experience” (Sterponi et al, 2015, p.1).

SAG participants referred to echolalia when speaking about the words they used in their appliques. The SAG participants described examples of delayed echolalia, when a person repeats a word or phrase that they hear from someone else for example a TV program, a film, a podcast, social media or meme. Several participants used words they have repeated as delayed echolalia in their appliques and spoke about echolalia as expression, to express words creatively or just for the enjoyment the word¹⁰³.

The autistic community have spoken about stimming and echolalia, a form of vocal stimming, as a language for some time. As Julia Bascom, an autistic writer and self-advocate, put it “echolalia is a metalanguage... Echolalia is what you use when language is too much. It’s just also what you use when it’s not enough” (Bascom, 2012a, pp.299–300). Simply put, Bascom sees echolalia as a language about language, just as Jaworski et al (1998) see metalanguage as not just a ‘design feature’ of language but “How people represent language and communication processes is at one level, important data for understanding how social groups value and orient language and communication (varieties, process, etc.)” (Jaworski et al., 1998, p.3). They also describe metacommunication using “numerous framing devices [such as]... verbal art and play” (Jaworski et al, 1998, p.4). As SAG participants also spoke of ‘verbal stims’, sounds and words they find appealing and

¹⁰³ It has been suggested to me that there might be a hidden history of echolalia within the arts, especially within poetry. For example, this from Gertrude Stein which feels like it has an echolalia quality to it: <https://www.poetryfoundation.org/poems/55215/if-i-told-him-a-completed-portrait-of-picasso>.

like to repeat over and over, there seems to be agreement between SAG participants and Yergeau (2018) that echolalia is a form of stimming. Yergeau refers several different types of echo:

- *“multimodal engagement with echoing, or what might be termed echophenomena... (including)*
- *echolalia (the repetition of words or phrases)*
- *echopraxis (the repetition of the body movements or configurations)...”*
(Yergeau, 2018, p.193)

These have ‘multiple meaning[s]’ depending a person’s feelings which might spread over time, or might have “multiple means and feelings simultaneously” (Parker, 2013). This consensus of many autistic individuals appears to indicate that this might warrant more research conducted in reference to stimming, including verbal stimming and echolalia, as some form of communication.

The Importance of Other Senses

As part of the Object Description Workshops, it was noted that many of the objects participants chose to bring in were in relation to participants’ sensory experience of these objects. There was a representation of all senses when participants were referring to why these objects symbolise their experience of being autistic. Touch, sight and smell were the most referred to however, taste, hearing and vestibular (body in space) senses were also described throughout the SAG workshops.

Several participants described themselves enjoying the tactile feel of fabric and others had special interests in objects because they liked the way they felt and

smelled. Other participants had interesting obsessions with food, including gravy and other foods eaten routinely every day, as well as having obsessions with colours that elevated their mood. This relates to findings of Zachor and Ben-Itzhak (2013) that looked at unusual and negative sensory interests in autistic people. In a group of 679 children, they found that 70.4% had 'unusual sensory interests' and 66% had 'negative sensory experiences'. I would suggest that these are examples in late diagnosed AWCTN+ people of 'unusual sensory interests' or sensory seeking (Zachor & Ben-Itzhak, 2013).

Many participants also reported aversions to other sensory information, and I would propose that these are examples of 'negative sensory responses' (hypersensitivity to sensory information) such as smell and touch.

The qualitative study on autistic adults carried out by Kapp et al (2019) found that their participants stimmed in response to 'sensory dysregulation' which is in line with the viewpoints of occupational therapists and sensory integration theory (Kapp et al., 2019, p.1788). Their participants referred to 'overwhelming environments' that have 'demands of simultaneous multisensory processing' and 'sensory overload' from 'externally generated senses' as some of the reasons why they might stim to "self-regulate by blocking or reducing excessive input (sensorial)" (Kapp et al., 2019, pp.1785–1786). The SAG workshop findings refer to many cases of participants experiencing 'sensory overload' and using sensory tools (toys) to self-regulate, or assistive items such as noise cancelling headphones to "survive" (P11) and enjoy audio sensorial experiences.

The concept of differences with sensory processing and filtering appears to have been adopted by the DSM-5 (2013), which describes the ‘hyper’ and ‘hypo’ sensitivity of autistic people to sensory stimuli a little bit like a side note. In 2012, Caminha and Lampreia carried out a study observing the findings of all studies looking at sensory processing in individuals with ASC and stated, “Although not yet considered in the official diagnosis of autism, sensory problems appear to not only exert a considerable impact on the configuration of the disorder but also directly influence autistic persons in their daily lives” (Caminha & Lampreia, 2012). They go on to say that this could have serious implications for the triad of impairment (Wing & Gould, 1979), as sensory differences could be the cause for many of these behaviours, and ultimately sensory differences should be looked at much more closely than they have been in the past.

A more recent study by Thye et al (2018) six years later came to the same conclusion: “We find that altered sensory processing and sensory integration in autism affect language, communication, emotion, response to reward, and interpersonal functioning in individuals with ASD”, but concluded there remains a need for further research in this area (Thye et al., 2018). However, I do not agree with much of the language used in the article in reference to autistic people, nor their call for early intervention to alter the developmental progress of autism.

I suspect that the definition of autistic experience should be flipped so that sensorial experience is at the heart of much of autistic behaviour. If my sensorial experience of the world is different to yours, how could you judge the appropriateness of my reaction? No wonder there remains many communication barriers between autistic

people and the non-autistic population. Gemma Williams (2020) argues this in ‘*Perceptual deviants: understanding subjectivities in a (not so) predictable world*’, in the *The Neurodiversity Reader (2020)*, in which she argues that the Theory of Mind in non-autistic people is not always accurate. She looks at an American philosopher, Thomas Nagel (1974), and paraphrases his argument in terms of relating autistic experience to non-autistic experience,

“...any conscious being must have some subjective sense of what it is like to be itself, and that is what we may say consciousness is. A bat uses sonar -a sense that humans do not (naturally) possess- as its principle means of interpreting and navigating the world. If we try to image the subjective experience of a bat, we would only achieve poor approximations as we are lacking in the necessary facilities to accurately represent a bat’s way of being in the world” (Williams, 2020, pp.38–39).

Williams makes the link between perception, experience, and imagination, all of which indicate theory of mind. Her work adds to the growing body of autistic academics that reveals autistic people experience the world differently to non-autistic people and ‘perceptual deviants’. I would encourage further research into the role of autistic perception and its relation to autistic actions and behaviours.

Subtheme 4.1 Fascination and Object Personification

Many SAG participants were focused or fascinated with certain things, such as clothing of people that they loved and clothing from their past however, interestingly, as the smell or texture aged and faded with time, the degree of comfort these items

afforded was reduced too. Other SAG participants were drawn to objects that represented their passions or 'special interest'. Again, the common denominator was the association of these objects with positive/soothing emotions; an association with those aspects of their life in which they were able to focus and forget about everything else. Although the association between 'special interests' and 'positive and calming' emotions are well documented (Koenig & Williams, 2017; Grove, 2018), SAG participants appeared to experience positive emotions from objects that, for them, represented these 'long-term passions', which I think are synonymous with 'special interests'.

There are recognised potential advantages of autistic people's fascinations, be they special or preferred interests. Individuals who were able to pair their special interests with education and training noted enhanced employment opportunities (Koenig & Williams, 2017, p.137). It is noteworthy that some of the SAG participants also had recounted this experience.

Interestingly, findings from this study reinforce those of Grove et al (2018) that challenge the notion that autistic special interests are 'restricted', circumscribed', 'narrow and deep'. Like Grove and their team's participants, the SAG group report having several special interests throughout their lifetimes and that these vary widely (Grove et al., 2018, p.773). SAG participants reported multiple 'long term passions' and many were in the process of adopting new 'special interests' during the workshops.

Another part of the fascination with these objects appears to be related to anthropomorphising (object personalisation) of these objects by SAG participants.

Several SAG participants personified objects by gendering and naming objects such as plush toys.

This phenomenon has been noted by other studies including a qualitative study into anthropomorphism in autistic and non-autistic adults by Negri et al (2019). They found that people, whether they were autistic or not, displayed very comparable experiences of anthropomorphism. They started to develop initial features of this phenomena including how participants; “described anthropomorphism as comforting, promoting a sense of safety and friendship with, and feelings of empathy and sympathy towards, nonhuman agents” (Negri et al., 2019, p.286). They also found that Autistic adults felt that anthropomorphism objects performed a significant part in their lives, especially when they were children, to make them feel less isolated and assisted them to better understand feelings and connections with other people.

Negri and his team reported that both autistic and non-autistic participants have concern, and sometime feel distress, about the emotions and welfare of the personified objects (Negri et al., 2019). In another article on object personification, White and Remington (2019) found similar results in a larger study using an online survey that, “object personification occurs commonly among autistic individuals, and perhaps more often (and later in life) than the general population” (White & Remington, 2019, p. 2). This seems to be in line with the findings of the SAG workshops; many participants anthropomorphised objects as children and still do so as adults, naming and gendering objects that have significance to them, they ‘loved’ these objects and found these objects ‘soothing’ throughout their lives.

Theme 5: Articulating and Revaluating Autistic Needs

Participants reported that the workshops built a safe autistic space - a protected environment with boundaries - from the neurotypical world. Participants were encouraged to express autistic sensorial experience that are otherwise stigmatised, and supported to celebrate the discovery of the similarities and differences that make up the multifaceted experiences and intersectionality of autistic people. This protected space also encouraged participants that they could ask for their needs to be met in their own lives, that they could articulate and reevaluate their needs, to create their own boundaries as autistic people. Participants felt the SAG workshops helped them reflect, to develop a positive collective identity which in turn helped them to develop more self-worth through this validation.

SAG autistic space is similar to Sinclair's (2010) 'autistic space' in that it was run for and by autistic people with special attention given to modulating the sensory environment to make it autistic friendly, and autistic sociality and stimming was encouraged. However, SAG workshops were more structured in nature, exploring autistic experience and participants were given many creative opportunities (verbal and nonverbal) to articulate their experiences. In addition to this, the SAG space removed boundaries that may constrain experiencing and articulating the participant's autistic experiences. Participants were encouraged to be their authentic autistic selves. The workshops provided a judgement-free community for participants to express and articulate their needs - something that was quite unique to many of them.

The underlying hope of SAG was to foster an environment that allowed SAG participants to accept their autistic selves within this safe autistic space. Cage (2020) has proposed there might be a strong interrelationship between 'autism acceptance' and 'mental health' of autistic people, and proposes that acceptance not only of self- but also acceptance by others would lead to positive changes to mental health (Cage et al, 2018; Cage, 2020). Evidence of this is reported in a synthesis of fourteen qualitative studies that revealed the impact of self-determination across five derived domains: 'positive identity'; 'social relations/participation'; 'advocacy'; 'stress management'; and 'employment' (Kim, 2019). It could be said that SAG participants may show signs of improved self-determination when participants were reporting, reflecting, recognising and articulating their needs as autistic individuals to others.

Cage et al carried out a study in 2019 exploring the increased risk of experiencing mental health difficulties of autistic adolescents and the importance of 'identity development' in relation to 'acculturation'. The definition of acculturation "refers to the process of cultural and psychological change results following meetings between culture" (Sam & Berry, 2010, p.472). Cage et al likened the feeling of moving to a new country as similar to the process that an autistic person experiences when navigating a self-identity in a neurotypical world. Using this method, they found that 'assimilated' autistic youths had better self-identity than 'marginalised' autistic youths (Cresswell & Cage, 2019). Their findings suggest autistic youths "should be encouraged to explore autistic culture and supported in constructing their identity" (Cresswell & Cage, 2019, p.2901).

Strengths and Limitations

The qualitative interviews used to analyse participants involvement in the Super Autie Gang workshops and experiences are a strong part of this study, which allowed for the gathering of detailed data. Nonetheless, my analysis requires careful reading as I was not able to employ additional coders and, I personally recognise that as a refractive researcher (Barad, 2007; Barad, 2014) that, subjective bias was possible and may have directed the expansion of the themes that were identified.

In hindsight, it would have been valuable to have captured data using a validated tool such as a psychometrics, to capture the participants mental health before and after the workshops to be able to measure this effect more accurately.

As a participant and observer, I am usually an astute documenter for my own creative practice, taking detailed video and photographic documentation of my work and practical workshops I have done in the past. However, I found this much more difficult working with a group of autistic people who were not artists and who found just having their picture taken a difficult process. I felt that the participants were vulnerable and apprehensive about taking part in many of the exercises I developed with them, and the intrusion of a stills camera or video was not going to make them feel more comfortable. I felt that to document too heavily would be a betrayal of their trust and tip the very precarious scale of power in the wrong direction. I worked hard to develop relationships with the participants and, from the start, there seemed to be a level of trust evidenced in the interview transcripts in which the participants stated they did not feel like test subjects or that my interest in them was only to get what I needed out of them for my research.

I also had not worked at this scale before in relation to developing a series of workshops completely on my own without the help from a creative organisation such as a gallery or performance venue, or the structure of working with students in a college or university to document the work. In hindsight, it would have been useful to document the workshop and interviews much more thoroughly to capture the nonverbal aspect of communication, especially in relation to stimming, and the creative activities that were nonverbal, such as the stim circle and stim dancing. I might have benefited from asking one of the participants to act as an intern or work experience assistant to document the workshops and be in charge of downloading this information.

My Experience as an Autistic, Dyslexic, Dyspraxic Facilitator

The process of carrying out these workshops was not always a smooth one. This is due to many factors including my own sensory processing differences, executive functioning differences, as well as my own communication style as an autistic, dyslexic and dyspraxic person. I found it difficult to navigate working with a large group of Autistic people with a whole range of sensory profiles and neurodivergences, as well as our social communication styles and the years of internalised oppression that most late diagnosed autistic people deal with.

One of the things I felt really helped the process was my involvement with many of the participants as part of a social group/support group set up by the University which I had joined in November 2016. I was a trusted member of the group as an autistic person myself. However, I know this brings up other issues of bias and my interpretation of the data could be influenced by my own views as a part of this autistic community. Being neurodivergent also made it difficult to navigate what was

the most important part of the research because the exploratory nature of the original question was so wide, and I sometimes get lost in the beautiful details - this happened often. I was in a continual state of fascination and recalibration to make sure that I remained true to the lived experience of the participants and the meaning behind this.

In future research, I would like to go further with asking the community to help me develop the research and research questions more fully. I would make use of focus groups and, if I were to develop a larger research project, I would make sure to include a steering group representative of autistic people from as many intersectional backgrounds, and cultures as possible, including representations of autistic people with intellectual disabilities and/or significant barriers to communication. SAG workshops were dedicated to articulating the experiences of the late-diagnosed AWCTN+ participants, this also included the acknowledgement of the intersectionality of the participants and how this impacted the project.

The strength of this project is the multidisciplinary nature of the project by working on a practice as research project that incorporates multiple ways to interact and take part in the process including: watching or taking part in a participatory solo performance; participating in a series of workshops; being interviewed; or taking part in a collaborative performance and a focus group. I felt that this project could have more impact on the autistic community as well as articulate the experiences of a group of AWCTN+ people. I took inspiration from the ethos and ideas of the Participatory Autism Research Collective (PARC). Their main ethos was to bring autism researchers and clinicians together with autistic people, including academics and advocates. They sought to create a community where those who wanted to “see

more significant involvement of autistic people in autism research” and share their knowledge and expertise (Fletcher-Watson et al., 2019, p.947).

In an article involving several participatory autism research projects, they set out five important topics that they felt needed to be addressed when carrying out

Participatory Autism Research including:

- ‘respect’: ‘how to respectfully represent lived experience in research’,
- ‘authenticity’: how to make sure that autistic communities can meaningfully form autism research,
- ‘assumptions’: the need to address assumptions about autism,
- ‘infrastructure’: how to support autistic researchers and advocates, and
- ‘empathy’: addressing the double empathy problem¹⁰⁴ which Milton (2012) explains as the ‘mutual incomprehension’ that can occur between many non-autistic and autistic people in society at large and how this needs to be addressed when collaborating on a research project (Fletcher-Watson et al., 2019, p. 946-947).

At the time of my own research this article was not published however, I feel that my research incorporated many of these recommendations - it was very important to me that I was respectful of the participants and their lived experience and that the

¹⁰⁴There are several research papers supporting the ‘double empathy problem’ such as a study that found non-autistic people struggle to read the mental states of autistic people (Alkhaldi et al., 2019) and misinterpretation of social interaction between autistic and non-autistic people seems to be a regular occurrence. As well as the ‘perceptions, judgements and social decisions’ by non-autistic people that can create a negative bias when interacting with autistic people. This research looking at autistic and non-autistic interaction discovered that neurotypical people may judge autistic people instantly based on several factors including ‘social presentation style’ but not the content of verbal interaction. This negative perception of autistic people can add to the double empathy discussion (Alkhaldi et al., 2019). Other research supporting the double empathy problem includes Crompton et al (2020) which found that autistic peer-to-peer information transfer is highly effective, however cross neurotype communication was not (Crompton, Ropar et al., 2020)

research be authentic. As an autistic researcher myself, I was aware of the barriers to autistic academics and was also able to encourage, and possibly inspire, many of the participants who happened to be interested in academic careers themselves.

Slow Science

The SAG project is complex and multifaceted, incorporating a solo performance that articulated my own personal experience as a late discovered autistic person. It was important to me to build a genuine autistic community as a part of this project. I joined the autistic Tuesday group in November 2016 and many that attended these meetings ended up taking part in the SAG workshops (2018) and the final SAG performance (2019). I felt it was important to spend time with, and get to know, these potential participants and became a part of the community before designing the workshops, then created the collaborative performance with SAG participants. This helped me to develop the workshops around things that mattered to the participants.

I also changed the focus of many of the workshops during the process to incorporate ideas that developed during the workshops, such as incorporating two stim workshops instead of one, and creating a workshop geared towards creating articulation of individual needs for autistic safe spaces. This slow approach was in line with Fletcher-Watson's et al (2018) ideas on authenticity, making sure that the autistic participants could make an important contribution to the research, in which they reported:

“By spending time with autistic people, without an agenda or specific idea of what the researcher wants to do, we can build research questions on autistic input from the very outset” (Fletcher-Watson et al., 2019, p.948). They associated this with the ‘slow

science' movement (Allely, 2006) which talks about the “investment of time and resources in the thoughtful consideration and selection of ideas before data collection” (Fletcher-Watson et al., 2019, p.948).

Peer to Peer Support Autistic Led Groups

Another element that SAG workshops addressed was peer support. By creating an autistic community where participants connected and shared their experiences with other autistic people, participants reported that they felt more connected and less lonely. There was a positive narrative about themselves and the autistic community, and the participants were encouraged to be their authentic self and were accepted as such. Another example of other support programs that bring autistic communities together is Under Our Wings, created by Swann and Scottish autism, to run a one-year pilot autistic-designed peer-led mentoring program. There was a mentor training period including: “training in mentoring, networking, business start-ups, utilizing creativity and IT skills” (Stewart, 2019, p.1). My research is very different from this program however it was autistic lead and did include peer to peer support. The evaluation of this study found that “most people experienced an increased confidence, an improved sense of self and identity, and self-esteem. Some did not complete the programme but still found they had benefited from the experience” (Stewart, 2019, p.1). Peer to peer communication experiences for autistic people seem to be important, due to ease of communication within autistic communities, and appear to be better than cross neurotype communication.

Another project that is similar to SAG workshops is entitled, ‘*Exploring Being Autistic*’ developed by Caroline Hearst (Crane et al., 2020). This was an autistic led ten-week peer support program for newly diagnosed, (self) diagnosed autistic people, and has

some similarity to SAG workshops. However, *Exploring Being Autistic* worked with a mixed group of autistic adults aged 24 to 52 years old. SAG workshops were more exploratory and were interested in articulating the AWCTN+ participants experience through creative activities. The participants of *Exploring being Autistic* were interviewed and researchers identified three pre-program themes, with a “desire for: (1) Explore autism, (2) empowerment and (3) the development of practical strategies and coping mechanism” (Crane et al., 2020, p.1). The post-program interviews discovered three other themes: “(1) appreciation of the autistic-led nature of the programme; (2) unity in diversity; (3) developing a positive practical outlook on autism” (Crane et al., 2020, p.1).

Areas of Further Research

Future research should be devoted to the development of positive autistic identity - the programs that can help to facilitate the creation of a network of small autistic communities within towns, cities, villages, countries within neurotypical society (as too large of a group can have its own problems in relation to autistic overwhelm and the clashing of different social communication and styles). This should happen online whenever possible, and in-person to be as accessible as possible. A colleague, Chloe Farahar, who was a fellow PhD student in social psychology specialising in the stigmatisation of people with mental health issues and neurodiversity, and who also was a participant in the SAG workshops, and I have developed a pre- and post-diagnostic autistics support programme. This programme is for people seeking diagnosis, newly diagnosed, self-diagnosed or people that are not quite sure if they are autistic or not. We titled it, ‘So You’re Autistic?’ (SYA; Please see our website <https://soyoureautistic.com/>), and this includes all of the elements that we learned through the creative methodology develop as part of SAG workshop including;

embedding the knowledge of the importance of stimming, sensory, and shared autistic space for positive identity and wellbeing. Additionally, it contains a series of discussions and lectures developed with Farahar's knowledge of neurodiversity and autistic culture. In the future, this will entail large grant funding to develop, evaluate, and deploy an autistic diagnostic support programme within the NHS that potentially could be part of National Institute for Health and Care Excellence (NICE) guidelines for autistic people.

It should be noted that the themes that emerged from this research appear to challenge the validity of the male and/or male brained model of diagnosis, which does not appear to adequately describe the experiences of AWNBT+ people. The data suggests that the diagnostic criteria should be revised. Arguably, the diagnosis criteria should be refined to include a larger group of autistic people that do not fit into the hegemonic stereotype of autism. I would assert that the use of binary oppositions – male phenotype versus female phenotype – are not useful and can at times be harmful stereotypes. It would be important to recognise that autism is not a gendered phenomenon, whilst respecting the gendered experiences of autistic people. Inclusion of internal autistic (masking) criteria to the diagnostic process of assessment can be included without assigning biological sex or gender to autism. This would make visible the truer spectrum of autistic people, making it possible for discovery of one's autistic identity regardless of gender.

Personal Reflections and Analysis on The Adventurers of Super Autie Gang

(SAG)

The Evolution from Super Autie Grrl to the Super Autie Gang: Crippling/ Queering 'Autism'

This piece was created over a limited number of rehearsals¹⁰⁵ with five autistic non-performers, four out of the five collaborative performers (co-performer) had no or little experience with visual or performance/live art prior to taking part in the workshops. This performance was adapted from an original solo piece titled *Adventures of Super Aspie Grrl* that I performed two years earlier, April 2017 at the first Autism Arts Festival.

Originally, I created *Adventures of Super Autie Grrl* (2017) as way of articulating my own experience of being a late diagnosed autistic woman to a neurotypical audience. To express an understanding of being autistic to a neurotypical audience from a personal perspective that goes beyond stereotypical representations of autistic people.

However, after the initial performance I realised that this piece was more for the autistic community than a neurotypical one. This was apparent in the tremendously positive response I received from the mostly autistic audience at the *First Autism Arts Festival* in April 2017. Many of my friends from the autistic social group attended

¹⁰⁵ Rehearsals six in total were usually three hours in length and took place 10/04/19, 17/04/19, 18/04/19, 23/04/19, 24/04/19, 27/04/19. Not all participants took part in all rehearsals and sometimes participants went home early due to other commitments, autistic overwhelm or tiredness.

the show, as well as other autistic people and autistic artists (that were a part of the festival). I had several people come up to me after the show and stress to me how important my work was to the autistic community. One of the artists at the festival, a well know comedian who was performing but not opening out as autistic or even officially diagnosed at the time, spoke to Shaun May, the Autism Arts Festival Organiser, about her experience,

“Performance poet Kate Fox, in particular, described the strong influence that it had on her. Fox’s performance at the AAF (Autism Arts Festival 2017) was, as she described it, part of a ‘phased coming out’, having previously only discussed her autism in ‘closed, safe’ shows for the National Autistic Society and similar organisations. The publicity material for her show did not disclose her identity (using the pseudonym Una Q Horn) and if she spoke about the gig, she would maintain an ambiguity about her diagnostic status:

“But when I got to the festival itself, particularly seeing Annette’s show – which was such an important political call around the importance of autistic women having their voices heard... seeing something like that... made me think, ‘hang on, I have to stand up and be counted as well’...So because I felt comfortable and safe [within the festival environment], I was then able to be more receptive to this important message about voice, and representation, and visibility for autistic people and particularly autistic women. It just feels important to be more publicly part of that advocacy” (Fletcher-Watson & May, 2018b, p.411).

I also received positive reactions from a male audience member that teared up when they spoke to me about how they had seen themselves represented for the first time in the performance. This was significant as I had discovered many autistic people including late diagnosed cis-men that presented in a much more internal way and masked their 'autisticness'. I also received valuable feedback from my autistic friends who were part of the university student autistic social group on campus who had watched and participated, and audience volunteers in the performance. There was one part of the performance where I asked audience members to come on stage in solidarity for the autistic community and the entire audience came on stage.

A work in progress of *The Adventures of Super Autie Gang (2019)* was presented at the Autism Arts Show in Canterbury in April 2019 (Figure 37). This was a culmination of three-years of Practice as Research looking at articulating AWCTN+ people's experience of being autistic through participatory visual and performance art workshops and performances.



Figure 37 Super Autie Gang on stage as part of Adventures of Super Autie Gang (2019) Canterbury

The performance promoted neurodiversity and autistic pride, as the autistic author and scholar Sonya Loftis Freedman states in her book *'Imagining Autism: Fiction and Stereotypes on the Spectrum'* (2015):

"[T]he ways we think about, describe, and write about autism affect people labelled as 'autistic,' and this in turn affects the way that autistic people understand themselves, the way that their identity as autistics is enacted, and the way that people perceive and interpret the behaviour of autistics" (Loftis Freedman, 2015: 13).

This is a description of Ian Hacking's 'Making Up People'¹⁰⁶ and the 'looping effect' The looping effect' is defined as; the classification of people as 'objects of scientific inquiry' for many reasons; to control them, to help them, for their own good, or to protect them, and in turn we see these people defined by the classifications we choose to describe them with. However, this is not the case as people are always moving and changing, affected by the interaction with these scientific investigations and classification, and making them different people in the process (Hacking, 1985).

The workshops and rehearsals for *Super Autie Gang* created a space in which SAG participants felt secure enough to be their 'true autistic selves' and that being autistic and doing autistic things was encouraged, not discouraged: to stim; talking about your passions at length; get over excited/emotional/ overwhelmed; to be 'weird', playful or childlike. That goal was that the SAG performance (2019) would be understood by autistic people pre-eminently. My goal was to allow SAG performance collaborators (which I will refer to as co-performers) to embrace the awkwardness, chaos, messy and unorganised nature of being autistic itself in performance. The aim was to develop a new neurodivergent aesthetic that embraces difference, that encourages autistic people not to 'mask' or 'pretend to be neurotypical', that is accessible to all in any capacity to participate and is respectful of autistic culture (See Figure 38 for the SAG co-performers being their authentic autistic selves).

¹⁰⁶ Ian Hacking believes that the way we stereotype people and describe a group of people affects how that group of people see themselves and identify. This creates a 'looping effect' (Hacking, 1985).

Rehearsals of Super Autie Gang: ‘Crippling’ ‘Queering’ Autism

When rehearsals began it was important to make the co-performers feel comfortable with a structure as one co-performer stated in a focus group interview after the performance, “...*you have to start with the structure, and we [autistic people] are happy. I know I am anyway, if I know that there's a structure, if the structure changes but we're doing that together, that's fine...if there's no structure at all, I'm really unhappy and I won't want to do it*” (P9).



Figure 38 Film Still of The Super Autie Gang being their autistic selves stimming on stage, Adventures of Super Autie Gang (2019)

We began with the script from the last solo performance of Adventures of Super Autie Grrl at Invisible Festival in London April 9, 2018, as it was edited down from an hour long show to a thirty-minute performance. This gave room for new material to be created and fit in around the basic structure. It was important for the co-performers' voices to come through authentically for me and that the co-performers were comfortable to not mask and to be their autistic selves in the rehearsals and, ultimately, during the performance. This involved creating a tight knit community and

building up trust so that participants felt that they were inspired to tell their story.

Lomas (2007) states,

“Communities do not empower communities, individuals empower communities, Community dance does not empower communities, individual empowerment, self-intimacy, interactions with one’s authentic self, a sense of fulfilment, a feeling of achievement all contribute to the larger whole the community of solidarity, the ‘we’ and the ‘ours’; this affords a sense of security to individuals and communities of individuals” (Lomas, 2007, p.214).

Part of the process of my Practice as Research project was concerned with working with the ‘mess’ and ‘awkwardness’¹⁰⁷ of our experience, to show the ‘process’ of how neurodivergent people¹⁰⁸ maneuverer through the often disabling neurotypical world.

I have chosen a cross disciplinary approach looking at (feminist) materialism, community and participatory autism research, critical autism studies, crip theory, and queer theory for my research and methodologies. I have found it hard to work within ‘the clean lines of academic disciplines’ (Campbell & Farrier, 2015) and found much in common with the difficult and messy process described by Campbell and Farrier (2015) in their article, ‘*Queer Practice as Research: A Fabulously Messy Business*’. They state, “Queer PaR involves crossing disciplinary boundaries (often with scant regard to the propriety of those boundaries). These borders are both theoretical and

¹⁰⁷I want to recognise that the idea of ‘slickness’ and ‘awkwardness’ in performance, are concepts that are explored by Matt Hargrave (Hargrave, 2015) and Daniel Oliver (Oliver, 2019) respectively.

¹⁰⁸I am not only autistic, but also dyslexic and dyspraxic, and several studies have shown that it is very common for autistic people to have co-occurring differences that affect how they interact with the world (Kohane et al., 2012; de Bruin et al., 2007).

disciplinary yet also literally physical, often testing the limits of the inside and outside of bodies” (Campbell & Farrier 2015).

This experimentation and investigation with AWCTN+ people for The Adventures of Super Autie Gang and the embodied research I have been doing as part of an autistic community creates an everyday knowledge that is implicit, which Robin Nelson, who is the seminal writer on Practice as Research in the Arts, refers to as ‘liquid knowing’. This knowing then creates connections with more ‘hard’ knowledge (Nelson, 2013, p.60) Nelson speaks of the:

“importance of close-up, tacit, haptic know-how, seeks a means to establish as fully as possible an articulation of ‘liquid knowing’, and a shift through intersubjectivity into the know-what of shared and corroborated soft knowledge, in turn resonating with the harder know-that of established conceptual frameworks” (Nelson, 2013: 60).

I am partial to the idea of Queer or possibly (Crip PaR¹⁰⁹) practitioners “as bags of knowing liquid” (Campbell & Farrier, 2015). Campbell and Farrier argue that fluid is hard to contain:

“...it finds cracks and holes to permeate and flow through, thus coming into

¹⁰⁹ ‘Crip’ referred to here as a reclaimed word, as a ‘self-identifier’ for some disability performers. There are whole disciplines coming out of disability studies and queer theory about the idea of ‘cripping the queer’ and ‘queering the crip’ - basically queer disabled artists taking back words that have been used against their community to mess with, deconstruct the status quo as Petra Kupper (2017) states in a way that, “some activists and theorists see ‘crip’ as similar to ‘queer’ no longer firmly grounded in a binary divisional stance (disabled/nondisabled; gay/straight), but more aligned with a fluidity that acknowledges historical oppression but does not seek essential legitimization (see Sandahl, 2003)” (Kuppers, 2017, p.11,12).

potentially eroding or corrosive contact with 'established conceptual frameworks'. This potential for change to established knowledges via corrosive or eroding contact..." (Campbell & Farrier, 2015).

To restate this in another way, my research and queer/crip's PaR's challenge is to muddle with and dismantle these dominant and 'normalizing' dialogues as much as I can as a researcher (Campbell & Farrier, 2015). This in turn relates to the process of making and presenting *Adventures of Super Autie Grrl*, which was all about de-normalizing the neurotypical aesthetic of performance and live art. To mess with the idea that PaR PhD performance work needs to be 'slick' and have a particular type of 'rigorous', that the experiences of most AWCTN+ people is not 'slick' and, although there is a 'rigor', it is in a seemingly chaotic, messy, awkward and abstract way. Queer PaR is attracted to this messiness to disrupt the cleanliness of normative research that often tries to 'neaten' their theories to adapt to the dominant forms of 'objectivity' (Campbell & Farrier, 2015) which often results in inaccurate findings that are too simplistic, and marginalise populations such as late-diagnosed AWCTN+ people. This was apparent even in the costume that I chose to create for these performances. The *Super Aspie Girl* patch is safety pinned to my unitard as I did not have time originally to sew it to the costume, I decided consciously not to sew it to the costume after the initial performance to stress the point that it takes me longer to do things and things often get forgotten in the stress of everyday life for an AWCTN+ person, so things remain unfinished, often indefinitely.

I have learned that it is better to just go with what you have, even if it is not perfect or finished, instead of trying to make everything perfect¹¹⁰. This is my conscious effort as an autistic self-advocate to stop trying to appear 'perfect' in an attempt to not perform as 'neurotypical' or a 'supercrip'. Kumari Campbell in her book, *Contours of ableism: The production of disability and abledness*, sees internalised oppression to be an understandable reaction to "living in a culture where disability is relentlessly and inherently negative..." (Campbell, 2008, p.20). Campbell (2008) goes on to say that 'internalised oppression' can also create, 'dispersal' and 'emulation'. 'Dispersal' is when disabled people distance themselves from other disabled people; this can be seen in the autistic community.

For several years after my late discovery (at the age of 39), I felt isolated and did not know other autistic people. I felt that I did not fit the 'stereotypical' hegemonic definition of an autistic person. I thought I would not have anything in common with other autistic people which in part, I suggest, could be due to masking or camouflaging so well that I did not see your own autisticness (Cage & Troxell-Whitman, 2019; Hull, Petrides et al., 2017).

Queering and Crippling Autism? 'Autisticizing' the Neurotypical World?

What does this mean, crippling/queering autism in relation to Carrie Sandahl's (2003) article, *'Queering the crip or crippling the queer?: Intersections of Queer and Crip Identities in Solo Autobiographical Performance'* (2003)? Based on Sandahl's

¹¹⁰ From my research, this was a consensus among participants. In the third applique workshop (06/03/2018), one of the participants from the workshops stated "*I want to make a star badge that says 'you tried'*" (P11, talking about perfectionism). Another participant wanted an applique to say "Perfectionist but not perfect" (P8).

definition, crippling/queering autism would be the act of verbalising coming out as queer and autistic on stage, “the public display of sexualised bodily difference¹¹¹, and the process of bearing witness to past and present injustice” (Sandahl, 2003, p.28). Sandahl positions crippling/ queering as “possibilities for academic and activist actions in performance and day to day life” (Sandahl, 2003 p.35). Sandahl (2003) additionally speaks of disabled actors creating performances in alternative, accessible spaces for a disabled audience (if there are not spaces accessible for themselves as co-performers and their audience) such as, *The Autism Arts Festival*.

Inspired by Sandahl’s (2003) theory of analysing solo queer crip performance, I am proposing autistic people should be included in this theory. Due to the delayed acceptance and creation of an autistic community to carry out self-advocacy, the queer and crip community is farther ahead and can inspire the new generation of autistic people that want to tell their story and advocate for autistic acceptance and representation. The intersectionality of disability prompts me to suggest a new term: ‘autisticing’, or ‘to autisticate’. Sandahl (2003) analyses disabled performers and how they address ‘social invisibility’, such as declaring an undistinguishable sexuality and disability. I am interested in addressing the ‘social invisibly’ of autistic people.

I will also address the invisibility of a generation of autistic people who did not fit the pathological paradigm’s stereotypical autist, which could be called the hegemonic autism, and therefore were either mis- or under- diagnosed or outside of the system, unaware themselves that they were autistic. Sandahl (2003) also discusses the

¹¹¹I address in the final act of *Adventures of Super Autie Gang* that, as someone with an invisible disability, I crip/queer autism by showing the sexualised autistic body. I do so by writing the words that have been used to externally and internally oppress me as a late discovered, queer, autistic woman who identifies as she/they on my skin in Sharpie marker.

“important role in articulating for the disability community and the culture at large the paradigm shift of disability from individual medical tragedy to minority activist identity” (Sandahl, 2003, p.30). I am sure she would include autistic performers’ adoption of the Neurodiversity paradigm and the rejection of the pathological paradigm in this definition as well. Crippling/queering autism then, according to Sandahl (2003), is “deployed to challenge oppressive norms, build community, and maintain the practitioners’ self-worth” (Sandahl, 2003, p.38). I will be addressing this in six key instances in the *Adventures of Super Autie Gang*.

1. Preshow: Synaesthesia Diagnosis Machine

The first instance of ‘autisticizing’ within *Adventures of Super Autie Gang* is when autistic co-performers, P9 and P16, carry out a preshow participatory performance commenting on the clinical labelling and experience of diagnosis of autistic people. P9’s performance as an autistic clinician ‘autistics’ the clinical labelling of autistic people. P9, with a clipboard in hand, asked each person that entered the space if they were neurotypical. If they said no, they congratulated them and invited them enthusiastically into the performance, if they said yes, they were given a sticker that simply stated ‘neurotypical’ to wear during the show. This was to flip the labelling of autistic people by clinicians and society around so that autistic people are enthusiastically encouraged and invited into the space and neurotypical people are given a label to wear. P9 comments on their experience handing out neurotypical labels, “*but that's the point. It happens to us [being labelled negatively] all the time. Yeah. And we're trying to flip it on its head and things*”¹¹².

¹¹² This labelling reminds me of a new initiative within the UK police organisation of a card that the London Metropolitan Police are designing for autistic people to carry in case they have dealings with the police. This is well meaning, however it singles out autistic people from the rest of society, which

At the same time, P16 is 'autisticizing' the clinical diagnosis of autistic people with their own version of the *Synaesthesia Diagnosis Machine* where, due to their synaesthesia, they see autistic people as regular shapes such as a triangle, circle or square and a colour. They see non-autistic people as irregular shapes and colours. They sat in a booth made out of a cardboard box with a hole cut out and underneath the hole was a sign that read *Synaesthesia Diagnosis Machine*. Synaesthesia has been linked to autism in several studies (Simner et al., 2006; Baron-Cohen et al., 2013; Bouvet et al., 2019) and was found to have almost three times greater prevalence than a control group, (Baron-Cohen et al., 2013). P16 gave people a piece of paper which illustrated the shape and colour they saw when they looked at them.

This was an attempt to criticise the clinical diagnosis that most autistic people are given. They are given a piece of paper that states all the ways in which they are disordered and their diagnosis of autism. Anecdotally, most autistic people have no idea what that means and are given no real indication of what it means or what they can do, and feel they have been left with no support (Crane et al., 2018). This is mirrored in the act of giving audience members the shapes and colours as they are meaningless until later on in the performance where P16 explains their Synaesthesia via a verbatim audio recording while co-performers carry around cardboard shapes representing the shapes and colours that they were given and give out irregular shapes to some of the neurotypical people in the audience.

could have a negative impact on the autistic people's self-esteem and their inclusion within society (Gibbs, 2021).

P16 commented on their experience as the *Synaesthesia Diagnostic Device*: “it was hilarious. It was fun. Because, like, they were looking to me for answers. So, like, it's like, the opposite way around, isn't it? Rather that they were like, they were looking to me for answers, because they wanted to know why they had the sheets and stuff. Like they were confused and not feeling fitting in. And I was like, ‘I'm the one in charge here’”.

2. The Rejection of Walking Neurotypical and ‘Autistic’ of Autistic Stereotypes

(Please see the video clip of this exercise here: <https://youtu.be/ohRQnHsQBmc>)

The next instance of ‘autistic’ is in the entrance on stage of the co-performers. The Super Autie Gang including Annette, P1, P2, P9, P16 and P17. We wanted an entrance to the performance that solidified us as a gang, an autistic gang. In one of the Super Autie Gang workshops on March 13, 2018, the participants and I (participants: P1, P2, P4, P5, P8, P9, P11, P12 and P13) carried out a practical movement-based exercise based on the question, ‘*what do neurotypical people walk like?*’ There were some great responses to this from the group including walking very upright with shoulders and back, quite stiff but comically deliberate. P12 also walked very confidently, almost arrogantly, and made eye contact with the audience several times, winking and nodding at the audience, gesturing what it is like for an autistic person to be approached by some neurotypical people¹¹³. P4 walked up

¹¹³ My analysis of this action was that P12 was commenting on how much neurotypical people use facial expressions and body language to communicate, and possibly that some neurotypical people do not always seem genuine, or give out contradictory signals sometimes in these forms of communication.

facing the audience and stated, *“I am the status quo, you need to be me”*. This could be P4’s frustration with the expectation that autistic people need to ‘pretend to be neurotypical’ or mask their autisticness. P12 walked up to P6 and just said in an exaggerated way with big hand gestures, *“Words, words, words, words, words”* and then P6 replied, *“small talk?”*. P12 replied with, *“small talk, small talk, small talk”* while making exaggerated hand gestures. P4 also walked up to P12 and said, *“I am bored, weather, weather”*, P12 spoke back as if they were having a conversation, *“Weather, weather”*. Both of these exchanges show the frustration autistic people have with small talk, as many do not see the purpose of it, and it seems a waste of time. Talking about the weather is one of the topics that is easy small talk but equally non-important. Autistic people on the whole are most interested in real conversation that is meaningful, talking about news, art, culture, philosophy, and things that they find fascinating rather than ‘small talk’ (Heasman & Gillespie, 2018; Morrison et al., 2019).

Small talk is a chore for most autistic people to appease neurotypical people, to not appear to be rude (Cage & Troxell-Whitman, 2019). Some autists, however, just don’t care about looking rude and have such an aversion to small talk that they just don’t do it at all. There have been many first-person accounts and clinical studies proposing that autistic people hide their differences in social communication through masking or camouflaging and how this has led to misdiagnosis or no diagnosis at all, as well as mental health problems such as stress, anxiety and depression among others. This is due to substantial mental exertion for autistic people to camouflage their autisticness and pretend to be neurotypical or ‘pass’ (Cage & Troxell-Whitman, 2019; Hull, Petrides et al., 2017; Lai et al., 2012; Willey, 1999; Mandy, 2019). It can

also be suggested that this has an effect on self-esteem issues due to hiding their 'autistic self' which can be seen as not good enough for the neurotypical world.

P1 began their interpretation of 'walking neurotypical' by walking and talking on the phone at the same time. Many autists would find this annoying (from the perspective of the caller and a person walking by). Many autistic people find talking on the phone difficult as they find it hard to process sound and therefore hear everything and nothing at the same time, so the sound on the street would make it very difficult for them to hear the person they were speaking to on the phone. As I have stated before but feel the need to reiterate due to the importance of this topic, differences in sensory perception are very likely to be the motivation behind much of autistic behaviour. From my own perceptual experience and my understanding of the SAG workshops participants through qualitative research, sensory experience differences are very prevalent among the SAG participants and should be acknowledged as more important in the diagnosis criteria (Caminha & Lampreia, 2012; Thye et al., 2018). Morgan (2019) carried out a review of papers on sensory experience and autistic people and found in the review of Crane et al (2009) and Elwin (2016) "that 94.4% of [autistic people], report co-occurring sensory differences that impact their daily life in a significant way" (Morgan, 2019, p.1). This is not a solely novel idea, since the beginning of autism research, sensory hyper and hypo differences were recorded (Robertson & Baron-Cohen, 2017). Nevertheless, it hasn't been taken very seriously until the DSM5 (2013) included it in the most recent list of 'symptoms'. This is something that the autistic community has known for a long time - that sensory experience affects how autists interact in the world. This is apparent in the ASAN (2020) description of autism on their website that I refer to in section 1, where they refer to sensory differences in the first line. Many autistic self-advocates do as

well; such as Neurodivergent Rebel in a blog post titled '*Filtered- My Sensory experience*', where they refer to their sensory differences as a 'filter' through which they perceive their environment (Holmans, 2017).

One could speculate that perhaps sensory processing differences could also affect the social communication styles of autistic people, as many autists would see talking on the phone in public as rude due to the hypersensitivity to sound that many autistic people experience. P1 began with a random conversation where they laughed in an obviously fake way (possibly commenting on the behaviour of neurotypical people to fake laugh to make someone comfortable and/or laugh at things that aren't funny instead of the autistic social communication style of saying what they mean literally. Or perhaps just to comment on the volume of neurotypical people when they are talking on the phone) and then stated, "*oh yes I know how to talk - I can do public speaking*" into the phone.

This seemed quite a noteworthy moment in the workshops as this encapsulated many things that autistic people struggle with on a daily basis, but it also was an example of how the workshops crip/queered neurotypical behaviour and autistic experience. The workshop environment and the exercise made it so that the autistic people were the 'normal ones' and the neurotypical people they were commenting on were 'strange' with odd and unusual behaviour. In that way, this exercise 'autisticated' the pathological paradigm stereotypical view that autistic people are disordered. This workshop exercise allowed the participants to look at neurotypical behaviour from a perspective that stated that their experience and behaviour was just as normal as neurotypical people, and sometimes more logical.

We felt it was important to include some of this in the introduction to the show. I also became fascinated with the idea of the Super Autie Gang walking on to the introduction music of the film *Reservoir Dogs* (Tarantino, 1992) - the iconic scene where the neurotypical gangsters in suits are walking down the street in slow motion. This has been recreated many times by other TV shows, films and YouTube videos (For example: <https://youtu.be/5qAUeO0X57g>).

We felt this important to show ourselves as a supportive interrelated gang¹¹⁴ (I define gang here as a group of people bonded together by a common theme to promote representations of real autists, in a positive way, that endorses the Neurodiversity Paradigm). The aim of the autistic walk and stimming on stage was to celebrate the Super Autie Gang and our 'autisticness' and a way to show autistic pride, rejecting the neurotypical walk and the tendency to camouflage our natural walk or mask who we are, to fit into a neurotypical world. We decided to try to follow the scene of *Reservoir Dogs* and walk out the first time emulating how they (the white, straight, neurotypical men) walk, wearing suitcoats- in a famously neurotypical way: head up, shoulders back, confident heel-toe walking, with hands swinging quietly at one's side (Figure 39).

¹¹⁴ The title Super Autie Gang came from the group. Originally it was called Super Aspie Grrl Workshops, but it was apparent and pointed out to me early on in the workshops this title was not inclusive enough. We changed Aspie to Autie as P8 stated, "that is a little old fashion isn't it Annette?" and I felt that due to the divisiveness of high functioning labels and the fact that none of the participants identified as an Aspie, as they were all diagnosed under the DSM 5 that uses autistic Spectrum Condition instead of separating Autism for Asperger's (Please see Appendix 6 for more explanation of this), we would change it to a more modern 'Autie'. 'Grrl' was from the idea of Riot Girls, but really was not inclusive of non-binary and trans- people, so we decided on gang after going over several alternative names.



Figure 39 Film Still of Super Autie Gang demonstrating Neurotypical Walk, *Adventures of Super Autie Gang* (2019)

However, we wanted to stop halfway through this performance of a neurotypical walk and say, '*NO, this isn't working*', then walk back, take off the coats to show my costume underneath and participants' normal clothing, to walk back on as autistic women and non-binary people (3 out of 6 co-performers are queer). We decided an autistic walk would be more free, less stiff and include some toe walking, as P16 was an avid toe walker from birth until they are told they either have to stop toe walking (Figure 40), as it is not 'normal', or they are told they have a shortened Achilles tendon and they need surgery or behavioural therapy to 'correct' their gait (Titman, 2018; Hodges, Wilder & Ertel, 2018). Many studies have shown high instances of toe walking in autistic children (Barrow et al., 2011; Accardo & Barrow, 2015; Weber, 1978; Hodges et al., 2018). We also felt that wearing ear defenders should be included in the performance of the autistic walk because many autistic people are hypersensitive to sensory information including sound, and everyone in the gang had

this sensitivity¹¹⁵. Many autistic people wear ear defenders or over the ear headphones with noise cancelling to minimise their exposure to everyday noise, as they are hypersensitive to sound, and these types of headphones can help to prevent meltdowns and burnout from over exposure to noise, especially in a loud, crowded place, filled with people.



Figure 40 Film Still of Super Autie Gang demonstrating Autistic Walk, Adventures of Super Autie Gang (2019)

We also wanted to include stimming and a stim toy to the autistic walk as all the workshop participants stimmed in some way even if it had been hidden (even from themselves). One of the findings of the workshops was that we discovered how beneficial positive stimming was for autistic people's self-esteem and well-being, as it was a way for autistic people to self-regulate their sensory experience of the world (Kapp et al., 2019; Bakan, 2014). By stimming on stage and as a part of this walk, we are reclaiming a part of autistic experience and culture that has been

¹¹⁵ Part of my findings from the workshops were that the participants' traumatic experience of sound and smell was so bad that participants did not even want to show up to the workshop exploring these senses despite the fact that they were autistic-led workshops that were sensitive to autistic experience.

discouraged and pathologised. We wanted to encourage all autistic people to rediscover all the ways they stimmed as a child and to remember the pleasure they experienced from stimming, thus taking the negative stigma away from stimming as a distressing act of atypical/ abnormal individuals. This stimming would solidify the 'autistic walk'. In relation to the use of stim toys, as one of the co-performers, P17, is averse to all things plastic¹¹⁶, they decided that they would not carry a stim toy but knit while walking, as this is how they stim. They are continuously knitting, especially in social situations. We decided just to have P17 on stage knitting at all times when they were not busy performing, as this is what they would do normally in social, awkward situations like being in a performance.

My analysis of this autistic aesthetic and autistifying of the experience of performance as autistic co-performers, exposed the real experience of autistic people on stage and the result that this has to the 'audience', which could stand in for the 'neurotypical' world. It is possible to show how autistic experience and behaviour can be misinterpreted as looking messy, late/lazy, unprofessional, not proactive etc. Nando Messias (2016) talks about his failure as a gay man to walk 'like a man' and conscious choice to act and walk 'like a sissy' and exaggerate it. I identify with this as a queer autist and the 'autistic walk' we performed with its hold ups, mishaps, knitting, toe walking and stimming as an attempt to perform the failure of 'autistic walking' and embrace this messiness as an 'embodied understanding of exclusion' (Messias, 2016, p.286). Messias states this is a form of 'reverse discourse' (Foucault, 1980; Halperin, 1995), "In embracing the mistake, I allow room for plurality. Choosing to present myself as a sissy and exaggerating the gesture, I

¹¹⁶ Plastic makes P17 think of all the plastic in the sea and all the plastic that is polluting our forests, oceans and marshlands which means stim toys/tools tend to disgust them.

create space for new narratives to flourish” (Messias, 2016, p.287). Love’s (2007) definition of ‘reverse discourse’ (Foucault, 1980) is a dynamic adoption of your inability to ‘act normal’, and he feels it permits queer people to transmute, “the base materials of social abjection into the gold of political agency” (Love, 2007, p.18). This was, in many ways, the purpose of the ASAG (2019). To find a way, show a way, to give back agency to the autistic co-performers and hopefully the audience. As Messias (2016) points to the idea that this queer failure might be regarded as a ‘style’ (Messias, 2016, p.279) and I believe this ‘style’ of failure is also apparent in the ASAG performance. As autistic people we fail to perform in neuronormative ways daily and this ‘autisticness’ was what we set out to do with the autistic walk and many other elements within the ASAG performance. I propose that this failure to perform neuronormality is also an autistic style or aesthetic.

3. Dear Simon Baron Cohen Letter, Coming Out as Crip and Queer, and the Appropriation of the #MeToo Movement

The letter is a crucial part of the performance as it sets the scene by rejecting the hegemonic stereotype that autistic people were usually male and/or male brained. I reject the pathological paradigm and embracing the Neurodiversity paradigm with my personal story written as a letter to Simon Baron Cohen¹¹⁷.

In the performance of the letter, I also verbally come out as queer and autistic in the first paragraph: *“I am a 47-year-old queer¹¹⁸ woman and I am autistic”*. This letter

¹¹⁷ Please see *Letter to Simon Baron Cohen* in its entirety in Appendix 1.

¹¹⁸ I changed this from the solo performance; I added in ‘queer’. This was due to my experiences with the autistic participants in the workshops. Having completed the workshops with so many amazing autistic participants, whom I learned from immensely, I was able to be more accepting of my own identity as a queer pansexual and non-binary person who uses the pronouns ‘she/they’.

was a part of the original solo performance at the Autism Arts Centre in 2017 and was adapted for the performance of Super Autie Gang. It was really important to articulate myself using the language of the neurodiversity paradigm, “to [bear] witness to past and present injustice” (Sandahl, 2003: 23) and for the other co-performers and audience to identify and witness this ‘autistic’ing’. One of the co-performers comments on the importance of the letter:

“I would say that you framed your experience in the performance and then allowed other people to say, ‘that’s exactly what happened to me’. So, you gave the words and the space to people, like the ideas and the concepts. Where people might not have fully understood what happened to them. So especially the bit when you’re reading the letter, and people are saying, ‘and me and me and me’. It kind of makes, as a performer, or someone who was part of it, makes you feel as if you’re not only given a space to express but, also giving us the words. Okay, because my experience of being autistic is, it’s really hard to explain what’s difficult and it’s much easier when, like you did, you said, it’s not actually like, all of these people are saying, ‘it feels like this’. And then you’re like, that’s why it’s so hard, because everyone else is telling me it’s like this and it’s not at all its like Annette said” (P17).

I recite the letter whilst doing Yoga. P17 walks in the space and begins to do the yoga along with me as I run through a series of Sun Salutations while reciting the letter (Figure 41). While I am upside down in ‘downward facing dog’ with my cape over my head and my hair in my eyes, I stop the performance and address the audience.



Figure 41 Super Autie Gang reading Baron-Cohen letter while doing yoga with co-performers Adventures of Super Autie Gang (2019) Canterbury

“Ok, sorry, this isn’t working, I think I am still masking a little bit, I have got to stop sorry, umm... Not only am I autistic, I am also dyslexic and dyspraxic [my brain works in its own unique way]¹⁹ and I find it really hard to remember my lines. It doesn’t really matter if I forget my lines for the rest of the show, I am going to ad lib and delete things, you guys will never know, but with this letter, it’s really important to me and I think it’s important that you hear the whole thing. So, I am going to attempt to read it while doing yoga. So here I go!” (ASAG, Foster, 2019).

¹⁹ This was in the script however I forgot to say it in the performance. However, I feel it is important as it refers to the use of the Neurodiversity Paradigm for the performance, describing my brain as working in its own unique way, but not defective.

This quote is important as I am coming out and ‘bearing witness’ to my other invisible co-occurring conditions and to the fact that I am masking as a performer to appear ‘neurotypical’ in my ability to remember lines under stress and “rearticulate[ing] [the] oppressive laws that govern normalcy” (Sandahl, 2003: 38). I then ask P9 to come on stage and give them a copy of the script. I ask P9 to hold a stance like a sprinter to be ready to be a type of ‘prompter’, however instead of saying the lines to me they hold the script for me or whisper the words into my ear.

This was an important point to make about the representation of a neurodivergent aesthetic, that it would allow for accessibility for the co-performers as well as the audience and that this ‘support’ can many times be peer-to-peer support. I restarted the performance of the letter with the support of my peers, making the performance accessible to all including the co-performers. P9 goes on to help me, when I ask, bringing the script and holding it, sometimes between my legs while I am in various yoga positions, including a backbend, sometimes whispering the script as I can’t read it upside down.

(See Figure 42: P9 holding the script between my legs).



Figure 42 Film Still of Getting help from co-performer to read letter, *The Adventures of Super Autie Gang* (2019)
Canterbury

At the point where I say, *"I had years of misdiagnosis"*, P17 says, *"and me"*, P9 says, *"me too"*. The other co-performers start to enter the stage stating, *'and me'*, *'and me'*, *'and me'*. Each co-performer has their own yoga mat and holds a yoga pose that they feel comfortable in. I continue on with the sun salutation and the letter, *"a lifetime struggle with mental health issues"*. P17 states, *"yep!"* I continue with the letter in a yoga lunge stretch, *"I finally had an answer, I am different. I am autistic!"* The nameless technician¹²⁰, (P1), responds first, *"Me too"*, the other co-performers respond, *'and me,' 'and me,' 'and me!'* These can be seen as a reference to the *'#MeToo Movement'*, a fourth wave feminist social media movement against sexual

¹²⁰ This is what P1 wanted to be called during the show as they were not comfortable on stage. P1 participated in the workshops and rehearsals, giving advice, and took on a technical role as well as recording an audio story that is performed too by the gang later in the piece.

harassment and assault that went viral on October 17, 2017. This phrase was first coined by Tarana Burke¹²¹ almost ten years earlier as she was motivated to use the 'Me Too' expression after a young teenager disclosed to her about being sexually assaulted and she was unable to respond. Thinking about it later, she felt she just could have responded, "me too". The feminist community has started this, and the autistic community has done similar hashtags for the autistic community.

The autistic community is very proactive online, especially on twitter, and there are many hashtags such as #ActuallyAutistic whereby it is possible to search for people and tweets or posts from autistic people themselves, instead of sifting through all the well-meaning, but still pathologised, posts by parents, carers and clinicians that sometimes drown out actual autistic voices. Another hashtag that the autistic community uses is #TreatMyAutism, which is a response to the pathologised treatment of autism by the clinical community. Autists talk about how they 'treat' their autism by finding humour in the word treatment, where they give their autism a 'treat' instead of treatment.

This is significant because it refers to the #TreatYourAutism hashtag which was an example of how the autistic community online can 'autisticate' the language of the pathology paradigm that is used by many parents, carers and clinicians. Many autistic people believe they do not need treatment for being autistic, but they do need support dealing with the ableism that autistic people experience on an

¹²¹ Many felt that Tarana Burke was not credited enough for the #MeToo Movement due to the fact that she was a woman of colour. "What history has shown us time and again is that if marginalized voices - those of people of colour, queer people, disabled people, poor people - aren't [centred] in our movements then they tend to become no more than a footnote. I often say that sexual violence knows no race, class or gender, but the response to it does. Ending sexual violence [and harassment] will require every voice from every corner of the world and it will require those whose voices are most often heard to find ways to amplify those voices that often go unheard" — Tarana Burke (Onwuachi-Willig, 2018, p.105)

everyday basis. This is an example of the social model of disability and how it is used by the autistic community, similar to the crip and queer communities. The social model of disability (Barnes & Mercer, 1996) makes a clear delineation between 'impairment' and disability. Impairment is a difficulty that is biological and the 'real' pain of 'lived experience' of disabled people and should be acknowledged (Mulvany, 2000; Crow, 1996; French, 1993; Hughes & Paterson, 1997; Shakespeare & Watson, 1995). 'Disability' is the disadvantage that is caused by society's inability to make the world accessible for the impairments and differences of disabled people. This takes the blame away from the individual that has the impairment, they are no longer seen as the problem, but instead disability is seen as 'socially constructed' (Brownlow, 2010; Goodley & Lawthorn, 2006). It has been disputed by academics whether autism is even a developmental condition and said by some to be as much a 'socially defined constructed' (Hacking, 1999) as it is developmental condition (Haney, 2017). Sandahl's (2003) writing and theories about crippling and queering is positions in both queer and disability studies and I would argue the neurodiversity studies could be included in this, as it has roots in, and current links with, activism and a 'history of injustice', which shows the similarities within these movements:

"...Sexual minorities and people with disabilities share a history of injustice: both have been pathologized by medicine; demonized by religion; discriminated against in housing, employment, and education; stereotyped in representation; victimized by hate groups; and isolated socially, often in their families of origin. Both constituencies are diverse in terms of race, class, gender, sexuality, religion, political affiliation, and other respects and therefore share many members (e.g., those who are disabled and

gay), as well as allies. Both have self-consciously created their own enclaves and vibrant subcultural practices” (Sandahl, 2003:26).

I would argue that one of the autistic communities’ ‘enclaves’ is the online community and where ‘autisticing’ happens on a daily basis with hashtags, memes and academic debates alike, showing the autistic communities’ constituents’ diversity and intersectionality. This is apparent in the next part of Adventures of Super Autie Gang where Super Autie Grrl/ Annette is saved from having a full-blown melt down in her tent by P16 and the rest of the gang.

4. Interactive Accessible Participation: Autistic Brain Demonstration

This part of the performance was added in addition to the ‘big autistic bus tour of my brain’ which was created for the earlier solo Adventurers of Super Aspie Grrl in 2017. This developed from the findings from the workshops that sensory experience was key to the workshop participants’ autistic experience. It became clear that sensory experience was interconnected with SAG workshop participants’ behaviours (such as stimming, eye contact and overwhelm) and that such behaviour was a reaction, negative or positive, to sensory experience. I felt it was important to differentiate the difference between the experience of autistic people and neurotypicals experience of sensory information within the brain and how this affects how autistic people experience the world and behave.

As part of my set, I recreated a representation of a diagram of the brain that shows the Reticular Formation, which is the antenna for the brain to collect sensory information. Different coloured electrical tape was used to represent the diagram of

the brain on the floor of the stage; this was used as a representation of my brain. In the earlier versions (April 2017 and November 2017), audience members were asked to volunteer to come on an imaginary bus tour in a bus made out of pieces of



Figure 43 The Big Autistic Bus tour with audience volunteers, The Adventures of Super Aspie Grrl (2017) Canterbury

cardboard that audience members and I held to create a bus. Volunteer audience members were taken on a tour of my autistic, dyslexic, dyspraxic brain (Figure 43). This was created to highlight the reticular formation and how it works differently in autistic brains to process sensory information. This section of the performance also touched on different senses that many SAG participants are hyper- and hypo-sensitive to such as sound, smell and touch.

The Brain Demonstration of the ASAG performance (2019) was created to be more interactive and explain how autistic and neurotypical brains, especially the reticular formation, process senses differently. To do this, seven to ten audience members

were asked to volunteer to illustrate this physically and visually with the diagram of the brain in electrical tape on the stage floor. It is explained in the performance that the reticular formation is the antenna or satellite disc of the brain to collect sensory information from our environment and that audience members will represent sensory information. One audience member volunteers and is assigned to be the sense gate. I explain that their role is to control how quickly the senses enter the brain by being a 'gate' that lets senses into the brain one at a time. One volunteer is assigned the role of a 'special sense' - they are representing the important sense that the brain decides to focus on while damping down the other sensory information that is sensed by the brain. The rest of the volunteers are assigned roles to be other senses. We demonstrate the neurotypical brain first. I asked the participants to carry out the demonstration after I have demonstrated their roles.

The gate controls and allows all the senses into the brain one at a time in an orderly fashion and each sense walks to a place in the brain and stands still while the 'special sense' walks continuously around the brain, highlighting that that sense is the most important and the brain is paying attention to it. My example used for this was when someone is walking down a busy city street with a friend telling a story with many noises, smells, sights, possibly people brushing past you. Your brain will pick the most important sense, possibly your friend's voice, so you can hear what they are saying, while dampening down all the other senses that are not as important.

Then I ask participating audience members to help me demonstrate an autistic brain in action and the different ways that autistic brains process sensory information. I tell the participants that this time there is no 'special sense', that all the senses are of

equal importance, and the gate keeper is having a party and wants everyone to come in, so it is much more chaotic and intense. Audience members are ushered into the brain and then told to walk faster and faster, even run and bump into each other and clap to show what an autistic brain is like when all these senses of equal importance are bouncing around the brain (Figure 44).



Figure 44 Autistic Brain Demonstration with audience volunteers, The Adventures of Super Autie Grrl (2017)

There were several changes that I made to this part of the performance in response to autistic audience members participation in it. They pointed out that I should warn autistic people that this participation would require you to run around in a tight space with other people and, if they do not like being touched, they might not want to participate. I also decided to modify the way people moved around inside the brain. I

didn't ask participants to run, and I replaced the clapping with flappause as the noise of clapping might be overwhelming to many autistic audience members. I also made sure that in the following renditions of this performance as well as Adventures of Super Autie Gang that I was more responsive to the audience members that participated in this part of the performance.

5. #TreatYourAutism Wheel and the Joys of Toe Walking

The gang created an *Autism Treatment Wheel*. This is an example of autistic people making fun of, or showing frustration with, the existing 'treatments' for autistic people and the fact that they are called 'treatments'. As if you can cure autistic people or give them a medication to stop them from being autistic, instead of something more positive such as coping strategies or autistic Life Hacks (or which that we decided to call treats). We see the treatment wheel as an opportunity to give 'treats' to our autistic selves. The *Autism Treatment Wheel* is inspired by the hashtag #TreatYourAutism. This had been used on twitter by the autistic community to poke fun at the 'treatment of autism' which usually included such things as Applied Behavioural Analysis (ABA). This treatment could be seen to oppress autistic expression and behaviours that the medical professions and neurotypical culture deem 'weird' or 'distressing' (for neurotypicals), (Gibson & Douglas, 2018). It also includes unhelpful treatments like 'resilience therapy' where autistic children are put in stressful situations to develop their flexibility and adaptability, i.e. resilience (Gibson & Douglas, 2018). Instead, this makes it so autistic people are expected to adapt and be flexible to the neurotypical world which can cause stress, anxiety and internalised oppression as the autistic person is asked to change, without coping strategies, support and a better adjusted sensory environment where they have

better mental and physical wellbeing. An autistic person might feel pressured to pretend that they are not stressed or in distress, instead of asking for accessibility adjustments in their environment. I felt that society at large and neurotypical people need to make some adjustments to what they feel is normal and 'distressing' so that autists are free to be autistic, healthier and happier, in a world that accepts them for who they are, instead of trying to change them into neurotypical people (Pearson & Rose, 2020).

P9 is then called out and the Autism Treatment Wheel (please see Figure 45) is projected on the large screen behind the co-performers. This wheel shows our version of treats we would like to give ourselves as autistic people to better our wellbeing. These Autism treatments includes; hanging out with other autistic people, spending time in nature, exercise, toe walking, daydreaming about an autistic planet, buying a stim toy, stim dancing, synchronised tent dancing (this happens later in the performance where all co-performers dance together inside of their own Over Whelm Avoidance Device tents) and Fabric Creep (this is what one performer, P1 the Nameless technician, named themselves because they have an urge to touch fabrics in clothing stores – this is a very typical autistic sensory seeking stim).

“But even when I come out and I was like, ‘I know how to treat your autism!’ I hear some people were like, hmmmmmm [like a unapproving sigh] in the audience before I did what I was gonna say, and then they found it even more hilarious because they had got slightly angry at it, which was good. It was, that was what we wanted. Really, wasn't it?” (P16). This shows that many of the audience that are not autistic were autistic advocates or allies who are versed into the language of the Neurodiversity

paradigm, and of the autistic advocate community's rejection of the language of the pathological paradigm and the vibrant subculture that this group has online.



Figure 45 'Treat your Autism' Wheel, *The Adventures of Super Autie Gang* (2019)

These #TreatYourAutism choices are used by the co-performers as hacking or coping strategies to help us survive in a neurotypical world but also help with the 'impairment' of being autistic, such as sensory overwhelm, burnout from masking and other co-occurring conditions such as anxiety and depression. However, for autistic people, the anxiety they feel is real. Many autistic people avoid crowded noisy places because the sound and proximity of people to their personal space can be extremely overwhelming. These are not irrational fears, they are real and have different motivation than possibly a neurotypical person experiencing anxiety. From

the practice as research SAG workshops happening from February to June 2018 it was clear that the autistic participants found many things helpful and beneficial to their well-being including:

- being in nature (unless you were so sensory sensitive that you felt assaulted by nature¹²²),
- being part of an autistic community where you are not expected to mask and you can talk to other autistic people about the experience of being autistic and just be yourself,
- sensory stimming with the body (stim dancing, toe walking, flapping hands, vocal stims) and objects (such as stim toys, craft, everyday objects, fabrics such as P1s fabric creeping/ sensory seeking activities),
- and exercise can help to regulate the sensory stimulation that affects autistic people and can cause overwhelm.

The regular addition of these things, such as being a part of an autistic community and regular stimming, had a positive effect on the co-performers mental and physical health and these were things that the co-performers wanted to highlight for the audience. Many of the co-performers and workshop participants added these things to their lifestyle, experienced better mental health and had a more positive outlook on life.

¹²² For example, some autistic people including P9 are so sensitive (this sensitivity can vary depending on mental and physical health, lack of support, Social Economical status, culture, etc.) they would be adverse and feel pain for the rain falling on their skin, wind blowing their hair in their face or eyes, bugs on their skin, grass, sand, dirt makes their skin itch, and they felt every grain of sand, blade of grass and rain drop - they ultimately would not enjoy being outside.

When reflecting on the impact of the performance, co-performers felt they had the ability to create tools needed to be autonomous by reclaiming hashtags (#TreatYourAutism) and take back the treatment of autism – with the autistic treatment wheel part of the performance - and incorporating practical strategies they created in the rehearsal process. *“But that is the point”* (P17), *“We are taking it back, yeah”* (P9), *“Because it’s [the treat] something special”* (P17). *“It’s really exciting. Instead of like, Oh, my God. Yeah. You’re doing the treatment. You’re deciding. You’re in charge. Not someone else coming along [clinician], going ‘that is a problem, that’s what we are going to do to it [treat you]’...Yeah. So, this is you saying, ‘it’s not a problem’. But it means ‘well I am allowed to do this!’”* (P17).

As the performance continued, P16 elaborates on their love of toe walking which is a reference to something that P16 and many other autistic people have experienced; where toe walking has been discouraged and seen as a ‘deficit’ by the clinical profession and the biomedical model, something that needs to be eradicated because it is not ‘normal’ or a neurotypical way of walking. P16 was discouraged and pressured not to toe walk to such an extent that they only do it in private or when ‘neurotypical’ people are not looking as they stated, *“I love treating my autism to toe walking! ...there are three types of toe walking, let me tell you all about it”* (P16, 2019). They go on to describe a subtle toe walking you can do with neurotypical people around (see Figure 46) and P16 states, *“So this one you walk normally and stay up on your toes just a little bit longer than you might expect”*. P16 goes on to explain the third kind of toe walking which she calls *“...completely shameless toe walking”*

“Oh, yes, first arms on your hips, but first check for neurotypicals first down the corridor, no neurotypicals, you’re not going to scare them, ... Ready and you just GO FOR IT! TOE WALK, TOE WALK, TOE WALK!” (P16).



Figure 46: The Super Autie Gang toe walking on stage, *The Adventures of Super Autie Gang* (2019) Canterbury

It is apparent here that P16 goes to lengths to not be seen toe walking in front of neurotypicals, to the point that they check for them and they are afraid of ‘scaring them’. However, this is something that gives P16 joy and should be expressed as they are not hurting anyone.

6. Plate Licking and Fabric Creepers (Experiences from Object Workshop and Embracing Autisticness)

The object descriptions that were part of workshops seven and eight became the inspiration for the next part of the performance. Participants had brought objects into

these workshops that represented their experience of being autistic. The object stories from the workshop participants that were included as part of this performance reflected the celebration of the participants' true authentic autistic selves. We decided that the stories should be audios of the co-performers speaking, as remembering and speaking lines in front of an audience, for some of the co-performers, was overwhelming. Co-performers sat in their tents ready for the next section. Many of the object stories portrayed autisticness that we all recognise in ourselves and can laugh about now as a part of a community that values this. This autisticness is celebrated in the *Super Autie Gang* workshops (2018) and performance (2019), a shared understanding between participants laughing with each other about the obvious autisticness of some of our experiences. This autisticness is the part of ourselves that, as late discovered autists, we tried to hide at all costs for fear of hostility, alienation and bullying. These stories represent this autisticness when our masks are not quite right, or where we do not know we need to mask, where our difference or 'weirdness' is pointed out or found out. These stories are examples of autisticness and something that the participants carried out throughout the workshops, where participants shared stories of specific acts, behaviours, that had been pointed out as 'weird' or 'strange' by the neurotypical world. These became ways for autistic people to bond and understand that they were not alone in their strangeness and that they can have pride in their weirdness. That they were, and are, simply autistic, and that other autistic people experienced and did similar things. As Yergeau, an autistic self-advocate and author, describes in *Authoring Autism* (2018),

"... autism is also a story about communication or generally about enriching our ideas of rhetoricity and eye contact and the beauty of the shiny objects.

It's a story about disability culture, it's a story about stories and who or who is determined to be storyable. It's a story about empathy and expression and reclamation... But what's at risk here is who tells my story and more broadly, who tells the story of my people" (Yergeau, 2018, p.24).

Yergeau (2018) points out here that autistic stories need to be told by autistic people, that we cannot allow non-autistic people to tell our stories anymore. That these stories that autistic people tell either by telling actual instances where their autisticness was apparent or, as she calls it, neuroqueer. Yergeau (2018) states "rather autistic conventions can be more capaciously read as a neuroqueer mode of engaging, resisting, claiming and contrasting the interstices of sociality" (Yergeau, 2018, p.23).

In hindsight, my idea of 'autisticizing' is my own word to describe the phenomenon of Neuroqueering. At the time of writing this, I was more influenced by Crip and Queer theory than by Walker (2015) and Yergeau's (2018) definition of neuroqueer. However, I believe them to be one and the same. I noticed when reading Yergeau's (2018) book, *Authoring Autism*, after I wrote this section, that they used a similar word to my term 'autisticizing'. They used a related term for autistically (interestingly only once in the book) but put a 'k' in the word, autistickly, where they state, "... to put it more autistickly,..." (Yergeau, 2018, p.151). As a Rhetoric scholar, they are much better at creating neuroqueer words and autistic 'style' words than I am, nevertheless it is very interesting that we came up with similar arguments in relation to the 'queerness', 'cripness' of autistic people. Mine heavily influenced by Sandahl (2003) based on collaboration with co-performers and articulating real-life

experiences from the SAG workshops, rather than Yergeau's (2018) in-depth autistic cultural research and linguistic-based perspective.

With this idea of neuroqueer storying in mind, I look at the stories told by the co-performers' instances of autisticness (or neuroqueerness). The first object story is by P9 (See the ASAG performance (2019) script in Appendix 12). Her story is about her childhood habit of licking plates after every meal and the strict routine that P9 did after school every day. This is a story about sensory experiences of food, autistic behaviours that have been pathologized, terms such as rigidity, obsession and the need for routine. Due to the need for sameness in food, many Autistic people, including P9, only like certain foods due to strong sensory experiences of taste, texture and smell. As the audio of P9 telling the story was played, the other co-performers Annette, P17, P16 and P2 collected plates from P1 who was handing them out and stood in the middle of the stage in a line facing the audience. When P9's exact description of how to lick the plate was playing, co-performers demonstrated the licking pattern on their plates for the audience (see Figure 47).

“But then I would have to lick the melted ice cream in a particular pattern, which was like an Asterisk. So, you'd like start like that, and you'd have a lick down the middle, and then make a cross, so that it was going across and then you would start like an asterisk, you go up to the top and then lick that way. And then start from the other side and licked that way, and then there would only be like a tiny little bits left and you would just lick those off” (P9's audio recording from Super Autie Gang).



Figure 47: Film Still of Licking Plates, *The Adventures of Super Autie Gang* (2019) Canterbury

This once again was a description of autisticness, that no one noticed during P9's childhood, something she did not even know to hide, this was accepted by her grandparents especially her grandfather (whom P9 also sees as autistic). She had a need for sameness and routine for her after-school lunch. After all the participants heard this story, they related with other stories about sensory inclinations with food, texture and taste as well as the need for routine and sameness. P5 stated, "*I think this is a room full of plate lickers*". These stories are ways in which the participants bonded and as they saw themselves in these stories, the 'strange' and 'weird' things they do that have been pointed out to them their whole lives now had context, they were now 'normal' within this autistic society.



Figure 48 Fabric Creeper Object Story performance. *The Adventurers of Super Autie Grrl* (2019) Canterbury

The third story was P1's experience of their autisticness (or neuroqueerness) in relation to sensory experience: P1's love of touching soft fabrics, especially brand-new soft fabrics in department stores and describing themselves a 'fabric creeper'. The story tells of their experience as a young teenager touching some soft material that was on a manikin however, discovering as they touch this manikin that it was actually a real person. P1 stated, "*And unfortunately for me, my mother saw this and has never let me live it down. Really!*" (P1, Object story; See *The Adventurers of Super Autie Grrl* (2019) script in Appendix 12). This is performed at the back of the stage inside of co-performers' individual popup tents with one arm out of the tent zipper. Co-performers slowly creep downstage towards the audience with an arm extended in their own individual tents as the Fabric Creeper Audio plays (see Figure 48). When the audio gets to the discovery that the manikin is actually a woman they have just accidentally touched, all co-performers pull their arms into the tents and quickly move backwards back to their original place at the back of the stage.

These autistic stories are important, and the telling of these stories to an autistic audience Dawn Prince-Hughes (2004), a famous anthropologist and primatologist and late diagnosed autistic person, states “Much like the (D)eaf community, we (A)utistics are building an emergent culture. We individuals, with our cultures of one, are building a culture of many” (Prince-Hughes, 2005, p.7). So, telling these ‘culture of one’ stories with other autists can build as, Yergeau (2018) says, ‘counter-rhetoricity’. Or counter language/expressions/speech and excavating these autistic stories provides a way to build autistic identity, culture and community. All these stories that start to define autisticness, autistic identity, autistic culture such as stories of sensory fascinations, ‘perseverations’ (a term Yergeau (2018) uses to rename pathologized terms such as rigidity, obsession and routinisation) or stories that celebrate stimming, help to “...project autistic desires and autistic ideals” (Yergeau, 2018, p.25). I would add, helping to promote and recognise Autistic culture.

Conclusion: Autisticing or Neuroqueering of ASAG

These six instances of autisticing or neuroqueering represented in the ASAG performance (2019) are representative of the findings from the SAG workshops. These results are autientangled within the stories told in ASAG performance (2019) and extremely interconnected. I will try to break down the themes presented in each significant autisticing performance section; however, there is intra-action between all the themes the co-performers and I observed within the performance of ASAG (2019):

- 1.) *The Preshow: Synaesthesia Diagnosis Machine:* This performance section addressed the theme of reappropriating labels and autistifying the idea of autism and of diagnosis.
- 2.) *The Rejection of Walking Neurotypical and 'Autistifying' of Autistic Stereotypes:* This performance section focused on the theme of reappropriation (of bodily movements i.e., walking) as labels by autistifying the neurotypical walk and re-claiming and identifying the autistic walk.
- 3.) *Dear Simon Baron Cohen Letter and Coming Out as Autistic and Queer and the Appropriation of the #MeToo Movement:* This section concentrated on the themes of reappropriation of labels; particularly expressing the entanglement of autistic experience and intersectionality, especially in reference to gender expression and sexual identity (LGBTQIA+) through the act of 'coming out' as autistic and queer on stage. This also touched on the theme of masking stims, pointing out unconscious autistic masking, identifying with an autistic aesthetic or style (or neuroqueer) in our rejection of masking by trying to be our authentic autistic selves which included stimming on stage. This performance section also celebrated the autistic connectivity/community (online and offline) via the #ActuallyAutistic hashtag and the connectedness of the SAG.
- 4.) *Interactive Accessible Participation: Autistic Brain Demonstration;* including the theme of the importance of sensory experience to the autists'

daily life and how interconnected this is to how we move, think, talk, see the world.

- 5.) *#TreatYourAutism Wheel and the Joys of Toe Walking*; This performance section addressed the themes of re-claiming and re-evaluating autistic needs to better suit autistic experience by autistifying the 'treatment of autism', celebration of stimming and pointing to its connections to well-being. Also stressing the importance of autistic identity and community for better autistic quality of life.
- 6.) *Plate Licking and Fabric Creepers (Experiences from Object Workshop and Embracing of Autisticness)*: This performance segment stressed the importance of autistic identity and community for better autistic quality of life, through the sharing of autistic stories within an autistic community.

The themes of SAG workshops were represented through the portrayal of the lived experiences of the five participants that took part as co-performers with me. This was a chance to share the findings of the SAG workshops with the autistic community and the phenomenological experiences of these five co-performers in more detail. The themes included in the ASAG performance were: autistic space; labels and identities: reappropriation; stimming / body signs including masking or sublimated stims; autistic sensory experience; autistic connectivity and autistic space/community; and articulating and re-evaluating autistic needs.

Final Conclusion

With this thesis research, I aimed to explore autistic women (cis- and trans-), and non-binary people's experience of being autistic via performance, visual art and participatory autism research. I used a series of workshops, and a final collaborative

performance that included a small group of participants from the workshops, to explore these experiences. I also used a series of one-to-one interviews with participants and applied elements of grounded theory (Glaser & Strauss, 1967; Charmaz & Belgrave, 2015) from which five themes emerged.

The five emergent themes were:

Theme 1: Autistic Connectivity and Autistic Space

This included connecting with self, connecting with others and future connections. Participants were interested in connecting to their own autistic background and discovering more about who they were as autistic people. Participants were also interested in connecting with other autistic people and, in turn, created an autistic community and an autistic space to explore themselves. They felt this group had mutual understanding and empathy and recognised that the participants' experiences were unique. Participants' differences were accepted by the group along with their commonalities. Some participants said they wanted to reproduce this autistic community in the future (Please see Appendix 21 on the Awareness of Autistic Culture and Appendix 22 Tips for creating autistic space).

Theme 2: Labels and Identities: Reappropriation

This theme also included the important subtheme 'intersectionality labels and identities'. Participants adopted words and phrases that had been previously used in a derogatory manor and reappropriated these. Some labels also displayed intersectionality in the form of linking autism with gender or sexual orientation. Participants found these workshops celebratory; the making pieces of art (applique using these words and phrases) was considered to be empowering for participants to

reconceptualise their own previously conceived identity that was pathologized to a positive neurodiversity paradigm.

Theme 3: Stimming/ Body Signs

This include masking/ sublimated stims due to stigma, and recalibrating self-awareness and the autistic experience. Participants had a varied experience of stimming, some experiencing stims that could be seen as harmful, others experiencing stimming as calming; many participants were aware of their stims be associated with both negative and positive emotions (happiness, excitement and anxiety). Most participants experienced negative reactions to their stimming and realised that they had altered, or sublimated, their stim to something that was more acceptable to their family and peers. Some participants observed that some sublimated stims became harmful (scratching, nail biting, hair pulling, rubbing skin). Having completed the workshops, participants reported they no longer viewed stimming as a stigma and they started to explore and adopt novel stims. These new stims were particularly related to positive emotions and included adopting stim tools or toys to enhance emotional regulation.

Theme 4: Autistic Sensory Experience

Participants discovered the intensity of sensory experience was shared amongst the group, although the mode and sensitivity were unique to each individual. The group recognised that they craved or were drawn to the stimulation of certain senses (sensory seeking) or had a strong aversion to some senses (hypersensitivity). Some participants used this newfound knowledge to be able to better manage their anxiety levels by altering their environment to enhance positive sensory experience and

reduce negative sensory experiences. Participants were encouraged to create hypothetical technologies to help moderate their sensory overload (i.e., multi adjustable ear defender). Participants also recognised the relationship between sensory seeking modes and objects that they became 'fascinated' by. These fascinators often combined associations with key people and also had a physical property that appealed to the sensory mode the participants were drawn to. These objects were often anthropomorphised, and participants reported feeling empathy towards some of these objects. Another dimension of fascination relates to participants' previously labelled 'special interests' which united their hyper-focus abilities with a sense of positive emotion (calmness and enjoyment). Ultimately, sensory experience was central to many of the participants experiences and affected many aspects of their lives.

Theme 5: Articulating and Re-evaluating Autistic Needs.

Participants found that, having completed the workshops, they had a better sense of what they would need moving forwards to keep themselves well regulated. Issues such as boundaries, environment, communication, self-esteem, self-acceptance and pride in being autistic were all articulated by participants. There was a sense of increased self-acceptance and pride, both as individuals and as the SAG group. This was manifested in the final performative piece entitled, Adventures of Super Autie Gang (2019) (for video and photographic documentation of Adventures of Super Autie Gang Performance [REDACTED]).

This work has provided a small insight to the lived experiences of a group of late-diagnosed AWCTN+ people, for which little research had been previously published. Although the issue of biological sex within autism studies has been discussed, this work probed the experiences of gender and sexual identity in relation to a diagnosis of being autistic. This work goes partway to rebalance the traditional hegemonic theory of the extreme male brain, which I believe has been to the detriment of late-diagnosed AWCTN+ people. I found that late-diagnosed AWCTN+ people have a variety of ways of organising and interpreting the world, as do neurotypical people. Autistic people are no more likely to be binary systemisers or empathisers than non-autistic people.

This project also successfully used creative performative methods to explore, articulate and educate late-diagnosed AWCTN+ people's experiences and in so doing, appears to have had a positive impact on their self-esteem, self-acceptance and their ability to be able to express their needs. This would be a fruitful area of future research, as incorporating creative self-exploration in a structured format could be potentially very effective. It could help other sectors of autistic people to function more successfully, and possibly thrive, in not only academia but potentially in other environments: schools, workplaces, local communities. With some modifications, perhaps it could also run online. It would be important to incorporate reliable and valid outcome measures to chart the effectiveness of these workshops across domains such as: quality of life, academic achievement, employability, job satisfaction, as well as more obvious domains of negative effects (anxiety, depression and mental health).

The template provided by this project is scalable, however it would be important to assess the cost effectiveness of running these workshops. My personal opinion is that, despite having run this whilst I was a fulltime post graduate student on a very small budget and given free workshop and rehearsal space by the University of Kent, I believe the workshops would be relatively cheap to run. The main cost would be training group facilitators and sourcing appropriate spaces to hold the workshops and performance. It is my opinion that the benefits of running this program outweigh its costs.

Using a phenomenological approach has assisted me in reframing my relationship with the medical paradigm that requires so called objective measures or observations by an 'expert' in the field to create a label of a disorder or condition that then needs to be managed by some form of intervention. Being involved with SAG participants has made me shift my view of the importance of getting a diagnosis - I am now of the opinion that self-discovery/ identification as autistic is just as useful. However, I am still aware that in order for people to obtain support and funding, a diagnosis is still needed to validate. I am also aware that this is problematic for autistic people with other learning and/or physical disabilities and/or with a much higher need for support, and that a diagnosis is the only way of validating and assessing needs. I do not have an answer to these questions but feel that there must be a way to validate autistic culture without the devaluing the autistic way of life. Being autistic does not, and should not, be viewed as a disorder or condition; it simply is a way of being. I also understand that the medical model has value as some autists need high levels of support. There needs to be a way the neurodiversity social movement and ethos can influence the medical model so that autistic people can be treated with respect and as individuals, as well as a part of a rich diverse

community of people. That autistic culture and sociality should be valued as a rich sphere that needs to be researched and explored more thoroughly - we are, after all, the autistic (neuro)queer pioneers.

EPILOGUE

This project has been a process of becoming, many people say that when you discover you are autistic, you become a child again or a 'baby autistic'.

You have to learn how to become yourself

your autistic self again

your true nature

reclaim what you have lost

every time I was told that I am

weird, strange, hysterical, too sensitive

every time I was told to stop stimming, rocking, jiggling, fidgeting, twiddling,

squirming, dribbling, dripping, wiggling, shuffling, lumbering, tripping,

fretting, worrying, overthinking, agonising, bothering, disturbing, upsetting,

interrupting, interjecting, intruding,

to just stop,

I can't stop, and I don't want to stop

Basically, I was being asked to stop acting autistic

and to a certain extent this is what this thesis is about

I was a true baby autistic; I was not aware of the neurodiversity paradigm when I started my thesis.

I thought I was a person with autism, but I was always an autistic person

When I began this project all I knew is there had to be something different, something better.

Ultimately, I created this project for myself, to know other autistic people,

to know myself as autistic and possibly create a space where autistic people could feel more positive about being autistic

I came to this project with a simple idea to use my skills as an artist to make something that would give autistic women (cis-/ trans-), and non-binary people a voice, a place to allow autistic people to share experiences and help each other understand what being autistic means

to find commonality, uniqueness, difference

as a community,

not alone, isolated, solitary, lonely, secluded, separate

I wanted to turn the culture of autism, the stereotypical idea of autistic people on its head and ask this group of amazing autistic people to look at themselves, their autisticness as a positive

I discovered crip and queer theory learned how the project's very existence is crippling and queering or as I termed it autisticking or better yet neuroqueering all over the place.

In true queer PaR messiness, as well as my own neuroqueer messiness I was learning as I went along only to discover

I was neuroqueer without fully knowing I was neuroqueer¹²³

which is a normal and very usual occurrence for me

to not know fully what I am doing but somehow struggle, scuffle, trip my way over discoveries

¹²³ As Nick Walker (2015) describes it, "being both neurodivergent and queer, with some degree of conscious awareness and/or active exploration around how these two aspects of one's identity intersect and interact" (Walker 2015).

this journey to the SAG workshops' neuroqueerness started with the idea of creating appliques, items that celebrated being autistic, that took words that were used to alienate us, used to belittle, demean, cast aside, ostracise us and reclaim them as our own

Or even better to make up new words, stimmy words and phrases that represent autistic personalities, socialities and fascinations like flapulous, autilicious, shynypebble, bumfuzzle, autimash, quietly social, the great autismo, autistic queer pioneer, anti-fem, autisti-queer, autistic ace awesome, autistic sapien, artistic autistic, and autistic good¹²⁴

Or use words we love to say over and over and over (heck, heck, wholesome, wholesome, sausages, sausages, sausages) and make them badges of honour. Patches of pride, emblems of our autisticness.

I am now fully aware that the ethos of the SAG workshops was to neuroqueer, to celebrate all that is autistic

Basically, to neuroqueer is to partake in new ways intentionally to 'undo', unbutton, unknot, disentangle, unravel the social conditioning that teaches neuronormativity, with the hope to reclaim and be able to express your neurodivergences, your weirdness your uniqueness

¹²⁴ Appliques made in SAG and SYA workshops over the past 3 years.

to its full potential and proclivities (Walker, 2015).

I learned as much from the participants who were really my collaborators and the community we created about what it means to be autistic and autistic experience than from any book or theory. I asked the SAG participants to partake in neuroqueering by joining the workshops, as one participant stated the workshops were “[j]ust like letting a bunch of autistics loose in a room, you know, having fun being autistic...”

This of course involved stimming, and everything stimmy

To stim was something that many of the SAG workshop collaborators had had completely programmed out of their brains, including myself, due to self-preservation, to protect ourselves from ridicule, bullying and/or ostracization, we unconsciously or consciously masked to fit into the neuromajority.

To discover that stimming is fun, pleasurable, marvellous, fabulously flappy

The SAG workshop community was a joint learning process and we helped each other rediscover our autisticness, our autistic culture,

realising together that what we are doing is stimming, and what we used to do as a child that was stimming too and it is ok

Trying to discover when we stim, how we stim, why we stim

To stim to stim, to happy stim, to dad dance, to flap, to happy tap, fan, finger flick, jump up and down, to stimmy hug, to stim in pockets, these stims, these expressions

and communications are not something to eradicate, these are something that can help autistic people be themselves.

To stim, to stim as a group, to group stim, to celebrate the stim was a cultural awakening for me and for this small SAG community of autistics.

To stim, to express emotion, to communicate is neuroqueer, it goes against the medical model of autism that sees stimming as a symptom.

The very act of doing this PhD is neuroqueer
to walk into an academic institution
proclaim I am autistic, and I want to explore being autistic with a bunch of other autistic people was neuroqueer. I have always gone about my life traveling backwards on the path less beaten, usually not even visible, scrambling through trees, underbrush to create a path

Usually, my obscure path was right next to a highly beaten designated footpath that I did not see until the last minute and my journey was about to end

Because I was lost, unsure, confused, and this journey is no exception
I have learned that this is part of my process of learning and creating new things
To discover, you have to be bewildered and confused to find something new
only after falling repeatedly, getting turned around, upside down, becoming desperate and completely losing hope do I discover the most amazing thing,
my autistic self
to see what I have always been

Autistic

and that I was not alone

and that I could be Autistic with a group of other Autistics

neuroqueering all over the place

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Appendices

Appendix 1: Letter to Simon Baron Cohen and Documentation

1.1 Please see photographic documentation of the Simon Baron Cohen Letter Performance in Adventures of Super Aspie Grrl here: [REDACTED] and video documentation of me performing the letter in Adventurers of Super Autie Grrl: [Letter performance in Adventures of Super Autie Grrl](#), and in Adventures of Super Autie Gang:

[REDACTED]

1.2 Letter to Simon Baron Cohen

Dear Simon Baron-Cohen,

I am a 46-year-old woman and I am Autistic. I was diagnosed at the age of 39; after years of feeling confused, frustrated and alienated, because I was aware of my difference, but I didn't know how I was different. After years of misdiagnosis and a lifetime struggle with mental health issues, I finally had an answer, I am different, and I know why, I am Autistic!

Your theories have affected the way autism has been perceived making it seem as if all autistic people are basically male or male brained.

As Kirstin Bumiller said in her article Quirky Citizens (2008) a decade ago, your hypothesis endorses a view of autism, that emphasises cultural stereotypes of

gender using scientific evidence to stereotype the autistic community 'male brained' this has excluded and marginalised a large group of people (Bumiller, 2008).

You and your colleagues have oversimplified the very complicated and multifaceted autistic community (Bumiller, 2008).

I have reviewed the most recent research and found evidence that there has been a systematic pattern of sexism and essentialism from the beginning of autism research and this has continued to develop unchecked for the past 73 years (Bumiller, 2008; Jack, 2014; Fine, 2010). I postulate there has been a male bias since the beginning of autism research (Loomes, Hull & Mandy 2017; Pellicano, Dinsmore & Charman, 2014). Kanner began his research in 1944 with eleven children: eight boys and three girls, an imbalance in subjects weighted heavily to the male side (Kreiser & White, 2014). Asperger (1944) felt that autism was a an 'extreme variant of male intelligence' (Baron-Cohen, 2004, p.2)

I feel I need to say this to you, that you should apologise to all the lost people of autism, all the people not diagnosed due to you and your colleagues' short sightedness. I would greatly appreciate it if you would acknowledge that you were wrong, that autistic people suffered because of it and that you will try to make it right. This is important and it needs to be said to the world. We all have a responsibility to set the record straight. Autism researchers need to give voice to as many autistic people as possible, women (cis-/trans-) and non-binary people need to tell their stories.

The next generation of autistic people should have a variety of autistic role models to

look up to and identify with. The diagnostic criteria should be made more broad to include people of all genders. The social construct of autism right now is too narrow and excludes and marginalises a larger group of people.

Yours sincerely,

Annette Foster

Multidisciplinary artist,

PhD Researcher and Autistic self-advocate

This letter was used in all of my PaR contemporary performance piece, 'Adventures of Super Aspie Grrl' (later changed to Super Autie Grrl). Parts of it were shown as a work-in progress in my first year of my PhD and premiered at the Autism Art Festival 2017. I also performed a revised version of this solo piece for the Disability History month at the University of Kent November 2017, and for the Invisible Festival 2018 at Rich Mix, London. Another modified version was used in Adventure of Super Autie Gang (2019).

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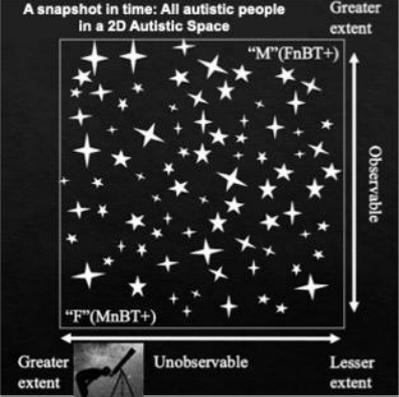
Appendix 2: Poster of 3-Dimensional Internal-External-Autistic-Space

The Three-Dimensional Autistic Space: Reconceptualising the spectrum

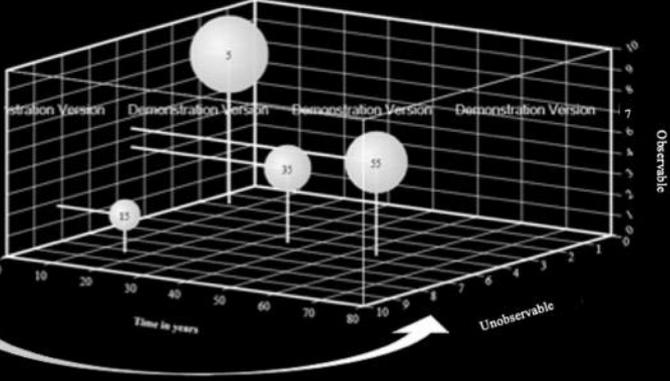
Chloe Farahar & Annette Foster
University of Kent | tlt9@kent.ac.uk | apf7@kent.ac.uk | SoYoureAutistic.com

Problem	Solution
<ul style="list-style-type: none"> ❖ Skewed female-male ratio within "Autism" research, diagnosis, & public understanding (male bias) ❖ Driven by the myth that autism is an "extreme male brain" & continued gendering with the "extreme female brain" (misguided concentration on biological sex) ❖ Invisibility of women (cis, trans) & non-binary people who are autistic, & men who do not present as the original conception of "classic male" autism ❖ Misunderstanding of the spectrum (as binary continuum), & of autistic development & growth 	<ul style="list-style-type: none"> ❖ De-gender autism conceptualisation ❖ More accurately represent the diversity of autistic experience ❖ Represent the reality of autistic development & growth across time <div style="text-align: center; margin-top: 10px;">  </div>

A snapshot in time: All autistic people in a 2D Autistic Space



Hypothetical lifetime of an autistic individual in the Three-Dimensional Autistic Space



Influences within the autistic space	Future
<ul style="list-style-type: none"> ❖ Culture/ethnicity society – social norms & pressures ❖ Context, environment, family ❖ Physical/mental wellbeing (feed-back loop) ❖ \leq/\geq support (adequate/inadequate support) ❖ Gender (& social norms pertaining to such, not necessarily biological sex) ❖ Socio-economic-status (SES) ❖ Genetic factors (to a lesser extent than literature would maintain) ❖ Co-occurring experiences (both physical, e.g. ME; epilepsy; IBS; Ehlers-Danos syndrome; etc., & neurological e.g. learning disabilities/differences; other neuro-developmental differences, e.g. dyslexia, dyspraxia, ADD/ADHD etc.) 	<ul style="list-style-type: none"> ❖ Is the Three-Dimensional Autistic Space framework more reliably describing individuals' experiences, more so than the binary of sex/gender? ❖ Can the framework help in developing a more inclusive checklist for identifying undiscovered autistics, one that does not focus purely on the externally observable, or gender? <ul style="list-style-type: none"> ❖ A checklist ought to consider how autistic people change due to influences/ers ❖ Can the framework help the public understand the diversity of the autistic community, to mitigate the "male Autism" stereotype (i.e. that autistics are not only the external/observable phenotype)? ❖ Gain feedback from/investigate those represented in different quadrants to identify validity



Key: FnBT+; MnBT+ | F = Female | M = Male | nB = non-binary | T+ = Trans & other



Appendix 3: Autistic Action Photos and Video link

3.1 For pictures and Videos of *Autistic Actions* performances, please see Autistic Actions folder by following this link: [REDACTED]



Autistic Action 1 by Annette Foster (2015)

3.2. Autistic Action 1 (AA1) link: [Autistic Action 1: Nottingham](#)

3.3. Autistic Action 2 (AA2) link: [Autistic Action 2: Canterbury](#)

3.4. Autistic Action 3 (AA3) link: Autistic Action 3 OWAD: Canterbury [REDACTED]

Appendix 4: Reflections on Autistic Action performances

The aim of my performances of *Adventures of Super Aspie/Autie Grrl* (2017) was to make the invisible visible, starting with myself, to hopefully create a dialogue with the public. To make people stare at me. Not a soul spoke to me with words, but they did communicate with me. They just walked on by. Many people stared or looked at me out of the corner of their eye, but I was used to all of this: being ignored, looked at, thought of as 'weird' or strange, or just being tolerated or humoured by people as someone that doesn't fit into the neurotypical world. My work and the sequencies of Super Autie Grrl in the public realm and on stage invited the audience to stare by labelling myself autistic, Neurodivergent, by coming out as autistic. My work as a Neurodivergent Artist is in line with other Disabled artists that forced the audience to stare, as Rosemarie Garland Thomson analyses in her 2005 article about three artists Cheryle Marie Wade, Mary Duffy and Carrie Sandahl. These artists "purposively enlist and manipulate the staring dynamic to mount a critique of dominant cultural narratives about disability" (Thomson, 2005, p.32). I purpose that my work is in line with these traditions. Thomson proposes that, "Staring is thus a kind of potent social choreography that marks bodies by enacting a dynamic visual exchange between spectator and a spectacle. Staring, then enacts a drama about the people involved" (Thomson, 2005, p.32). This includes the people who are different and the audience or the starers.

I recreated this performance in two different cities over a course of a year. Via 'doing' this simple intra-action¹²⁵ (Barad, 2007) or *Autistic Action* (as I titled it) of standing on a pedestrian street as a visibly autistic person, I was questioning the stereotypes of autism and neurodiversity. Why should neurodivergence be something that has to be hidden? Nick Walker in his article, *Throwing away the Master's Tools* (2012), discusses the pathology paradigm which states that there is a normal, healthy, right way for human brains to function. If the brain functions differently which results in changes in thought and behaviour then 'there is something wrong with you' (Walker, 2012: 227), i.e., it pathologises autism and autistic people. An example of this is the term 'high functioning and low functioning autism', whereby he explains that if there is no concept of 'normal' then how can low and high functioning be evaluated? Why is 'normal' the ideal standard against which everyone should be measured? The only way to change this perception is to begin to create a new language based on the neurodiversity paradigm making it valuable, natural, and healthy to have a brain that works differently to the greater part of the population. To bring about genuine change, autistic people must challenge the existing vocabulary that labels the autistic community as different or in deficit. As Audre Lorde states, "the master's tools will never dismantle the master's house" (cited in Walker, 2012: 229). To work within or outside of the system we cannot play by the pathology paradigm's rules, new tools will need to be created to dismantle the 'master's house'.

¹²⁵ Intra-action is taken from Karen Barad's framework of 'agential realism'. In her book, *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* (2007), Barad's term 'intra-action' means the shared composition of entangled phenomena. Intra-action works to identify that different phenomena do not come before, but rather materialise through, their intra-action. Phenomena (objects, people) are not recognisably different in a relational sense; they are only distinct in relation to their mutual entanglement. They do not exist as individual elements and hence they do not inter-act. The notion of intra-action is a re-working of certain traditional notions of causality (Barad, 2007, p.33).

Appendix 4 Bibliography

Barad, K. (2007). Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning, pp. 544.

Thomson, R.G.- (2005). Dare to Stare, Disabled Women Performance Artists and the Dynamics of Seeing. In: Sandahl, Carrie and Auslander, P. ed. Bodies in Commotion, Disability and Performance. University of Michigan: Ann Arbor, pp. 31-41.

Walker, N. (2012). Throw Away The Master's Tools: Liberating Ourselves From the Pathology Paradigm. In: Bascom, J. ed. Loud Hands: Autistic People, Speaking Speaking. Washinton D.C. USA: The Autistic Press, pp. 154–162.

Appendix 5: Adventures of Super Aspie Grrl April (2017)

5.1 I premiered this solo performance at the Autism Arts Festival April 30, 2017.

Please see photographic documentation of *The Adventures of Super Aspie Grrl* (April 2017) [REDACTED]

5.2 The Adventures of Super Aspie Girl (2017) first script, April 28, 2017, for the Autism Arts Festival, University of Kent, Canterbury

Section 1

Autistic action video 45 seconds- I am sitting in position in front of white blanket for next section.

Section 2

Autistic picnic- nonverbal struggle with symbolic objects (a telephone, first aid kit, stethoscope, an eggbeater and a martini glass) - audience participation

Section 3

Dear Dr Simon Baron Cohen

(Performing text while doing yoga – Sun Salutations)

Letter to Simon Baron Cohen

Dear really important autism researcher professor who knows everything about autism.

I am a 45-year-old woman, and I am Autistic. I was diagnosed at the age of 39 years old; after years of feeling confused, frustrated and alienated, after years of

misdiagnosis and my lifetime struggle with mental health issues, I finally had an answer, I am different, and I know why, I am Autistic!

(Look at audience)

You didn't make it any easier, did you?

Your theories have affected the way autism has been perceived making it seem as if all autistic people are basically male or male brained.

As somebody said a decade ago your hypothesis endorses a view of Autism that emphasises cultural stereotypes of gender using scientific evidence to stereotype the autistic community 'male brained' this has marginalised all minority gendered people.

You and your colleagues have totally oversimplified the very complicated and multifaceted autistic community.

This has marginalised all minority gendered people. Women (cis-/trans-) and non-binary people are much less likely to be diagnosed and to receive services. I have been diagnosed with everything under the sun-including social anxiety disorder, general anxiety, obsessive compulsive disorder, depression, chronic depression, manic depression. No doctor ever even mentioned autism to me until I was 39 years old, but I had been going back to doctor after doctor getting another wrong diagnosis.

I propose there has been a systematic pattern of sexism and essentialism from the

beginning of Autism research and this has continued to develop unchecked for the past 73 years.

The definition of autism has been based on sexist biased evidence that autism is a male condition. Women and how they present in terms of the diagnosis criteria now, were not considered for the diagnosis of Autism therefore there is little research that has included women. The scientific research then becomes biased, and the cycle continues.

(Turn to audience stand in tree yoga pose.)

I feel I need to say this to you, not because I want you to apologise, no I do want an apology – to all the lost people of Autism all the people not diagnosed due to your short sightedness- in person would be great but really I would be happy with anything: a tweet, Facebook post, Instagram or email. Something that acknowledged that you were wrong- that autistic people suffered because of it and that you will make it right!! This is important and it needs to be said to the world we all have a responsibility to set the record straight. Autism researchers need to give voice to as many autistic people as possible, women (cis-/trans-) and non-binary people need to tell their stories. The next generation of autistic people should have a variety of autistic role models to look up to and identify with. The diagnosis criteria should be made more broad to include women (cis-/trans-) and non-binary people. The social construct of autism right now is too narrow and excludes and marginalizes a larger group of people.

Sincerely,

Annette Foster

I composed a letter to an important autism research whose name will remain anonymous. My PhD supervisor has advised me not to use his name or to send it - but I might do it anyways, what do you think?

(Go down into a yoga squat hands in prayer position)

I am a lost person of Autism and I don't want to be lost anymore.

I feel I need to say this to you, it's important, I need to say this to the world. I need to call out to all women (cis-/trans-) and non-binary people lets tell our stories. Let's show autistic pride, let's set the record straight. The stereotype that Autism is a male disorder should end today.

Hi, my name is Annette and I have Autism, now let's try that again, as usually when I tell people this, I get a look of horror as if I have cancer or a horrible disease. Autism is not a disease. I am shocked every time I see this expression. Autism is not something to be embarrassed about. Autism affects how I perceive every part of the world, if you tried to take away my autism, I would no longer be who I am.

So, when I say, 'hello my name is Annette and I have Autism',

you say 'Hello Annette'

That would make me feel a lot better and we can start the show with a positive. I believe in the new affirming social disability model in that you see the difference in autistic individuals, not deficit.

Section 4: Introduction to the Overwhelm Avoidance Device – pop up tent.

Video during this section?

Section 5: The Big Autistic Brain Bus tour

Welcome to the big autistic bus tour of my brain and with so much to see there is only one way to see it. The Big Autistic Brain tour offers you a chance to see all my brains major attractions with thrilling uninterrupted views from my seat. The carefully designed tour includes every sight from the spinal cord to the reticular formation (you're not going to want to miss this, the reptilian brain home of the ever-famous fight or flight and the secret obsessive compartments of my brain. Now who would like to go on this tour I need some volunteer (all it's going to cost you is a little bit of your dignity).

(Wait for volunteers...)

Wonderful

(Start walking towards cardboard bus on stage)

While you relax in a luxurious, no expense spared, air-conditioned open top tour bus (gesture to cardboard) it's got every mod con!!!

I will introduce you to my autistic brain- the strange, the wonderful sensitivities and my ever-failing memory and a fun insight into the life of an autistic person.

(Talk to volunteers- how to hold bus and their parts as annoying people on the bus such as crying baby, annoying man on phone, or going through ring tones, or nosy teenagers laughing and giggling etc. Tell them P9 will start and they can follow their lead and improvise).

Is everybody set? OK Ladies and Gentlemen, you are going to take the ride of your life touring a real live autistic person's brain so sit back relax and prepare yourself.

We are slowly but surely making our way up the spinal cord and I just want to make you aware of the first and second vertebrae and disk- we are slowly going over them right now (make bus go over speed bump) I have had several back injuries throughout my life snowboarding- I actually broke my tailbone that time – not nice then a kick boxing class that put me out for a month and finally several bouts dancing in my thirties. So just be really careful at the area nobody really wants to get off at that spot.

OK moving on now we are traveling up the spinal cord and you get to brain stem which is called the reptilian brain- which is in charge of your survival. It's in charge of the four F's: Feeding, fleeing, fighting and I am sure you can all figure out what F is next.

As you can see the Brainstems central core is the Reticular Formation. Now that is the seat of the four A's: Awake, Asleep, Arousal and Attention and thus consciousness. You can see the little alarm clock there poised to wake me up. So, Reticular Formation is important.

It's kind of like a sensory antenna or satellite dish of the brain and it picks up all the senses (except for smell for some reason- smell goes straight past the thalamus goes to the emotional part of your brain). And calls us to attention or quiets us down or excites us.

So, to prevent neurotypical brains from being totally bombarded from senses from all over the place- the reticular formation monitors and filters sensations and your brain kind of figures out what is most important, and it focuses in on that and it dampens other things coming in that are not relevant or important. An example of this is when you are watching TV and someone talks to you – your brain decides that the multisensory experience of TV is more important and filter the persons voice out, or a lawn mower outside etc.

For someone with Autism like me, the reticular formation doesn't really organise things and it is slower at checking and sifting through everything that is coming into your brain. It doesn't filter as much out. I just get bombarded by senses all the time and become overloaded.

Pub area of my Brain - Shot glass/ pint glass

I am going to bring your attention to the left here (point right) which is my friendly neighbourhood Brain Pub you can see that this pub only has shot glasses to drink

from this is because most neurotypicals usually have a pint glass to build up all the sensory information throughout the day but for me and other autistic people we have a shot glass so you can see why I am overloaded and overwhelmed, often a shot glass doesn't hold much.

Big Red Panic Button / fight or flight

And moving on Folks we are pulling up to big red panic button in my brain that sets off fight or flight we are still in the reptilian brain.

The experience of being overwhelmed is kind of like when you go into fight or flight mode when your brain senses danger (this could be from a back-firing car or a bus stopping extremely fast- like this) all of a sudden you are hyper aware and you can see, smell, feel and hear everything- intensely, including your heartbeat. Your hands become sweaty, you might jump unnecessarily from any noise or surprise and you may feel sick to your stomach, your mouth might go dry and you feel shaky. You perceive everything in your environment as a possible threat to your survival, even though rationally you know it's not. For most of my life this is how I have felt on a daily basis. So please, whatever you do, don't touch that button, be very careful it's very sensitive, we wouldn't want to set it off, I really don't want to go into fight or flight right now as I would not like to go into fight or flight right now.

Emotional Drainage

As you can imagine being in fight or flight mode can become very draining, emotionally and physically. You become irritated very easily and get upset more

easily. Moving on you can see pockets of this emotional drainage throughout the brain- seeping black sludge and red raw-there is a big pocket of it here right above us- you need to be on the lookout for these and make sure it doesn't drip as its very difficult to get it off once it hits you.

Antidepressants - Secret coping compartment

Here is the most exclusive neighbourhood of my brain - the secret coping compartments - you can see here that my brain is chemically altered as do you see that yellow line there that is from my first anti-depressant, nortriptyline, which is for chronic pain from me grinding my teeth and clenching my jaw constantly from anxiety and the pink line is for my second antidepressant, Sertraline, which is just for all other anxiety and depression I experience daily. I have been on anti-depressants for over 20 years- I have tried to go off them several times to disastrous results and I have just decided for me to cope with the world I need them to survive. Really, I wasn't built for this world.

Secret compartments of touch

Moving on to the next spectacular major attraction the secret obsessive compartments of touch. If you look to your right (point to left) the part of my brain that I responsible for my high sensitivity to touch. I am sensitive to all fabrics, tight clothing. I only can wear soft and breathable fabric like cotton and stay away from synthetics. I wear clothes that are usually too big for me and loose. I have to make sure I cut the tags out of fabric and I have to get every little piece of that tag or it will drive me crazy and actually be worse.

The wonderful big autistic brain tour just gets better and better- did I tell you that the seats recline? Have a go.

Folks have a look to the left where the compartments of executive functioning, I am extremely unorganised, find it hard to see the big picture and constantly distracted - unless I am in hyper focus mode and then I can do nothing but that task for days at a time. One of the things I am know for is putting my jumper on inside out at the start of the day and not realising until someone points it out to me hours later. Okay everyone on the bus lets wave to everyone in the audience. Hi how are you out there? I was wondering if you would all take your jumpers off (if you have one- no worries if you don't) and put them on inside out? Just to get the feel of what it's like to be me and I will feel more comfortable for once as I won't be the only one in the room with my jumper on inside out. Also, look under your chair there should be a sticker for you. I also tend to get things on my face like pen and various food and I thought it might be nice if you get the feel for this too. I secretly hope that you forget to take these off and two hours later someone tells you have a sticker on your face.

And if you look to the right ladies and gentlemen, I have a terrible memory and as you can see there are several sections in this area that are very hazy- I forget things like putting on a belt, my keys, wallet, important objects like cameras in public places.

No sense of time, late for everything- I always wear a watch and check it obsessively. I tend to count the hours I have to do things and then obsessively count down hours that I have left.

The worst sense for me is probably my sense of smell which is so strong I smell everything - Overwhelming sense of smell on a bus for instance I can smell the overwhelming smell of body odour, I can smell everything: what people ate and cooked, whether they took a shower, their hair. Can't sit directly behind people as the look and smell of dirty hair distresses me - open windows, I don't like to sit next to anyone - bag on seat next to me - don't like to be on the inside trapped.

Overwhelm

I get so overwhelmed sometimes I have to shut everything out. I either sleep or watch TV I can't, I can't handle the birds singing, children's laughter, people chatting and making plans, I can't even handle walking in the sun light. I just want everything to stop and disappear, I hide from the world I even find it hard to hear my own heartbeat - this time is agony to me – I know I could be outside enjoying the sun going for a walk having a nice meal meeting a friend for coffee making art or writing even reading but I am here alone hiding from the world crying angry at myself for being stuck again in this cycle - not knowing how to change the sound of someone making coffee or running water is too much -

why do people want to talk to each other can't they just be quiet, why does the bus have to stop and shake I need to be home I can't take it anymore I feel like there are bugs inside – why is it so bright? I can feel the sun burning my eyes I just want everything to stop. Why can't it stop I want to be in control I want it quiet I want it to be still and white, dark and warm. I want to close my eyes and be alone. I want to be wrapped in a warm blanket and feel happy again I want to be able to handle it all-, but it gets to me regular – I can't control it I'm 45 years old and I can't figure out how to live without this constant overwhelm

This is where I am

I sit here

This is where I am

I sit here

This is where I am

I sit here

Section 6: Overwhelm - head stand- sometimes it's not easy flying- everybody needs a little help sometimes – could you help me up- could someone else help?- thank you for your support.

Section 7: Running a marathon- out the stage doors

Section 8: Membrane- Nude piece- transition

Words have power, words can whisper under your breath and in your ear, words can smack you in the face, words can stick to you and leak into you. Words can hide in

your body, in the cracks and crevasses, words can seep out of you like inky
angry stigmas, like shadows, words can be a beast on your back.

I have been invisible for such a long time, these words need to be made visible, help
me make them visible, help me redress in these words...

Section 9: Audience stands on stage in solidarity?

Appendix 6: Name change from Super Aspie to Super Autie

I decided to change my superhero name to 'Super Autie Grrl' for several reasons, listed below:

- 1.) 'Aspie' refers to Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnosis of Asperger's Syndrome, which was my initial diagnosis in 2011. In 2013 the DSM-5 reclassified Asperger Syndrome as Autistic Spectrum Disorder (American Psychiatric Association 2013).

- 2.) I have identified as autistic since 2016 and chose to classify myself as similar to all other autistic people, irrespective of the degree of co-occurring differences. I therefore started referring to myself as 'Autie' and used 'Autie' in 'Super Autie Grrl and Gang.

- 3) The World Health Organisation International Classification of Diseases (ICD-10) still used the term Aspergers Syndrome until ICD-11 came out in 2019 where it has been replaced with Autistic Spectrum Disorder (World Health Organisation, 2018).

- 4.) Edith Sheffer (2018) in her book, Asperger's Children: The Origins of Autism in Nazi Vienna, revealed that the man that discovered 'Autistic psychopathy' which later was coined Asperger Syndrome by Lorna Wing (1981), Hans Asperger, was complicit in the Nazi party's "negative eugenics" and "actively endorsed forced sterilization laws" (Sheffer, 2018 p18).

Due to this, and rightly so, the term is discouraged from being used. Please see Asperger's Children: The Origins of Autism in Nazi Vienna (Sheffer, 2018) for more information about this.

Appendix 6 Bibliography

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[Accessed: 18 November 2018].

Appendix 7: Applique used in Super Autie grrl and Super Autie Gang

7.1 Video documentation of Applique used in Super Autie Grrl Performance

7.2 Video Documentation of Applique used in Adventures of Super Autie Gang

7.3 Autistic Applique Photos by Annette Foster.

[REDACTED]

Appendix 8: More Detailed Description of Stimming

It was not until DSM5 (2013) that sensory differences were included at all in the diagnostic criteria,

“Hyper- or hyperreactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)” (DSM 5, 2013).

These sensory processing variances lead on to different behaviours such as stimming (self-soothing or self-stimulation) including the most stereotypical stims; rocking, hand flapping, spinning. This may be due to over or under stimulation of the sensory information that is coming into the brain. Stimming, originally coming from the term Self-Stimulation, and is one of the main forms of repetitive behaviour that the DSM and ICD talk about as a way for autistic people to regulate their sensory input. This can be done in a myriad of ways including: physically through movements like shaking your foot, flicking your fingernails, or hand flapping; vocally by echolalia (saying words or phrases over and over again); auditorily via listening to the same song over and over again; tactilely through rubbing different textures on the skin, playing with hair, scratching or picking at skin or hair. Stimming can also be expressed through taste/smell, sniffing objects or people, and licking or biting objects. The expression of stimming can also be visual, for example by staring at a shiny object or watching the light catch on an iridescent object. Another form of stimming is mental, or thinking stims such as saying words in your head that are seen in the head, counting, saying a word repetitively or continuously replaying a

scenario in your head- usually a social situation. Proprioceptive stimming occurs via moving the body in space such as spinning and rocking, possibly to perceive where the body is in space.

I propose stimming has 3 benefits:

1. It can help to regulate sensory input by focusing in on one movement or sound, taste, smell, phrase etc. which has an intensely to block the myriad of sensory sensations or can distract from something that is distressing.
2. Stimming can excite hypo-sensitive senses that are not getting enough stimulation.
3. Stimming can express emotions and be an expressive form of communication and creativity.

It is worth noting that stims are not necessarily negative; or expressions of stress but communicates all emotions, many autistic people get great pleasure out of stimming and focusing in on sensations.

I suggest that some autists have developed careers around this intense experience of the sensory world such as having a career in the arts. There is much focus on the negatives of sensory processing differences, but many autists can experience great enjoyment, gratification, and ecstasy from stimming which is something that really has not been explored that much. Maqqi Mucoi Amolngatti Â (2018) presented a lecture at Autscope 2018 entitled Exploring the Art of Stimming where he analysed many of the stims above and put them into two categories, “(1.) Repetitive, Continuous and Reboot stims (2.) Sensory, Cognitive, and Emotional stims.” (Amolngatti AU, 2018).

There are so many varieties of stimming that have yet to be identified or categorised. I suggest that stimming could be thought of as one form of autistic communication, communication with self and other. Jim Sinclair (2005) speaks of stimming as a social behaviour which he used when he first started interacting with other autistic people; he would go on to establish the autistic Network International. 'I experienced another form of natural autistic social behaviour--interactive stimming:' The clinical and research community have just started to catch on to the importance of stimming to autistic culture. The article, 'People should be allowed to do what they like': autistic adults' views and experiences of stimming (Kapp et al., 2019) looks at stimming or stereotyped or repetitive motor movements from the experiences and ideas of autistic people. They found that autists see stimming as something all humans do and that stimming can be very helpful as a coping mechanism to self sooth and express emotion through their body (Kapp et al., 2019).

Appendix 8 Bibliography

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Appendix 9: Apologising for my Existence: Performance in OWAD

As a part of Adventures of *Super Autie Gang*, I explain and demonstrate the Overwhelm Avoidance Device (OWAD). I am inside my OWAD talking about the difficulty of being autistic in a neurotypical world. I talk about the experience of masking, that I can only mask for so long and when I start to meltdown I disappear from the world. The performance (literally hiding in a tent) and text reflects the internalised oppression I experience when I cannot mask as neurotypical any longer; the toll it has taken on my mental health over the years but also my awareness and intention to stop this,

I have this habit of apologising for my existence

I apologise for everything

I apologise for being late, for mixing up dates,

for going the wrong way, for being clumsy, for being too loud, for getting lost

for cancelling plans,

for not reading people's minds,

for generally annoying people

basically, I apologise for being myself and then I apologise for apologising

I am tired of saying I am sorry

but I can't stop myself

I apologise basically for being autistic and I am not going to do it anymore.

(Note: This script was improvised during the performance so is not word for word)

Please go to this online link to view this section of Adventures of Super Autie Gang performance link: [REDACTED]

Appendix 10: Adventures of Super Autie Girl for Disability History Month, University of Kent, Canterbury Nov. 2017

10.1 [Video documentation of Adventures of Super Autie Grrl \(Nov. 2017\)](#)

For photographic documentation of this performance here: [REDACTED]

10.2 [Second Script of The Adventures of Autie Grrl for Disability History Month, University of Kent, Canterbury Nov. 2017](#)

NB: *Comments on addition/changes to scripts is in red font and changes from original script are highlighted in yellow.*

Section 1

Autistic action video 1 min 43 sec seconds - I am sitting in position in front of white blanket for next section.

Section 2

Autistic picnic - nonverbal struggle with symbolic objects - audience participation
Changed this part of performance and objects used, based on my new understanding of stimming due to my increase involvement with the autistic community changed and added more about stimming and fascination of objects now.

Section 3

Dear Dr Simon Baron Cohen

(Performing text while doing yoga –Sun Salutations cycle through once basic)

(Sun Salutations with back bends)

Dear very important autism researcher professor who allegedly knows everything about autism.

I am a 46-year-old woman, and I am Autistic. I was diagnosed at the age of 39; after years of feeling confused, frustrated and alienated, because I was aware of my difference, but I didn't know how I was different. After years of misdiagnosis and a lifetime struggle with mental health issues, I finally had an answer, I am different, and I know why, I am Autistic!

(Downward facing dog - Look at audience)

You didn't make it any easier, did you?

Your theories have affected the way autism has been perceived making it seem as if all autistic people are basically male or male brained.

(Sun salutation with leg up in air and to ear)

As Kirstin Bumiller said in her article Quirky Citizens almost a decade ago your hypothesis endorses a view of Autism that emphasises cultural stereotypes of gender using scientific evidence to stereotype the autistic community 'male brained' this has excluded and marginalised a large group of people.

(Upward facing dog)

You and your colleagues have totally oversimplified the very complicated and multifaceted autistic community.

(Backbend from a downward facing dog)

Women and people with complex gender identities are much less likely to be diagnosed and to receive services. I have been diagnosed with everything under the sun-including depression and anxiety, social anxiety disorder, obsessive compulsive disorder, chronic depression, manic depression, and generalized anxiety disorder. In the 20 years of going back to doctor after doctor getting one misdiagnosis after another the word Autism was never mentioned to me.

(Plow pose)

I propose there has been a systematic pattern of sexism and essentialism from the beginning of Autism research and this has continued to develop unchecked for the past 73 years.

(Shoulder stand and inverted split)

The definition of autism has been based on sexist biased evidence that autism is a male condition. Women and other genders and how they present in terms of the diagnostic criteria now, were not considered for the diagnosis of Autism therefore there is little research that has included women and people with complex genders. The scientific research then becomes biased, and the cycle continues.

(Turn to audience, stand in tree yoga pose, lower to hip stretch.)

I feel I need to say this to you, not because I want you to apologise, no I do want an apology – to all the lost people of Autism all the people not diagnosed due to your short sightedness- in person would be great but I would be happy with anything: a tweet, Facebook post, Instagram or email. Something that acknowledged that you were wrong - that autistic people suffered because of it and that you will make it

right!! This is important and it needs to be said to the world we all have a responsibility to set the record straight. Autism researchers need to give voice to as many autistic people as possible, women (cis-/trans-), non-binary and other gendered people need to tell their stories.

(Triangle pose)

The next generation of autistic people should have a variety of autistic role models to look up to and identify with. The diagnostic criteria should be made more broad to include people of all genders. The social construct of autism right now is too narrow and excludes and marginalizes a larger group of people.

Sincerely,

Annette Foster

Artist, PhD Researcher and Autistic self-advocate

(Mountain Pose)

I composed a letter to an important autism research whose name will remain anonymous. Due to my PhD supervisor, advises me to not use his name or to mail it at any cost- but I might do it anyways, what do you think?

(Go down into a yoga squat hands in prayer position)

I am a lost person of Autism and I don't want to be lost anymore.

I feel I need to say this to you, it's important, I need to say this to the world. I need to call out to all women (cis-/trans-) and non-binary people, let's tell our stories. Let's

show autistic pride, let's set the record straight. The stereotype that Autism is a male disorder should end today.

Introduction

Hi, my name is Annette and I have Autism, now let's try that again, as usually when I tell most neurotypical people this, I get a look of horror as if I have cancer or a horrible disease. Autism is not a disease. I am shocked every time I see this expression. Autism is not something to be embarrassed about. Autism affects how I perceive every part of the world, if you tried to take away my autism, I would no longer be who I am.

So, when I say 'hello my name is Annette and I have Autism', I want you to be really energetic and like excited to meet me because I am autistic, let's turn the world upside for an hour – I went to Autscope which is like an autistic conference and retreat and that was the case it was brilliant, and I recommend it to all autistic people.

You say 'Hello Annette'

Now I don't have to practice this I can trust you to give it your all?

I feel a lot better and we are starting the show with a positive. I believe in the new affirming social disability model in that you see the difference in people, not the deficit.

Section 4: Overwhelm Avoidance Device

Introduction to the Overwhelm Avoidance Device – (I talk about device and demonstrate how the device works by pop up the tent and getting inside. After demonstration, P9 please play POD Video when I ask you too)

I came up with this idea.

I was walking down the street and it was a really busy pedestrian area with lots of people around and I started to feel a bit overwhelmed, my shoulders were going up to my ears (Shrug Shoulders, my shoulders up to my ears) My teeth started clenching (clench teeth while talking), I started to sweat and shake a bit. And I thought, wouldn't it be good if I had some kind of cape or backpack that could just pop up into a tent and you could just hide in it that pod for a little bit until you feel better then you could just pop it down again and go about your business.

So, I did some internet research and there was actually a tent that already exists.

The tents are like 6 ft 2 in tall and very narrow for campers to put their toilets in but it works! It's got an open top and open bottom- its black so it blocks out light and it's not too claustrophobic.

So, I bought one....

(Walk over to the tent)

It's just over here I modified it a little bit – I put some straps on it, it's still a prototype, as you can see I haven't had the time to sew it. I safety pin everything, I love safety pins (put backpack on)

So, I call this the Overwhelm Avoidance Device...

You can imagine, you are walking down the street (walk on the stage into the audience)

You're having a nice day and all of a sudden it starts to get a little bit more crowded and you decide you might go back because (turn around) I don't know if I can handle it, I think maybe I should just go home because actually being in town on a Saturday is not a good idea ever... So instead of doing that you can just get your overwhelm avoidance device out and you can just unzip it, it is very easy to use, and pop it up (pop tent up) and get inside and wah laaa!

(Pause while in the tent) I am just going to have a minute - I am still here - (unzip tent).

So, I decided I would just have this here on stage. So, I am just going to put it over here (carry tent to the left side of stage) and if anyone feels overwhelmed at any time in the performance you can just come on stage, run in here and zip yourself up and just stay in there as long as you like - there is no judgement here...

It's a safe space. Yeah, I might do it... especially if I forget my lines...

Ok so I actually took this out into the streets of Canterbury one busy Saturday, and I was a little bit worried that people would be shocked by it or get angry at me for being in their way or they would scream but actually we live in a YouTube prank culture and people didn't really blink an eye.

So, I came in my Super Aspie Grrl Costume, hidden underneath my clothes. I guess it's a representation of how I really have two identities, like superheroes, as I pretend a lot – pretend that I am OK, that the world is not overwhelming to me (P9 you can play the video now, thank you).

In this first clip, I actually popped my tent on the alley way right in front of the Cathedral. There was a woman in a wheelchair that I popped up the tent right in front of her path, she was really nice and patiently waited for me to unzip the tent and run away down the street as Super Aspie Girl, luckily her friend pushed the tent to the side, and they were on their way.

I got pretty good at popping up the tent efficiently and by the end I was pretty quick. Oh, this part is great because look at his expression – he's like what the hell and then just shrugs and hardly blinks an eye, he just goes on with his day.

Change of script and addition of Audience Participation due to increased involvement with the autistic community, trying a range of more sensorial experiences would be a better representation of a neurodivergent aesthetic and better received by a neurodivergent audience. I felt that a verbal, visual and kinesthetic experience for volunteer participants and audience would be easier to understand.

Section 5: Neurotypical/ Autistic Brain Demonstration with audience participation.

OK I am sure you have been wondering what all that electrical tape is doing on the floor, well it's my brain, I kind of brought it with me as a show and tell. This is a diagram here of my autistic, dyslexic, dyspraxic brain. I hope you enjoy it!

It's a diagram of the brain showing the reticular formation It's kind of like a sensory antenna or satellite dish of the brain and it picks up all the senses sounds, smells, tastes, touch, sight, proprioceptors - which is how your body knows where say your arm or foot is in relation to the body, and vestibule sense which is related to your sense of balance, from wherever they are connecting to like your fingertips or your leg muscles well everything your conscious brain can only handle about 130 messages per second in any meaningful way, go brains by the way - that is amazing! So it absolutely needs some way to sort out what is important and prioritize those millions of messages from your body. The reticular formation limits the messages down to a more manageable flow.

So, we are going to demonstrate the difference between a neurotypical brain and an autistic brain – or, well, at least my brain. By the way, this show is by no means scientifically accurate. **I need some volunteers to play the sensorial information that go into the brain for me, Can I have at least 10 volunteers?**

(Talk to volunteers- Ask volunteers to line up - the first person is the gatekeeper, and they need to let one person in at a time say 5 seconds after each other one volunteer halfway down the line is the important sensory information so they keep moving

around- everyone else are sensory information that is organised and not given as much importance so you go into the brain and stand still in a different part.

Say this while they demonstrate?)

So, to prevent neurotypical brains from being totally bombarded from senses from all over the place - the reticular formation monitors and filters sensations and your brain kind of figures out what is most important, and it focuses in on that and it dampens other things coming in that are not relevant or important. An example of this is when you are walking down a busy street talking to someone and your brain decides that that person is the most important so it filters all the other sounds, smells, visual stimuli, etc out so that you can hear that person better.

Most neurotypicals usually have a pint glass to build up all the sensory information throughout the day but for me and other autistic people we have a shot glass so you can see why I am overloaded and overwhelmed often, a shot glass doesn't hold much.

For an autistic person like me, the reticular formation doesn't have a very good gate keeper they have trouble organise things and it finds it more difficult at sifting through everything that is coming into your brain. It doesn't filter as much out. I just get bombarded by senses all at the same time and become overloaded.

Ok thank you volunteers now we are going to demonstrate what an autistic brain is like. (Tell participants) the gatekeeper is not so good so let everybody in but maybe

stop once – so there is no special sensory information this time so just walk into the brain one after another, then walk around the brain, then walk faster and start bumping into each other -then start talking then get louder and speed up-

The experience of being overwhelmed is kind of like when you go into fight or flight mode when your brain senses danger, suddenly you are hyper aware and you can see, smell, feel and hear everything- intensely, including your heartbeat. Your hands become sweaty, you might jump unnecessarily from any noise or surprise and you may feel sick to your stomach, your mouth might go dry and you feel shaky. You perceive everything in your environment as a possible threat to your survival, even though rationally you know it's not. For most of my life this is how I have felt on a daily basis. This is an autistic brain in overwhelm.....

Thank you to all the participants give them a big round of applause.

Addition to Script Section 6: Mother Fucker Applique Quilt

(Talk about applique quilt/cape, pillows, researching Autism- difficult, how I deal with it, new words, misspelling neurotypical, being dyslexic having trouble reading things, busy colorful- they need to be overwhelming- to show you what overwhelm is like- Neurodivergent Flag/ Mexico- fuck normal etc.)

Section 7: The Big Autistic Brain Bus tour

P9 Play Autistic Brain Audio

Right now, ladies and gentlemen you are in for a treat.... Welcome to the Big Autistic Bus tour of Annette's brain and with so much to see there is only one way to see it.

The big autistic brain tour offers you a chance to see Annette's my brains major attractions with thrilling uninterrupted views from your seat. This carefully designed tour includes every sight from the spinal cord to the reticular formation, you're not going to want to miss this, the reptilian brain home of the ever-famous fight or flight and the secret obsessive compartments of Annette's brain.

(Start walking towards cardboard bus on stage)

while you relax in a luxurious no expense spared, air-conditioned open top tour bus (gesture to cardboard) with every mod con!!!

Annette will introduce you to her autistic brain - the strange, the wonderful sensitivities and her ever-failing memory and a fun insight into the life of an autistic person.

(Audio Ends)

Now or this part of the show I need some volunteers to go on the luxurious bus with me, all its going to cost you is a little bit of your dignity.

(Wait for volunteers...)

Wonderful

(Talk to volunteers - how to hold bus and their parts as annoying people on the bus such as crying baby, annoying man on phone, or going through ring tones, or nosy teenagers laughing and giggling etc. Tell them P9 will start, and they can follow their lead and improvise.)

Is everybody set? OK Ladies and Gentlemen, you are going to take the ride of your life touring a real live autistic person's brain so sit back relax and prepare yourself.

We are slowly but surely making our way up the spinal cord and I just want to make you aware of the first and second vertebrae and disk – we are slowly going over them right now (make bus go over speed bump). I have had several back injuries throughout my life snowboarding - I actually broke my tailbone that time – not nice then a kick boxing class that put me out for a month and finally several bouts ballet dancing in my thirties. So just be careful at the area nobody really wants to get off at that spot.

OK moving on now we are traveling up the spinal cord and you get to brain stem which is called the reptilian brain - which is in charge of your survival. It's in charge of the four F's: Feeding, fleeing, fighting and I am sure you can all figure out what F is next.

As you can see the Brainstems central core is the Reticular Formation. Now that is the seat of the four A's: Awake, Asleep, Arousal and Attention and thus consciousness. You can see the little alarm clock there poised to wake me up. It is no coincidence that I have an afternoon performance.

Big Red Panic Button\fight or flight

And moving on Folks we are pulling up to big red panic button in my brain that sets off fight or flight we are still in the reptilian brain.

So please, whatever you do, don't touch that button, be very careful it's very sensitive, we wouldn't want to set it off, I really don't want to go into fight or flight right now.

Emotional Drainage

As you can imagine being in fight or flight mode can become very draining, emotionally and physically. You become irritated very easily and get upset more easily. Moving on you can see pockets of this emotional drainage throughout the brain - seeping black sludge and red raw - there is a big pocket of it here right above us - you need to be on the lookout for these and make sure it doesn't drip on you as it can seep into your skin and burn - it's very caustic. Please, if you came here with children, make sure to keep your hands inside the bus.

Antidepressants - Secret coping compartment

Here is the most exclusive neighbourhood of my brain the secret coping compartments - you can see here that my brain is chemically altered...

Ok we are going to have a treasure hunt now who can spot my first antidepressant, it's white, can anyone see it? It's an oval tablet shape and white. Yes, that is it, well

done. This is my main antidepressant, Sertraline, which is for the anxiety and depression I experience daily which is brought on by living in a neurotypical world and pretending to fit into that world and ableism (talk about first going on antidepressants- broken arm etc- immediate response feeling better....) I take this at lunch time as it used to make me sleepy if I took it in the morning.

OK, who can spot my second anti-depressant, nortriptyline, which is round and pink. Great you found it, I take this before I go to bed. This one is for chronic pain because I grind my teeth and clenching my jaw constantly from anxiety.

Who can spot my third anxiety medication, it's a red and white and oval capsule (talk about PhD anxiety) I take it twice a day in the morning and evening.

I have been on anti-depressants for over 20 years - I have tried to go off them several times to disastrous results and I have just decided for me to cope with the world, I need them to survive.

Secret Compartments of Touch

Moving on to the next spectacular major attraction the secret obsessive compartments of touch. If you look to your right (point to left) this is the part of my brain that is responsible for my high sensitivity to touch. I am sensitive most fabrics & tight clothing - they make me feel itchy and claustrophobic. I only can wear soft and breathable fabric like cotton and stay away from synthetics. I wear clothes that are

usually too big for me and loose. I have to make sure I cut the tags out of fabric and I must get every little piece of that tag or it will drive me insane all day long.

The wonderful big autistic brain tour just gets better and better- did I tell you that the seats recline? Have a go.

Folks have a look to the left where the compartments of executive functioning are, I am extremely disorganised, find it hard to see the big picture and I am constantly distracted - unless I am in hyper focus mode and then I can do nothing but that task for days, weeks, months at a time.

Addition to script Audience participation in their seats due to increased involvement with the autistic community, trying a range of more sensorial experiences would be a better representation of a neurodivergent aesthetic and better received by a neurodivergent audience. I felt that a verbal, visual and kinesthetic experience for volunteer participants and audience would be easier to understand.

Jumper Inside out

One of the things I am known for is putting my jumper on inside out at the start of the day and not realising until someone points it out to me hours later. OK, everyone on the bus let's wave to everyone in the audience. Hi how are you out there? I was wondering if you would all take your jumpers off, if you have one - no worries if you don't, and put them on inside out? Just to get the feel of what it's like to be me and I

will feel more comfortable for once as I won't be the only one in the room with my jumper on inside out.

Stuff on face/stickers

Also, look under your chairs there should be a sticker for you. I also tend to get things on my face like pen and various food and I thought it might be nice if you get the feel for this too. I secretly hope that you forget to take these off and two hours later someone tells you have a sticker on your face. If you came with someone, please don't remind each other that you have a sticker on your face?

Folks this takes us to my terrible memory, as you can see there are several sections in this area that are very hazy- I forget things like putting on a belt - so my trousers fall down all day long, I forget my keys, wallet, and other important objects like cameras & laptops in public places regularly.

Moving on, I also have no sense of time, late for everything - I always wear a watch and check it obsessively. I tend to count the hours I have to do things and then obsessively count down hours that I have left. Possibly spending too much time counting. You can locate that area of my brain, as there are just random numbers everywhere. Now folks speaking of my terrible sense of time try not to be worried, I promise I will get you home at some point tonight... Or maybe tomorrow?

Now our last stop is the side show attraction of my extreme sense of which is so strong I feel like I smell everything – Overwhelming sense of smell on a bus for instance I can...

I smell peoples' body odour, I can smell everything: what people cooked, what they ate, deodorants, perfumes, hairspray, fingernail polish, whether they took a shower, their hair - especially dirty hair. I can't sit directly behind people as the look and smell of dirty hair distresses me - the first thing I do when I get on a bus is open the windows, and please don't sit next to me on a bus and never touch me.

Oh no did someone touch the big red panic button?

Section 8: Overwhelm

I get so overwhelmed sometimes I have to shut everything out.

I either sleep or watch TV

I can't, I can't handle the birds singing, children's laughter, people chatting and making plans,

I can't even handle walking in the sun light.

I just want everything to stop and disappear, I hide from the world

I even find it hard to hear my own heartbeat-

this time is agony to me – torture

I know I could be outside enjoying the sun, going for a walk having a nice meal meeting a friend for coffee, making art or writing even reading

but I am here alone hiding from the world, crying, angry at myself for being stuck again in this cycle- not knowing how to change

the sound of someone making coffee or running water is too much

why do people want to talk to each other? Can't they just be quiet, why does the bus have to stop and shake? I need to be home I can't take it anymore I feel like there are bugs inside – why is it so bright? I can feel the sun burning my eyes I just want everything to stop. Why can't it stop I want to be in control I want it quiet

I want it to be still and white, dark and warm. I want to close my eyes and be alone. I want to be wrapped in a warm blanket and feel happy again I want to be able to handle it all- but It gets to me regular – I can't control it I'm a 46-year-old and I can't figure out how to live without this constant overwhelm

This is where I am

I sit here

This is where I am

I sit here

This is where I am

I sit here

Section 9: Meltdown

(Run to Overwhelm avoidance device- be quite tearful still while talking to audience)... I'm sorry to abandon you guys it's just... I just need a little space to calm... down... I am just having a little time out... sorry... I'm not usually like this... Sorry... it's just I have been so busy... I am finding it hard to cope... (Change into Super Aspie Grrrl Costume)

(P9 play Wonder woman soundtrack when I come out of pod – wonder woman poses- ham it up!!!!)

(Overwhelm- head stand- Wonder woman video soundtrack until after the first long headstand- then just silence and the sound of my struggle... I fall over and lay on the floor...)

.... it's not easy flying - everybody needs a little help sometimes – could you help me up - could someone else help? - thank you for your support.

Section 10: Running a marathon - out the stage doors

(Put socks and running shoes on while talking about...) Occupational therapy helped me to realise that daily strenuous exercise could be my strongest coping mechanism. I started doing yoga and Pilates every day, I was already taking 3 dance classes a week and took up walking and running. Now every runner's dream is to run a marathon and since that probably will never happen for me... I am more of a walking runner - I thought you guys could help me make my dream come true...

(Ask audience to come on stage) if you really don't want to that is OK but obviously the more the support the better - and help cheer me on to run a marathon-

(P9 to open stage doors – lock on top and bottom... Audience come and stand in two lines from door way so they can see me run away... Ask them to cheer me on

as if I was running the marathon- like the people at the side of the road do holding water etc.)

(P9 to close the doors...)

(Thank the audience for their support...) If I have the right support system in place, I can thrive sometimes... (Tell them they can go back to their seats).

Section 11: Membrane

(Nude piece- transition – stand at back of stage and start to take off close while talking...)

Words have power, words can whisper under your breath and in your ear, words can smack you in the face, words can stick to you and leak into you. Words can hide in your body, in the cracks and crevasses, words can seep out of you like inky angry stigmas, like shadows, words can be a beast on your back.

I have been invisible for such a long time, these words need to be made visible, help me make them visible, help me redress in these words... Words have power... I wear a membrane of these words. I take them with me, like a beast on my back... words have power

(I sit down in front of audience... I scrunch my hair up, and mess it up and growl.... I write words with sharpie marker on my body and back. I ask audience members to help me write on my back as I can't reach... ask for volunteers 2 or 3

I start to scrub with soap and water the words off my body, I stand up to wash the words and then ask if I can get a volunteer to help me wash my back?)

Section 12: Stand in Solidarity

I take the tablecloth off the floor and hide the megaphone under it. I then ask the audience if they are autistic or knows someone who is autistic or just wants to support me to come on stage and stand in solidarity with me.

(I speak through megaphone): Thank you for giving me a voice... Thank you for giving us a voice!!

Appendix 11: Making Visible the Invisible: Membrane of Internalised Oppression



Figure 49: Private performance of Membrane: Adventures of Super Aspie Grrl, Nottingham (2016)



Figure 50: Private performance of Membrane: Adventures of Super Aspie Grrl, Nottingham (2016)

As part of the solo PaR performance, Adventures of Super Aspie Grrl, the last section of the performance articulated my own experience of ‘internalised oppression’ as a late diagnosed queer autistic woman. I wanted to articulate how much power language and words can have, especially when the pathological paradigm puts negative value on neurodivergence (Walker, 2013). In her article *Presenting the Self: Negotiating a label of autism* (2010), Brownlow analyses and compares the language used by different professional who support autistic people and the autistic community in online forums. Brownlow discovered that, until now, the description, treatment, techniques and interventions that have been used with Autistic people by professionals has focused on deficit rather than difference. This

has left little room for autistic people to have a self-confidence and made it more difficult to discover their positive attributes. As Brownlow (2010) states,

“A construct of autism that predominantly focuses on negative characteristics associated with autism renders the individual’s positive attributes largely invisible. This has important implications for the life style choices presented to adults with autism (autistic people), who need to challenge the negative construction of their abilities if they are to develop a positive self-identity and successfully negotiate their differences within an NT (neurotypical) dominated world” (Brownlow, 2010).

Bumiller’s seminal article, *Quirky Citizens: Autism, Gender, and Reimagining Disability* (2010), argues that to counteract this social construct of autism as deficit and autistic people as less than human, autistic people need to ‘antinormalise’ autism by intentionally challenging societies stereotypes of autistic people. This could be done by rebelling against society’s arbitrary and judgemental social conventions, including rejecting social conduct rules when they do not fit the needs of autistic people (for example NT’s negative reaction to autistic people stimming in public) and rejecting gender binaries. She is looking for a “more expansive model of inclusion” (Bumiller, 2008) and states, “The insistence that autistic citizens must modify harmless idiosyncrasies for the comfort of others is unreasonable and oppressive” (Bumiller, 2008). I would suggest this might be the way forward for the diagnosis and categorization of autistic people, to expand the definition of autism using a spectrum of neurocognitive styles, instead of binary opposites, which would include all genders not just male. Bumiller concludes that autists and neurodiversity

I write the first word; Autistic, in defiance of the negative stereotypes it holds. I continue to write in a circular pattern around each breast covering them with other negative words that are used to describe people like me: dyslexic; crazy; too sensitive; weird; loner; strange; hysterical; touchy; bitch, ... you must turn your head to read the words in a spiral pattern and some of them are hidden, hidden in the cracks, enveloped in skin. This is a reclaiming of these words, I own them now, they are predetermined, things that have been said, whispered, shouted and that I unconsciously say to myself over and over (Figure 51).

I continue to write on my, skin checking my notebook for more scripts, I write on the places of the body that take more ridicule, as if words collect in these areas: the knees, a weakness; the stomach, another easy place to attack. The patterns of the words are very intentional like a downward spiral of emotion, an emotional landscape and a map of experience. Once I have meticulously, zealously, covered my body completely, I conceal this film of self-doubt, self-loathing, of internalised oppression, with another layer, my super autie costume, an emblem, a badge of my positive self-identification that I am autistic.



Figure 52: Private performance of Membrane; a part of Adventures of Super Autie Grrl, Whitstable beach (2017)

At the end of the hour-long performance, I finally shed the Super Autie Grrl costume that I also use to hide my ‘internalised oppression’ by appearing ‘supercrip’. I stand in front of the audience naked and vulnerable with Sharpie marker stigmatised words all over my body (see Figures 52 and 53). I speak to the audience...

“Words have power, words can whisper under your breath and in your ear, words can smack you in the face, words can stick to you and leak into you. Words can hide in your body, in the cracks and crevasses, words can seep out of you like inky angry stigmas, like shadows, words can be a beast on your back.

I have been invisible for such a long time, these words need to be made visible, help me make them visible, help me redress in these words...Words have power..” (Foster, 2017).



Figure 53: Audience member writing a word on my back with Sharpie marker; Adventures of Super Autie Grrl, Canterbury (2017)

I silently gesture for audience members to come on stage to write on the places I cannot reach (see Figure 53). I ask audience members to write specific words that I point out in my notebook. The audience members become complicit in this ritual of using these words to label me. When I am covered completely, I pick up the domestic cleaning brush, it looks like it is going to hurt. I dunk it in the bucket of soapy water and the room suddenly smells of mint and tea tree oil. I begin to scrub, and the surface is altered. These words are only skin deep, but the ink gets into the cracks, things leak in, deep, the scrubbing of the skin, the soapy water, red, cleaning



Figure 55: Audience member scrubbing my back; *Adventurers of Super Autie Grrl*, Canterbury (2017)

In this piece, I was especially interested in how the vocabulary of the pathological paradigm is used to describe autistic people, even when they are not officially diagnosed. I was misdiagnosed with various mental illnesses and so I was crazy, sick, hysterical, nervous, overly sensitive, lazy, difficult etc. (see Figure 51) And I heard these words so often that I started to use these words to describe myself, they became an internal dialog or script that ran over and over in my head. I began to feel I was not 'normal' and therefore broken in some way. Penni Winters, a well-known autistic self-advocate and author, talks about her experience of being late diagnosed, normalization and internalised oppression, in her seminal article *Loud Hands and Loud Voices* (2012),

"This is not theoretical. I have spent decades of my own life straining to make myself over into that elusive 'normal' and hating myself for not succeeding. I

saw myself as 'less than' others, furiously lashing myself for me-- as I saw it-- weakness and stupidity. I lived with chronic depression, overwhelming anxiety levels, and rock bottom self-esteem. The more normal I tried to be, the less normal I secretly felt- and the more of a failure. Even when I was able to 'pass', I lived with what I now call 'imposter anxiety,' the fear of being exposed and rejected- 'You're not normal!'" (Winter, 2012, p.112).

The article *Throw Away the Master's Tools: Liberating Ourselves from the Pathology Paradigm* by autistic self-advocate and scholar Nick Walker (2012), points out that new words needed to be created to describe a new paradigm (Neurodiversity Paradigm) that did not see autists as inherently negative, but just another human experience (Walker, 2012). What if this other language did not necessarily have to be verbal, maybe there are other forms of communication that would work better for the autistic community? However, words are the dominant form of communication for the neurotypical world, and we need words to describe our experience to the neurotypical world as well. Nick Walker states, "All we need to do is take careful stock of our words, concepts, thoughts, beliefs and worries and see whether they still make sense if we throw out the concept of 'normal,' the concept that there's one 'right' way for people's brains and minds to function" (Walker, 2012, p.235).

In the remaking of *Adventures of Super Autie Grrl* into the multi-participatory 'Adventures of Super Autie Gang', I was joined in this process of writing words on my body, of exposing my internalised oppression by one of the autistic participants, P17. They decided that they wanted to do 'the naked part of the performance' (as it was called among the participants) with me and, in some ways, transformed this process.

[REDACTED]

Figure 56: Participant and my knees after we finished writing text on our bodies for Adventures of Super Autie Gang, Canterbury (2019)

I was not alone any longer, we carried out the process of writing the words together (see Figure 56) and we were there to support each other on stage. Having P17 join me in this performance (private and public) had made the process so much more about 'self-acceptance' for me and for our community. It gave me a chance to see this ritual carried out by another fellow autistic that identified with this process of making this invisible 'internalised oppression' visible. It made me realise how much had changed for me over the process of this PaR PhD project. I was now part of a tight knit community, Super Autie Gang. We were also part of wider autistic community that my fellow autistic friends and I had created over the two years between the performances via attendance of an autistic support group and my series of creative workshops for AWCTN+ people from February-July 2018.

Penni Winters stresses the importance of autistic community in her article, *Loud Hands and Loud Voices* (2012),

“My belief is that becoming part of the autistic community has to be the first step. Without it, we are isolated and alone, and it's almost impossible to break free of the pressure to be 'normal,' and the consequent self-hatred. The community of autistic(s), while not perfect (but then who is), is crucial to developing strong self-esteem, and to realisation of our essential humanity and self-worth” (Winter, 2012, p.112).

The hours of writing words on the body... didn't seem as hard... we did it together. P17 was afraid to come out of the tent once we had taken our clothes off, but I supported P17 in their vulnerability, we shared vulnerability. We shared making our internalised oppression visible, together (see Figure 57).

[REDACTED]

Figure 57: A participant and me performing 'the naked part' with the stigmatised word projected behind us in Adventures of Super Autie Gang, Canterbury (2019)

In this we were strong, and in sharing this with a mostly autistic audience and/or autistic allies we were even stronger. P17 was shaking throughout the performance, and I almost reached out for their hand, but then realised they were not a touchy-feely autistic like me, they didn't like to be touched¹²⁶, instead we exchanged glances of support from each other throughout. We spoke the text together,

“We have been invisible for such a long time, these words need to be made visible, help us make them visible, help us redress in these words” (Foster, 2017).

As we speak this text, a list of the words we have written on our bodies is projected behind us (see Figure 57).

Then I speak to the audience:

“People ask me what is the point of being diagnosed or self-diagnosing yourself now? at your age? Why do I want to label myself? I have been labelled and labelling myself for years with all these words. [I point to the projection behind me] I would much rather scrub, wash, scoor these words away and finally have a positive identity that fits, to become a part of a community, an autistic community. I would take autistic as a label over all these labels any day” (Foster, 2017).

¹²⁶ This is another example of how the Super Autie Gang consciously tried to not adopt 'neurotypical' behaviour, as much for the co-performers (P17 didn't like to be touched and therefore I didn't touch them) that would allow 'neurotypicals' to identify with the co-performers. We wanted to be our 'autistic-selves', which included not doing things that were acceptable behaviours to adopt in certain situations- but to stay true to our 'autistic-selves' and to our fellow autistic co-performers. If participants didn't like to be touched, then I would not touch them.

[REDACTED]

Figure 58: A participant and me performing 'the naked part' with Autistic projected behind us in Adventures of Super Autie Gang, Canterbury (2019)

The word 'autistic' replaces the list of stigmatised words on the projection behind us. This represents our adoption of autistic identity (Figure 58). This signifies the embracement of autistic community and how this helped to us to accept ourselves for who we are. So that we can scrub off the lifelong pain of prejudice and discrimination just for being different. This can be painful and take time, like the scrubbing off of Sharpie marker, but we are not alone, and we can do this together. In autistic community spaces like the Super Autie Gang workshops (2018) and performance (2019) we can remove the stigma together, we can scrub it away and replenish it with the validation for our embodied experiences of the world that are qualitatively different but not less than the non-autistic experience. We start to help each other not only see our challenges but our strengths for the first time and start to speak more authentically about ourselves and use positive language that can builds self-esteem.

We are starting to see research finally establishing that having a positive autistic identity (Cooper, et al., 2017; Cooper et al., 2020) and actually knowing and being a part of a community with other autistic people has a protective effect for autistic wellbeing (Crompton, Hallett, et al., 2020b).

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Appendix 12: Documentation and Script for Adventures of Super Autie Gang

April 2019 Autism Arts Festival, University of Kent, Canterbury

12.1 Please see video documentation of Adventures of Super Autie Gang in <https://youtu.be/kSyrXQtXTMc>

12.2 Script for Adventures of Super Autie Gang April (2019)

(Things that need to be on stage: 5 yoga mats in place, towel and robe in place, hot water in bucket with soap and 1 brushes, sketchbook/script and 2 Sharpie markers downstage left. Letter to Simon Baron Cohen. 3 or 4 plates, P17's 12 pompoms, 4 pop up tents, 3 headdress ear defenders, cardboard shapes, P9's clicker, PowerPoint with videos and sound. Men's jackets).

Front of house help people find a seat and explain the Synaesthesia Diagnosis Device.

Section 0 P9 asking people if they are neurotypical and giving them stickers

P16 (*Synaesthesia diagnostic machine*) doing their shapes and colours or readings from inside a cardboard box? (P16 sorting people, non-verbal, writing down the shape and colour and giving it to them or flags?)

Section 1

We walk into the space as if we are doing an exaggerated neurotypical walk then stop and say it's not right then put ear defenders on pick up stim toys etc., slow autistic walk like the opening scene to reservoir dogs. Everyone dresses as

themselves at their most autistic with makeshift capes. Wearing ear defenders, holding favourite stimming toy possibly autistic walking toe walking/ tripping/ wandering?

We stand in a line in front of the audience and look at each other as if ready. The video plays in the background as we stand there.

Autistic action video 1 min 43 sec seconds

We all Happy Stim

Introduction

(With ear defenders on yelling) **Annette:** Hi, I am super Autie Grrl formally known as Super Aspie Grrl, we are the Super Autie Gang, and our names are Annette,

Gang say names: P9, P17, P16, P2

Annette: and P1 in the shadows as our technician.

(Take earphones off)

More Intro

Annette: I did a show 2 years ago at the first Autism Arts Festival titled Adventures of Super Aspie Grrl this was about my own experience of being a late diagnosed autistic person and the beginning of my PhD where I wanted to articulate the experience of all women (cis- /trans-) and non-binary people. A lot has happened

since then! I have learned so much working with many amazing autistic people over these past 3 years. I ran a series of 10 exploratory creative workshops with autistic people and this is the result.

Oh, also instead of clapping in the common way could we clap the deaf way (co-performers waves their hands) like this? As many autistic people are sensitive to noise as we are so this makes it less overwhelming. Great?

Also, we are going to try and remember to schedule happy stims and silent breaks into the show to ensure that we are not overwhelmed. Does everyone know what happy stims are? Usually, all humans stim it's a way to regulate stimulation that goes into our bodies and brains- it's usually a repetitive gesture of some kind like hand flapping or rocking -autistic people tend to do this more and for all types of reasons not just when they are anxious also when we are happy- this is my happy stim- (the whole gang comes out and does happy stim dance) there is not right or wrong way to do this just what feels good!

You are welcome to join us in happy stimming and or silence during these breaks.

Ear Defenders Fashion Show

Annette: OH, I forgot to take the ear defenders off sorry about that, were we shouting? One of the reasons why we wear ear defenders is that we perceive the world differently and sound can become very overwhelming sometimes. Shall we show them?? (Gang says yes and goes backstage to get ear defenders on).

Annette: So, in many ways ear defenders or noise canceling headphones have become a stereotypical feature of the autistic community. When you see someone with ear defenders on unless they are shooting a gun or using heavy machinery you think- oh they are probably autistic. But they are so boring and kind of ugly they have no personality, maybe you can get them in a few different colours, but they are just not that attractive and they don't show the individuality of multifaceted autistic community. And frankly I think we can do better! So, I have begun to design a high fashion line of ear defenders for every occasion. Bespoke pieces to give some flair, some fabulousness, some much needed individuality to these utilitarian objects.

Can I have the first model out please-

(I describe the headdress as each performer (P2, P17 and P16) comes out with headdresses on – they do a model walk and model turn, walk back off stage -then once all three are out and done a walk they stand together at the back of the stage with P16 in the middle and walk out together and do a model turn?)

Annette: This is P2 wearing the multi-coloured pompom ear defenders you can see they are very useful in a crowded place and interesting to look at. These ear defenders will set you out from the rest. These are good when you are out and about at a football game or holiday shopping or more casually to just go for coffee. They are made out of 100% biodegradable material and super soft to the touch. Pompoms are nice for petting too.

This is P17 wearing the Spring inspired May Queen ear defenders, they are good for a ball, music festivals or just a stroll in the woods. These are for the autistic with flair and finesse. They go with everything and are sooo pretty. Right on trend right now.

And our finale is P16 in our Los Vegas Show girl inspired ear defenders, as you can see, they are quite flashy and can be worn on a night out on the town, to a burlesque evening or a night at the theatre- although you might want to sit at the back of the theatre with this on. As you can see, they are very versatile and can be worn with so many outfits from evening wear to jeans. You could even wear this to the zoo as she looks like an elegant peacock.

These are just the first three in the line I would like to create these for everyone I do take suggestions and requests they can be bespoke. Thank you, models, didn't they do a good job?

Section 2

Dear Dr Simon Baron Cohen

(Performing text while doing Yoga –Sun salutations cycle)

(Sun Salutations with back bends)

Annette: Dear very Important Autism Researcher Professor who think you know everything about autistic people,

I am a 47-year-old queer woman, and I am Autistic. I was diagnosed at the age of 39; after years of feeling confused, frustrated, and alienated, because I was aware of my difference, but I didn't know how I was different. I had years of misdiagnosis

(Pause- P17 says 'Me too!' Brings yoga matt on stage and starts to do yoga)

Annette: and a lifetime struggle with mental health issues,

(P16 says 'me too', P9 says same here they both come out on stage yoga mats and try to do yoga)

Annette: I finally had an answer, I am different, and I know why, I am Autistic!

(Downward facing dog; Look at audience)

Annette: You didn't make it any easier, did you?

(P2 says 'no you didn't' - P2 comes on a stage and does her yoga pose with mat; P1 says 'Big mood')

Annette: Your theories have affected the way autism has been perceived making it seem as if all autistic people are basically male or male brained

(P17 says 'Not me').

(Annette stands up)

Annette: Ok Sorry this isn't working I have got to stop sorry umm, so I never remember my line, I am horrible at remembering my lines. Not only am I autistic, I am also dyslexic and dyspraxic my brain is all over the place and works in its own unique way, which I am still trying to figure out. It doesn't really matter if I forget my lines for the rest of the show, I am going to ad lib and delete things, you guys will never know, but with this letter, it's really important to me and I think it's important that you hear the whole thing. So, I am going to attempt to read it while doing yoga. So here I go!

(Sun salutation with leg up in air and to ear)

Annette: As Kirstin Bumiller said in her article Quirky Citizens almost a decade ago your hypothesis endorses a view of Autism that emphasises cultural stereotypes of gender using scientific evidence to stereotype the autistic community 'male brained' this has excluded and marginalised a large group of people.

(Upward facing dog)

Annette: You and your colleagues have totally oversimplified the very complicated and multifaceted autistic community. (P2 says Boo!)

(Backbend from a downward facing dog)

Annette: All women (cis-/trans-) and non-binary people are much less likely to be diagnosed and to receive services. I have been diagnosed with everything under the sun-including: *(say this slowly so people can comment)* social anxiety disorder, general anxiety, obsessive compulsive disorder, depression, chronic depression, manic depression. The word autism was never mentioned to us in the years of going back to doctor after doctor getting one misdiagnosis after another

(Plow pose)

Annette: I purpose there has been a systematic pattern of sexism and essentialism from the beginning of Autism Research, and this has continued to develop unchecked for the past 73 years.

(Turn to audience stand in tree yoga pose, lower to hip stretch.)

Annette: I feel I need to say this to you, to have some acknowledgement that you were wrong- that autistic people suffered because of it and that you will try to make it right!!

This is important, and it needs to be said to the world we all have a responsibility to set the record straight. Autism researchers need to give voice to as many autistic people as possible, all women (cis-/trans-) and non-binary people need to tell their stories.

(Triangle pose- into balance pose?)

Annette: The next generation of autistic people should have a variety of autistic role models to look up to and identify with. The diagnostic criteria should be made more broad to include people of all genders, race and cultures. The social construct of autism right now is too narrow and excludes and marginalizes a larger group of people.

Sincerely,

Annette Foster

Multidisciplinary artist, PhD Researcher and Autistic self-advocate

I composed a letter to an important autism research whose name will remain anonymous. Due to my PhD supervisor, advises me to not use his name or to mail it at any cost- but I might do it anyways, what do you think?

(Head stand)

Annette: I am a lost person of autism, and I don't want to be lost anymore.

I feel I need to say this to you, it's important, we need to say this to the world.

Everyone/Gang: We need to call out to all women (cis-/trans-) and non-binary people let's tell our stories. Let's show autistic pride, let's set the record straight. The stereotype that Autism is exclusively a cis-, white, male condition should ENDS TODAY.

(Comes down from headstand and in restorative pose)

(Talk out of bum here)

Autism Monster

Annette: I hate it when people say your autism or you don't have the same autism that he has, Autism is not a huge entity, some theoretical object, some strange ball of tissue, hair and teeth that you can take out of an autistic person and say here, this is your autism, your cured, there is no such thing as a BIG AUTISM just Autistic people.

Section 3: Neurotypical/ Autistic Brain Demonstration with Audience Participation.

Annette: OK, I am sure you have been wondering what all that electrical tape is doing on the floor, well it's my brain, I kind of brought it with me as a show and tell. This is a diagram here of my autistic, dyslexic, dyspraxic brain. I hope you enjoy it!

It's a diagram of the brain showing the reticular formation. It's kind of like a sensory antenna or satellite dish of the brain and it picks up all the senses: sounds, smells, tastes, touch, sight, proprioceptors- which is how your body knows where say your arm or foot is in relation to the body, and vestibule sense which is related to your sense of balance. Your conscious brain can only handle about 130 messages per second in any meaningful way (go brains by the way- that is amazing) so it absolutely needs some way to sort out what is important and prioritize those millions of messages from your body. The reticular formation limits the messages down to a more manageable flow.

So, we are going to demonstrate the difference between a neurotypical brain and an autistic brain- or well at least my brain. By the way this show is by no means scientifically accurate. **I need some volunteers to play the sensorial information that go into the brain for me, Can I have at least 10 volunteers? I did tell you this is a participatory performance – don't worry it's not hard you just walk around my brain; you do a bit of hand flapping and stomping. Also, if you don't like to be touched, I ask people to speed up and they tend to bump into each other.**

(Talk to volunteers- Ask Volunteers to line up volunteers-the first person is the gate keeper, and they need to let one person in at a time say 5 seconds after each other one volunteer half way down the line is the important sensory information so they keep moving around- everyone else are sensory information that is organised and not given as much importance so you go into the brain and stand still in a different part.)

Annette: So, to prevent neurotypical brains from being totally bombarded from senses from all over the place- the reticular formation monitors and filters sensations and your brain kind of figures out what is most important, and it focuses in on that, and it dampens other things coming in that are not relevant or important. An example of this is when you are walking down a busy street talking to someone and your brain decides that that person is the most important so it filters all the other sounds, smells, visual stimuli, etc out so that you can hear that person better.

Ok thank you volunteers please come out of my brain correctly, keep the illusion alive.

(Annette gets very excited and starts jumping up and down)

Annette: Now we are going to demonstrate what an autistic brain is like.

Ok so the gatekeeper is just incredibly friendly, and they just want to Also there is no special sensory information this time- you are all of equal importance! So just walk into the brain one after another, then walk around the brain, then walk faster and start bumping into each other -then start talking then get louder and speed up-

The experience of being overwhelmed is kind of like when you go into fight or flight mode when your brain senses danger, (ok stomp louder and start hand flapping) suddenly you are hyper aware and you can see, smell, feel and hear everything- intensely, including your heartbeat. Your hands become sweaty, you might jump unnecessarily from any noise or surprise, and you may feel sick to your stomach,

your mouth might go dry, and you feel shaky. (OK speed up) You perceive everything in your environment as a possible threat to your survival, even though rationally you know it's not (can you go faster?). For most of my life this is how I have felt on a daily basis. This is an autistic brain in Overwhelm.....

(Annette starts to walk then run around the brain with the people inside)

Section 4: Overwhelm Avoidance Device

Annette: I was walking down the street and it was a really busy pedestrian area with lots of people around and I started to feel a bit overwhelmed, my shoulders were going up to my ears My teeth started clenching I started to sweat and shake a bit. And I thought, wouldn't it be good if I had some kind of cape or backpack that could just pop up into a tent and you could just hide in it that pod for a little bit until you felt better then you could just pop it down again and go about your business.

So, I did some internet research and there was actually a tent that already exists. The tents like 6 ft 2 in tall and very narrow for campers to put their toilets in but it works! It's got an open top and open bottom- its black so it blocks out light and it's not too claustrophobic.

I put some straps on it to make it a backpack, It's still a prototype backpack

So, I call this the Overwhelm Avoidance Device...

So, whenever you are feeling overwhelmed, you can just get your overwhelm avoidance device out and you can just unzip it (it is very easy to use) and pop it up and get inside and wah laaa [voila]!

(Annette Runs into the Tent on stage and zips it up. Pause while in the tent- moment of silence break)

Annette: I am just going to have a minute- I am still here

(Annette is Overwhelmed)

Annette: You know what it's like, well some of you know what it's like, most of you don't I just get really overwhelmed and I don't really know how to stop it-yoga helps, exercise in general unless it's with too many people or with loud noise then it has the opposite effect. I need a lot of alone quiet time where I have to shut the world out. I end up doing too much and then I am in shut down again-I guess this is like an internalized meltdown- I just can't do anything during this time. I know I need to try and take more rests regularly, do less, stop saying yes to everything and be able to say no to people so I don't get to this point, but I do, and I am back in that place again.

(On the way back to the tent spot down stage right)

Annette: I have this habit of apologising for my existence, I apologise for everything, I apologise for being late, for mixing up dates, for going the wrong way, for being clumsy, for being too loud, for getting lost, for canceling plans, for not reading people's minds, for generally annoying people basically I apologise for being myself

and then I apologise for apologising. I am tired of saying I am sorry, but I can't stop myself. I apologise basically for being autistic and I am not going to do it anymore.

Autistic Treatment Wheel

P16 and P9: Don't worry Annette We can treat your autism.

(Explain the wheel)

(Spin Wheel)

(P16 explains 'I like to treat my autism to a bit of toe walking')

(Describe two types of toe walking)

(Spin Wheel)

P9: I like to treat my autism to a bit of daydreaming about a totally autistic controlled planet.

(Spin wheel)

(Happy Stim - All co-performers do a happy stim)

(Spin wheel - synchronized tent dance)

(It lands on Tent Dance

We Begin Synchronised tent dance to music:

Swan Lake: The Dance of the little swans?)

(This is choreographed, and P17 calls out the instructions to the co-performers as they do the moves in their own individual tents as synchronised as possible).

(P9 stops dance sticks her head out of the tent)

P9: Right hold on hold on! Seriously, are Neurotypical people going to understand this as they are not very good at Empathy?

(The rest of the co-performers stick their heads out of their individual tents and answer)

All: Yeah; Yes, who doesn't like synchronised tent dancing?; It's cool right? (talking all at the same time)

Object story section and actions (Audio Recordings)

(All Co-performers in tents at the back of the stage)

P9- Plate Licking (plates) Transcription of Audio (0:51 sec) playing while co-performers (P16, Annette, P17 and P2) carry out an action

P9: Yeah, so I have obsession with eating the same thing after school before dinner. So it was like a pre-dinner, dinner. umm it was like, Turkey, Bernard Matthews thin turkey slices, that I would like dunking in salad cream and eat that. And then I would have a bowl of chocolate ice cream. But then I would have to lick the melted ice cream in a particular pattern, which was like an Asterisk. So, you'd like start like that, and you'd have a lick down the middle, and then make a cross, so that it was going across and then you would start like an asterisk, you go up to the top and then lick that way. And then start from the other side and licked that way, and then there would only be like a tiny little bits left and you would just lick those off

The group: (Everyone laughs hysterically)

P9: But I'm not autistic,

Annette: *and you did that every day*

P17: *Every day?*

Annette: *for how long?*

The group: *(laughter from group)*

P17: *Or Just Monday to Friday?*

P9: *That is true, its probably was just Monday to Friday.*

Co-performers actions:

(Co-performers come unzip their tents and walk to the side of the stage stand in line ready to collect a plate from P1. Co-performers walk to the middle of the stage standing next to each other in a line facing the audience. When P9 starts to direct on how to lick a plate, participants demonstrate this on the plate they collected. Then participants complete the demonstration wait for the audio to end and walk over to and hand their plate back to P1 at the side of the stage. Co-performers walk back to their tent, get inside of it and zip it up.)

Synesthesia – P16 (cardboard shape walking) (transcription of audio (0:45 sec) playing why co-performers (P9, Annette, P17 and P2) carry out actions.

P16: *Most people have a shape and/or a colour. And autistic people tend to have smooth shapes like squares and triangles and regular shapes. And neurotypical people tend to have spiky shapes and irregular shapes or no shape, you might just have a colour. Um, but, yeah, not everyone has a shape and not everyone has a colour, but most people have shapes and colours and usually autistic people have*

like the nice shapes. (P16 Laughs and others in the group laugh with her) And neurotypical people have annoying (irregular) shapes.

Annette: *annoying shape?*

P16: *or a pattern, like, they could be striped, that's a shape like.*

Annette: *Okay, so what about [P9]? What is [P9]?*

P16: *[They are] a circle.*

Annette: *[They're] a circle.*

P16: *You're a rectangle.*

Annette: *And I'm rectangle. What are our colours? Do we have colour? Or just rectangles?*

P9: *Am I just a rectangle and you're a circle?*

P16: *Um, Ummm you're RED.*

Annette: *I'm red. She's red.*

P16: *I think you are both red?⁸⁸*

Annette: *What about [P17]?*

P16: *She's a [P17] oval, obviously.*

Co-performers actions: Co-performers picked up cardboard shapes from the side of the stage and walked around the stage with the cardboard shapes in front of their bodies, one cardboard shape was given to an audience member. Co-performers were gestured to when their shape and colour was introduced in the audio. When the audio recording ended co-performers dropped off their cardboard shapes at the side of the stage and walked back to their tents got inside and zipped them up.

⁸⁸ P16 would like to note that Annette's colour stated was, in retrospect, the colour of her masked self, and she is now seen by P16 as a purple / blue swirled rectangle.

P1- Fabric creepers -creeping tents (transcription of audio playing while co-performers (1 min : 30 sec) (P16, P9, Annette, and P17) carried out actions)

P1: Technically, I have always been a fabric creeper, because um, one of the stories my mother will never let me forget is a um, they have this large market place in Athens, you know. I wouldn't say the bowels of Athens but it's behind the like, established more touristy areas, even though, all the tourists go there. And they have a lot narrower streets a lot of little shops. And we went there one time, I went with my family when we were living there. And I was really bored, my parents, my mother just kept on going through shops and my sister wanted to go into some I don't know, some fancy hippie shop they had like tie dye clothes and everything looked cool, I guess it looked shiny.

And I wanted to interact because I wanted to stop just standing there being bored, so I got to the dress, I'm like Oh, this looks nice. And I start stroking it.

And it turns out this was not a mannequin. This was a real human being!

The Group: (Laughter)

P1: who's not part of the shop and instead just had a young, young child come, I was actually that young. I think I was a young teenager really, start stroking her. Luckily, she didn't say anything, but she did give me a look and left.

(More giggle from group)

P1: And unfortunately for me, my mother saw this and has never let me live it down.

Annette: Really

The Group: (laughter)

Co-performers actions: Co-performers stood up inside of their tents and started to slowly move their tents forward towards the audience with one hand stuck out of the tent reaching towards the audience. The co-performers inside of the tent reach the front of the stage right in front of the audience. When the audio narrator mentions that they discovered that the mannequin they were stroking was an actual human being, the performers quickly take their hands back into the tent and move quickly (inside of the tents) back to the back of the stage.

P17 Pom Poms

P17 gives a live solo monologue story (I wish my son was a plate licker) about her autistic son throwing things out of his window while she watched outside. While P17 tells this story, she is throwing handmade wool pom poms out of the tent on to the stage.)

P17: Ok, so, um I get overwhelmed just like Annette, I have children and it can be quite a responsibility when I am finding it hard to cope with my own stuff. Take, for example, the other day I was sitting in the lounge and a chair appeared outside the window as if it was floating in space. I walk outside to investigate and shout, '[Son] stop hanging furniture out the window.' And there was stuff everywhere. 'Why are there headphones out here? Why is there a ruler out here? Oh my god [Son] why are all the teaspoons and pens out here?' Sigh, and I thought to myself, 'I wish he was just a plate licker.'

Section 6: Membrane- ... (projection of text that is written on my body)

(Annette and P17 come out of tent naked covered in words written in sharpie marker)

(Annette and P17 stand/sit in the middle of the stage

P17 and Annette share text)

Annette: Words have power, words can whisper under your breath and in your ear,

P17: Words can smack you in the face, words can stick to you and leak into you.

Annette: Words can hide in your body, in the cracks and crevasses, words can seep out of you like inky angry stigmas, like shadows, words can be a beast on your back.

P17 and Annette: We have been invisible for such a long time, these words need to be made visible, help us make them visible, help us redress in these words...Words have power...

(We sit down in front of audience... We write words with Sharpie marker on my body and try to write on my back. We ask audience members to help us write words of our choosing on our back as we can't reach... ask for volunteers 2 or 3. Ask audience member to write a word on your back. Say the word out loud to audience as participants write on your back. Thank them.)

(Then we start to scrub with soap and water the words off my body, we go red from the scrubbing. I stand up to wash the words and then ask if we can get a one or two volunteer to help us wash our back?)

Annette (something like this?):

People ask me what is the point of being diagnosed or self-diagnosing yourself now? why do I want to label myself? I have been labelled and labelling myself for years with all these words. I would much rather wash these words away and finally have a positive identity that fits, to become a part of a community, an autistic community. I would take Autistic as a label over all these labels any day.

Section 7: Stand in Solidarity

We then ask the Audience if they are autistic or knows someone who is autistic or just wants to support me to come on stage and stand in solidarity with me.

We take the Neurotypical labels off of neurotypical people and they are given badges that say 'autistic allies'.

Annette: ...Thank you for giving me a voice...Thank you for giving us a voice!!

Appendix 13: Super Aspie/Autie Gang Workshop Recruitment Poster

SUPER ASPIE GRRLS WORKSHOPS



This is a call out to all Autistic women, nonbinary and trans people to speak out, to tell your story and celebrate our unique perspective in a creative and supportive enviroment.

WHAT: Creative performance and visual art workshops exploring the lived experience of Autistic women, nonbinary and trans people.

WHEN: Tuesdays 5:30-7:30 pm Feb. 20 - May 15 2018

WHERE: Jarman Studio 2, University of Kent, Canterbury

Contact: Annette Foster a.p.foster@kent.ac.uk

No Experience needed apart from your own

University of
Kent



Appendix 14: Participant Information Sheet and Consent Form Samples

14.1 Participant Information Sheet Sample

Study: Creative Workshops and Interviews with women (cis-/trans-) and non-binary people on the autistic spectrum diagnosed formally or self-diagnosed.

Invitation and research purpose: I am Annette Foster a PhD researcher at the University of Kent, UK. I am also a multidisciplinary visual/performance artist, and autism self-advocate. I was diagnosed as autistic six years ago at the age of 39. The purpose of this research is to carry out practical research into what it looks/feels/smells/tastes/sounds like to be an autistic woman, non-binary or trans-person with the purpose of communicating our experience through multisensorial creative expression to a wider audience including clinicians. The University of Kent, School of Drama is funding this research.

I have devised and performed a one woman show titled, Adventures of Super Aspie Grrl about my own experience of Autism but I would like it to evolve into something that includes more autistic voices and becoming Adventurers of Super Aspie Grrls.

The culmination of this project will use this material to create and present a multidisciplinary performance and live art piece that is collaborative with autistic participants. Workshop participants will be given the opportunity to perform and/or contribute a visual art piece to be shown such as props/costumes/video/sound and/or multisensory installation that articulates their experience.

This study has been ethically approved by the University of Kent's Faculty of Humanities Ethics Committee.

Aim of Research:

The study's aim is to carry out a series of workshops with autistic adults (eighteen years and older) namely women and people with complex gender identities. The purpose of this project will be to expand the conversation about Autism Spectrum Condition to include often forgotten and invisible voices. The researcher's objective is to give autistic women (cis-/trans-) and non-binary people a voice and more visibility, sharing the experiences of adult autistic people with a wider audience.

These workshops will be on Tuesdays from 5:30 - 7:30 pm in Jarman 2 at the University of Kent, the workshops will be over a 12-week period. (Dates Feb. 20 2018- May 2018) The final 2 workshops are optional and will be for participants that would like to perform or be a part of Adventures of Super Aspie Grrls.

All workshops will be video recorded for research purposes only, but we may decide to create video or sound art during the workshops that could be potential creative material for The Adventures of Super Aspie Grrls All participants will be asked for their consent for the recording of the workshops and possible further distribution.

What you will be expected to do (should you choose to participate):

- You will be expected to attend at least five of the ten, two hour creative workshops.
- You will be expected to take part in two semi-structured interviews, one before the series of workshops begin and one after the series of workshops are completed. You would provide me with possible future dates and times when you would be available for a pre-workshop and post workshop interview (in person or via Skype).
- You will be expected to provide the researcher with your email and Skype information.
- You will be invited to provide a pseudonym (fake name) to maintain your anonymity in any write-up of the interview or observation in writing of the video documentation of the workshops.
- The interview will take place on a day and at a time you indicate and will not last more than 45 minutes - these interviews will be video/audio recorded so that it can transcribed (written-up) at a later date

Possible Risk and Discomfort:

You are being invited to discuss and develop creative artwork about your personal experience as an autistic woman, non-binary or trans- person. Please take this into account when deciding to participate in this study. A disability support advisor will advise Annette in the planning of these sessions and on how to deal with conflict or anything that arises during the 12 sessions.

Publishing results: The information generated by this study will be included in a PhD thesis. It may also be included in a conference preceding and/or included in a journal publication. Again, no identifying information will be included in these instances.

Information collected during this study will be held confidentially by the researcher in line with the UK Data Protection Act 1998.

Only researchers involved in the study and, if required, the body funding this research will be authorized to access the data.

Ethics complaint procedure:

If you have cause to complain or express concern about the ethical conduct of this study please email a detailed account of your specific concern to Nicole Palmer, University Research Ethics and Governance Officer N.R.Palmer@kent.ac.uk, telephone 01227 824797

If you have any questions now, or later, please contact the researcher directly:
Annette Foster apf@kent.ac.uk

Or the study co- supervisors:

Professor Nicola Shaughnessy nicola.shaughnessy@kent.ac.uk

Melissa Trimingham Melissa.trimingham@kent.ac.uk

Confidentiality and Right to Withdraw from Study

Please read the following statements and indicate your agreement:

- I confirm that I have read and understood the information for the present study, and understand that the research will involve my participation in creative workshops that will be video recorded and a video/audio recorded one-to-one interview (via Skype) of my experience as an autistic Person.
- I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily (via email with the researcher –Annette Foster apf7@kent.ac.uk).
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason (contact Annette Foster at apf7@kent.ac.uk to withdraw from this study, including withdrawal of your data after the study is finished).
- I understand that I can choose **not** to answer a question/s, without giving a reason.
- I understand that my responses will be anonymised and treated confidentiality before analysis. I give permission for members of the research team to have access to my anonymised responses. Any publication resulting from this work will report only data that does NOT identify me.
- I agree to extracts from the transcripts and observations of video documentation of workshops and potential performances being used in academic publications, such as books and journal articles.

I freely agree to participate in this study.

Signature and Date

14.2 Consent Form

Consent form

Title of project: Adventures of Super Aspie Grrls Workshops

Name of investigator: Annette Foster

Participant Identification Number for this project:

Please initial box

1. I confirm I have read and understand the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
1. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *(Please contact Annette Foster a.p.foster@kent.ac.uk or text/call 07983560655 if you would like to withdrawal from the project).*
1. I understand that my entrance and exit interviews will be audio or video recorded. I give permission for the researcher to have access to interview documentation/recordings. I understand that any publication of my interviews will be anonymised and any anonymised direct quotes, will be approved by me.
1. I do hereby grant Annette Foster as a PhD researcher for Adventures of Super Aspie grrl Workshops and Performance to take photographs, audio or digital/video recordings of all workshops which include me and use these for academic research purposes. I understand that any publication or showing of photographs, audio or digital/video recordings, will be approved by me and I give permission for the researcher to review and edit these documents.
1. I agree to take part in the above research project.

Name of participant

Date

Signature

Name of person taking
consent
*(if different from lead
researcher)*

Date

Signature

To be signed and dated in presence of the participant

Lead researcher

Date

Signature

Appendix 15: Super Autie Gang (SAG) Workshop Schedule Guides

15.1 Original Adventures of Super Aspie Grrls Draft Workshop Schedule Guide

Suggested structure that can be adapted and developed from week to week:

6.00-6.15: Warm up exercise (led by Annette, taking cue from week before)

6.15-6:50: Workshop A

6:50-7:00: Check in make sure everyone is comfortable with the session- give people 5 min. to decompress before moving on to Workshop B.

7:00 -7.45: Workshop B

7:45-8.00: Debrief and decompress to return to a safe space

Many of the workshops will be focused on the senses and creative explorations of how it looks/feels/smells/tastes/sounds like to be an autistic woman, non-binary or trans- person. There will be a semi- structure, but I will be flexible with the group so if you would like to cover something I haven't thought of I will develop the schedule around your ideas.

I will ask you to keep a sketchbook/diary/digital diary throughout this process focusing on a different sense each week, this can be a traditional diary or digital and possibly shared on the internet via a private Facebook group (that might be turned into a website at a later date?) as many autistic people feel this an easy way to communicate and build community. If you do not wish to join the Facebook group, you can do your diary in another form. This will also give me chance to connect with you throughout the week if any problems or questions arise.

Workshop 1

Tuesday Feb. 13: Jarman 2: 6-8pm

Sense Themes: Touch/Visual

Introduction to the project, concentrating on sharing your experiences as autistic people and getting to know each other while doing a task.

As part of the workshop, you will learn how to make your own appliqued t-shirts with bondaweb and fabric that simply says something positive about being autistic. Each t-shirt will be unique; you will select the fabrics and sew it yourself.

At a later date, you will have an opportunity to wear this t-shirt in a public Autistic Action- a bit like a small autistic flash mob. You can also take part in an art activist video piece by appearing in your appliqued t-shirt to help to show how diverse the autistic community is. I would especially like the video art piece to show that there are all types of autistic people and to dispel the stereo types making women (cis-/trans-) and non-binary autistics more visible.

Sense Diary assignment: Please keep a stimming diary this week, noticing when and how you stim and with what you stim. Take pictures of this if easier or just a collection of words there is no right or wrong way of doing this.

Workshop 2

Tuesday Feb. 20: Jarman 2: 6-8pm:

Sense Theme: Feeling/ touch

This session will be all about the pleasures and/or agony of stimming and the negative stereotypes of stimming and autistic people.

Please bring in 3 stimming objects... this can be anything

We will work with video and movement filming stimming toys

We will possibly develop some everyday stimming gestures that could be used to create some performance movement. Don't be scared you won't be doing pirouette turns or anything!

Sense Diary assignment: Create a taste diary next week, noting tastes that you like and things that you don't like. Note unusual tastes and things that you notice about taste during the week. This can be done however you like, digitally, in images, pictures or drawings, in a notebook or sketchbook whatever works for you but please bring in for workshop 3.

Workshop 3

Tuesday February 27: Jarman 2: 6-8pm

Sense Theme: Taste

Bring in your favourite tastes, and possibly something you dislike the taste of as well. Please remember your taste diary. We will have a taste feast where we work with food as a creative tool and inspiration.

Sense diary assignment: Please create a smell diary however you can over this week, noting things about smell, certain smells you like and certain smells that you can't stand etc. Anything you notice about smell this week jot it down or take a picture of it to bring in for the next session.

Workshop 4

Tuesday March 6 Jarman 2: 6-8pm

Sense Theme: Smell

Please bring in something that you own that you like the smell of and something you can't stand the smell of for this session. We will work with smell as a creative inspiration to develop some creative writing about our individual experiences of being Autistic.

Sense Diary assignment: Please keep a visual diary this week, taking pictures of things in your everyday life that please you visually, things or situations that overwhelm you visually or that you can't stand. Please also collect three objects that

you enjoy visually to look at. You may write about visual things or situation as well or any other form of documentation such as drawing, collected images form the internet etc.

Workshop 5

Tuesday March 13 Jarman 2: 6-8pm

Sense Theme: Visual

Please bring in at least 3 objects that you enjoy visually and possibly 1 object you can't stand.

This week we will be working with video filming objects, materials anything that we find visually enjoyable. I would also like to explore places or images that we find visually overwhelming. We can decide to film them if this is possible, making sure that everyone feels safe and comfortable with this.

Sense Diary assignment: Please keep a sound diary this week. Please record sounds with your phone you enjoy or encounter over this week. You may write about these sounds as well or any other form of documentation such as drawing, collected sounds form the internet etc.

Workshop 6

Tuesday March 20 Jarman 2: 6-8pm

Sense Theme: Sound

For this session, we will be using our sound diaries as creative inspiration to develop soundscapes or sound art pieces that illustrate our experiences as autistic people. This may include sounds that overwhelm us but again this will only be done if the group feels safe and comfortable with this.

Sense Diary: Please keep a touch diary this week concentration on how clothing, fabrics and other materials feel to you.

Workshop 7

Tuesday March 27 Jarman 2: 6-8pm

Sense Theme: Touch

Please bring in your favourite fabrics, clothing, materials, things you like to touch. This session we will be experimenting with materials, clothing, etc. We will discuss the pleasures and difficulties some people have with touch including fabrics on the skin, being touched by people, etc. We may also explore possible costume design for participants to develop their own Superhero personas and costume idea.

Diary: Please develop your superhero name, your superpower and costume design in your diaries.

Workshop 8

Tuesday April 3 Lumley: 6-8pm

Sense theme: all senses

Annette will performance for group -Object nonverbal and show the Canterbury Autistic Action Video.

This session focus on the feeling many autistic people (especially late diagnosed people) of not being heard, ignored or being invisible. We will work with movement and text to articulate what this feels like as autistic people.

Workshop 9

Tuesday May 8 Jarman 2: 6-8pm

Sense Theme: The Brain- Sensory processing and executive functioning

Annette will performance her 'Bus Tour' performance piece- illustrating how your brain works: this session will focus on sensory processing and executive functioning session. We will compare our brains and how they work. What do you struggle with? What do you find interesting and easy? How can we articulate this to other people, so they understand? So that we can understand?

Workshop 10-12

Tuesday May 15 Jarman 2: 6-8pm

Sense Theme: All the Senses

Development sessions devising performance for Super Aspie Grrls with all creative outputs from workshops 1-9.

Week 12

Tuesday May 22 Jarman 2: 6-8pm

Possible final performance for invited audience.

15.2 Revised Adventures of Super Aspie Grrls Draft Workshop Schedule

Suggested structure that can be adapted and developed from week to week:

6.00-6.15: Meditation/ chill out /warm up exercise (led by Annette, taking cue from week before)

6.15-6:50: Workshop A

6:50-7:00: Check in make sure everyone is comfortable with the session- give people 5 min. to decompress before moving on to Workshop B.

7:00 -7.45: Workshop B

7:45-8.00: Debrief and decompress to return to a safe space

Many of the workshops will be focused on the senses and creative explorations of how it looks/feels/smells/tastes/sounds like to be an autistic woman, non-binary or trans- person. There will be a semi- structure, but I will be flexible with the group so if you would like to cover something I haven't thought of I will develop the schedule around your ideas.

I will ask you to keep a sketchbook/diary/digital diary throughout this process focusing on a different sense each week, this can be a traditional diary or digital and possibly shared on the internet via a private Facebook group (that might be turned into a website at a later date?) as many autistic people feel this an easy way to communicate and build community. If you do not wish to join the Facebook group, you can do your diary in another form. This will also give me chance to connect with you throughout the week if any problems or questions arise.

Workshop 1 and 2 and 3

Tuesday Feb. 13, 20 and March 6: Jarman 2: 5:00-7:30

Sense Themes: Touch/Visual

Introduction to the project, concentrating on sharing your experiences as autistic people and getting to know each other while doing a task.

As part of the workshop, you will learn how to make your own appliqued t-shirts with bondaweb and fabric that simply says something positive about being autistic. Each t-shirt will be unique; you will select the fabrics and sew it yourself.

At a later date, you will have an opportunity to wear this t-shirt in a public Autistic Action- a bit like a small autistic flash mob. You can also take part in an art activist video piece by appearing in your appliqued t-shirt to help to show how diverse the autistic community is. I would especially like the video art piece to show that there are all types of autistic people and to dispel the stereo types making women (cis-/trans-) and non-binary autistics more visible.

Sense Diary 1-2 assignment (session 1-3): Please write down any observations you have about the appliqué task, please tell me about why you chose that particular statement to appliqué and any significant moments in discussions we had.

Sense Diary 3 assignment (session 4): Please keep a stimming diary this week, noticing when and how you stim and with what you stim. Take pictures of this if easier or just a collection of words there is no right or wrong way of doing this.

Workshop 4

Tuesday March 13th: Jarman 2: 5:00-7:30 pm

Sense Theme: Feeling/ touch

Stimming

This session will be all about the pleasures and/or agony of stimming and the negative stereotypes of stimming and autistic people.

Please bring in 3 stimming objects... this can be anything

We will work with video and movement filming stimming toys

We will possibly develop some everyday stimming gestures that could be used to create some performance movement. Don't be scared you won't be doing pirouette turns or anything!

Sense diary 4 assignment: Please keep a sound diary this week. Please record sounds with your phone you enjoy or encounter over this week. Please write about sounds that you enjoy and why? Sounds that you can't stand and that overwhelm you. You can use any other form of documentation such as drawing, collected sounds from the internet etc.

This session was avoided by some participants as Sound is once again very difficult for participants to deal with. We looked at capturing autistic sounds

Workshop 5

Tuesday March 20 Jarman 2: 5:00 -7:30pm

Sense Theme: Sound

For this session, we will be using our sound diaries as creative inspiration to talk about sounds, music and autistic noises. We recorded autistic echolalia sounds and music and sounds that illustrate our experiences as autistic people.

Sense Diary 5 assignment: Please create a smell diary however you can over this week, noting things about smell, certain smells you like and certain smells that you can't stand etc and why?

Workshop 6

Tuesday March 27 Jarman 2: 5:00 -7:30pm

Sense Theme: Smell--- And Stimming Circle Performance movement

We talked about our experiences with sound and stimming as autistic people and we did a stimming circle in which everyone shared positive/ happy stims with the group in a circle and we then repeated these movements as a group. We also worked with movement developing autistic walking and What is a physical representation of a neurotypical person walking.

Sense diary 6 assignment: Please bring in three objects that represent you as an autistic person (it could be anything a piece of clothing, a picture, a favourite object etc.) or that represents your experience of being autistic? Please tell the stories of these objects who gave you the objects, how long have you had them, how do they represent you? as an autistic person?

Also, students were asked to bring in 3 objects to the next session that represented them and their experience of being autistic.

Workshop 7 Tuesday May 15 5:00 -7:30pm

This session was held at the Woodlands meeting room where the autistic group meets. You were asked to bring in three objects that represent you and your experience of being autistic.

Each participant shared their objects and told the story of their objects and why they felt they represented themselves and their experience. These were recorded.

Sense diary 7 assignment: Please keep a touch diary this week concentration on how clothing, fabrics and other materials feel to you. What are things you like the feel of or like to touch and what are fabrics or textures you can't stand the feel of? Why?

Workshop 8 Tuesday May 22 5:00-7:30 pm

Performance movement and actions

Participants P9, P2, Sophie and Anna

We didn't make it round to all participants, so Sophie and Anna presented their 3 objects and told the stories of these objects and why they felt they represented themselves and their experience. Participants were asked to bring in their objects and we created performance and movement together representing our experiences.

Sense Diary 8 assignment: Please keep a visual diary this week, taking pictures of things in your everyday life that please you visually, things or situations that overwhelm you visually or that you can't stand. Please tell me why? Also collect three objects that you enjoy visually to look at. You may write about visual things or situation as well or any other form of documentation such as drawing, collected images from the internet etc.

Workshop 9 Tuesday June 5th 5:00 - 7:30 pm

Fantasy Safe Space

The Theme: Touch/ fabrics in particular, I asked people to bring in fabrics, clothes, objects that they like the feel of and to think about their experience of a touch.

I also asked participants to think about this question: If you could say anything to the neurotypical world what would it be? And why?

Participant were asked to think about and create their own fantasy safe space with electrical tape (the best they could) and describe their fantasy safe space with the group while inhabiting their space.

Appendix 16: Sample Session Guide - Adventures of Super Aspie Grrl Workshop 1 Applique

Date: Tuesday 13th February

Workshop focus: Autistic Actions: Feminist Art Activism: a crafty practical workshop

Sense Themes: Touch/Visual

Aims: Introduction to the project, concentrating on sharing your experiences as autistic people and getting to know each other while doing a task.

Outcomes: Allowing participants to speak about their experience and giving them a voice. To create a community where people feel safe (safe space).

Break out rooms: Room next to kitchen I on the third floor. Show everyone each day.

Materials/Prep

Refreshments (pack of biscuits) Diaries, materials for applique, irons, ironing board, t-shirts, bondaweb, applique circles, applique thread, scissors, cheese cloth, needles, needle threaders, fabric, photocopies of stencils, PowerPoint of pictures, video of *Autistic Action* performance, a ride to bring materials in.

Structure of workshops

Many of the workshops will be focused on the senses and creative explorations of how it looks/feels/smells/tastes/sounds like to be an autistic woman, non-binary or trans- person. There will be a semi- structure, but I will be flexible with the group so if you would like to cover something I haven't thought of I will develop the schedule around your ideas.

I will ask you to keep a sketchbook/diary/digital diary throughout this process focusing on a different sense each week, this can be a traditional diary or digital and possibly shared on the internet via a private Facebook group (that might be turned into a website at a later date?) as many autistic people feel this an easy way to communicate and build community. If you do not wish to join the

Facebook group, you can do your diary in another form. This will also give me chance to connect with you throughout the week if any problems or questions arise.

Activity/	why	When	What's needed	Notes
Intro to project.	So, everyone is aware of what the project is all about. Paperwork first documentation? Housekeeping- toilets, quiet room, fire exits, tea and coffee facilities.	6:00-6:15		Participants are asked to bring a piece of clothing or bag, pillowcase something they want to applique on to. T-shirts and fabric provided if participants forget. Tables and chairs set up with materials ready to work on appliques. Give plenty of room for participants so they don't feel crowded. Documentation equipment, video camera, go pro, tripod, extension cord, sense diaries to give to participants. Photocopy all participant information sheets, session guides and consent forms
Ground Rules Introductions and getting to know each other participants introduce themselves and tell us what they want to get out of the workshops?	To develop trust and a shared ownership. Getting to know each other (no obligation to speak if participants don't want to).	6.15-6.30		Large piece of paper and markers

<p>Discussion about Applique project and the idea of coming up with something positive about being Autistic. I share examples of t-shirts and appliqués that I created and that were created in trail workshops at Autscope, 2018.</p> <p>Think about the positives about who you are: what positive words and/or phrases can you use to describe you? What are your interests? Try not to over think this. Try and write at least 3? What positives can you say about autism and being autistic?</p> <p>Participants share ideas for short positive word or slogan with the group. Participants are helped by the facilitator or group if they are struggling to come up with something positive.</p>	<p>Taking inspiration from the Neurodiversity paradigm that autistic people are just different not disorder. To create new words or reappropriate old words that describe autistic people. To develop a counter to the stereotypical representations of Autism that contribute to autistic people feeling as if they are broken or disordered.</p>	<p>6.30-7.00</p>		<p>Applique samples from my own collection and from trial Applique workshops at Autscope, 2018.</p>
<p>Break tea, bathroom break</p>	<p>10 minutes time for break</p>	<p>7:00-7:10</p>		<p>Tea and coffee supplies, milk and alternative milks. Biscuits and alternative dairy and gluten free options.</p>

<p>Demonstrate first two stages of applique. Copying letters onto Bondaweb and selecting fabric.</p>	<p>To give participants tools they need to carry out task.</p> <p>Participants are given one to one help if needed and have the choice of creating letters by hand instead of using stencils and/or creating a picture instead of a phrase.</p>	<p>8.10-8.25</p>		<p>Photocopy of handouts on Applique with step-by-step instructions, and stencils for letters.</p> <p>Box of Fabrics, Bondaweb, scissors, pencils, pencil sharpeners, rulers, tracing paper.</p>
<p>Participants carry out applique tasks of copying letters for positive phrase and selecting fabric to iron letters onto.</p>	<p>To create a sewing circle atmosphere where participants can talk about their experiences of being autistic while carrying out a task.</p> <p>Facilitator prompts this with discussion topics. To create community and a sense of shared identity about being Autistic.</p>	<p>8:25-8:45</p>		<p>Box of Fabrics, Bondaweb, scissors, pencils, pencil sharpeners, rulers, tracing paper</p>
<p>Tell people about sense diaries and weekly assignments. Hand out free diaries for participants to take home. Participants are given the option of keeping a digital typed or voice recording diary.</p>	<p>To give participants to reflect on their experiences as an autistic person through sensory experience. Sense diaries questions will be discussed at the beginning of each session and many times focus of the workshop on their experiences as autistic people.</p>	<p>8.45-8.50</p>		<p>Bring sense diaries</p> <p>Sense diary task: Please write down any observations you have about the appliqué task, please tell me about why you chose that particular statement to appliqué and any significant moments in discussions we had.</p>
<p>Clean up materials and space.</p>		<p>8.50-8.00</p>		

Appendix 17: Example of line-by-line coding

Subthemes

116 P1: So as in has it changed because of the workshop?
 117 Annette: I don't know. Has it?
 118 P1: I mean, I mean I was diagnosed in February 2017 so
 119 I'm just going to say the beginning from then to 2018 was
 120 a whole year and now, so 2 years.
 121 Annette: So two years ago
 122 P1: So my diagnosis was very recent when we did the
 123 Workshops and I'm a lot more comfortable, not as if I was
 124 uncomfortable about it, but when something feels new it
 125 is like when you have a missing tooth you keep prodding
 126 at it. It's not painful, but its like, it's new and I want to feel
 127 what it is and now it just feels like oh OK it's just
 128 something that's there. It's like Oh yeah... Shrug. So I felt
 129 part of the workshop was me like exploring that and also
 130 like becoming comfortable in OWNING IT because I was
 131 happy being autistic, I was happily accepting I was
 132 autistic all along. I didn't really have to change my view of
 133 who I was as a person on an intrinsic level but I
 134 struggled quite significantly with like being Out and Proud
 135 sort of thing, like not over justifying every little action I had
 136 to outsiders, especially because I received such negative
 137 feedback on my diagnosis from family members... Uh
 138 like, you are just going to learn to be helpless and I was
 139 like um, I have not. I am just Helpless Naturally, thank
 140 you very much. I don't need to learn anything for this...
 141
 142 Annette: ha ha (laughs) Just helpless naturally (ha haha)
 143 NOTE {(maybe this is why P1 did the appliqué
 144 Wholesome Autistic- to a certain extent- its just a natural
 145 thing and they are proud of this? this is how they owned it
 146 - in response to the negative feedback they got when
 147 they were diagnosed)}
 148
 149 P1: I am like a turtle on its back with legs flailing um
 150 (cont) so I see the workshop part of that whole. like That
 151 was part of my whole...
 152 Annette: that time...
 153 P1: Period. it was new and I was coming to become more
 154 comfortable using the words and explaining things and
 155 sometimes especially because... my family are not very
 156 emotionally explicit. So when people ask things like how
 157 do you feel ... its like... I just Fucking feel you know what I
 158 mean.
 159 Annette: I have no idea.. Yeah

Line-by-line coding

118-120 Late diagnosed Feb 2017 age 20

122-124 Autistic Identity

workshops helped coming to terms with diagnosis- being comfortable.

128-135 Learning how to be autistic again. Used workshop to explore autisticness

135-139 Autistic Identity Owning it/ Disclosure- struggle with being Out and Proud.

135-140 Not Justification of behaviour to NTs Stigma? Used the word 'outsides' for NT- autistic community/ identity

150-51 Applique

Wholesome autistic- ask P1

Feeling Whole? Workshops were part of

Autistic Identity

Also in ability to describe feelings- alexithymia?

learning to describe feelings- autistic experience.

153-158

Autistic Identity

Line 153-158 Using words of neurodiversity paradigm to explain experience to family.

Appendix 18: Link to Raw data - Question by Question Analysis

[REDACTED]

Appendix 19 - Description of Super Autie Gang Workshop Activities

19.1 Super Autie Gang Workshop Information

The was also a focused on the senses and a creative exploration of how it looks/feels/smells/tastes/sounds to be an autistic woman, non-binary or trans-person.

There was usually a diary task which was assigned to participants at the end of each session in preparation for the next session. We would them discuss this topic in the following workshop. The guides provided a loose structure to the workshops, but also allowed me to be flexible with the group; if participants wanted to cover something that had not been thought of, the workshop structure could be flexible and change according to the group dynamic.

The participants were asked to keep a sketchbook/diary/digital diary throughout the process, which was designed to focus the participants attention on each of the different senses. Participants were given options as to the kind of diary they wanted to keep, as some autistic people find handwriting and typing difficult. Participants were given a short task each week to write, type, draw, or photograph about their own experiences of the sense that related to the next session and then used the 'homework' as a discussion topic in the next workshop. Completing the task was extraneous, as the tasks were designed to focus their attention about their experiences with the particular sensory input that was the focus of that session. These diaries were for the participants own exploration and not part of the study.

I provided chairs but also encouraged participants to feel free to sit or lay down on the floor and depending on the session, even to sit behind the large black theatre curtains that lined the walls of the drama space we used. This happened once or twice in the workshops when people wanted to take part but needed another layer of protection from the sensory world within a Sensory Space.

When the participants were taught craft-based techniques, I presented/provided step by step information in as many learning styles as possible while always being sensitive to the needs of the participants. I ensured all participants were reassured and that it would be perfectly natural to need one-to-one tuition and to repeat craft procedures, and I acknowledged it was hard to remember all the steps and that participants were rightfully nervous about 'doing it wrong'. I reminded participants: not to compare themselves to others; whatever they are doing was perfectly fine; and there was no right or wrong way to do any of the tasks. I emphasised that it was important that everyone recognise that everyone works at different speeds, and they should feel free to create something new and unique to themselves, for themselves. In the interview process many of the participants commented on this. P6 stated, *"Yeah and you felt like, yeah, there wasn't any right or wrong way to do it. Yes, yeah, that was, [Annette: And actually, I wanted you to move autistically] that really took the pressure away and that really, that really added to the experience"* (P6). I asked participants to move autistically, in that many participants are dyspraxic or feel awkward moving their body in a creative way, and I wanted to make it clear that there was no right or wrong way to do performance movement and that I was interested in how AWCTN+ people might move differently from neurotypical people and to celebrating this.

19.2 Applique Workshop 1,2,3:

I. Introduction: Also, as part of the introduction I felt it was important to tell the participants what I had planned originally for each session. I felt it was important to ask participants how they felt about it and what they wanted to do. It was important for them to feel they had control over the environment and could decide not to do something if they did not want to. This was communicated in the session guide printed and handed out to participants. This was continued throughout the sessions. I reminded participants what we were going to do the following week at the end of the sessions as well as on the Facebook page. I asked for honest feedback on the session plans from the participants before the sessions happen, usually at the end of the session and during the session to make sure that participants were comfortable with the sessions

II. Ground Rules

As part of the introduction the participants were asked to come up with 'ground rules'.

Consensually agreed Ground Rules created by the group:

- *Do not be very loud.*
- *Be yourselves and don't feel pressure to fit in, do what feels comfortable to you and don't be afraid to appear 'autistic' here. This is a safe space.*
- *Make sure we have a break room/ also po- up tent Overwhelm Avoidance Device*
- *Be Respectful*

- *Be as good a listener as you are a talker (conversationalist)*
- *Try to have one conversation going on at a time so it doesn't get too loud or confusing for some people*
- *Annette as facilitator will redirect conversation if a participant goes off on too long a tangent.*
- *Help each other as much as we can*

III. Applique Workshop background

The appliqué workshops stemmed from my preliminary visual and performance research for Adventures of Super Autie Grrl (ASAG) at the Autism Arts Festival 2017. Throughout this performance, and the other renditions of ASAG, in November 2017 Canterbury and April 2018 in London at the Invisible Festival, I developed a methodology of practice

These workshops were an introduction to the project, concentrating on sharing experiences as autistic people and getting to know one another while doing a task. It was an aim to teach the participants a new creative skill: Applique, to articulate their experiences of being autistic creatively. The aim of the workshops and this project was to be a collaborative project or an participatory autistic research project inspired by the Participatory Autism Research Community (PARC) that aims to, "...see more significant involvement of autistic people in autism research..." (PARC, 2020) and to create an atmosphere that was one where the participants felt that they had a say in the project, that there was collaboration between the participants and facilitator.

One of the participants (P1) reflected on the workshops,

“...I really didn't have many or really any reservations about being safe or explaining things you wouldn't understand, or I didn't feel like a subject, that is the things. In other studies, sometimes you feel like a test subject and you get that even when you talk to doctors and stuff and they look at you, especially if you have a late diagnosis they say that is curious can you tell me about it because it is new and I like data. I don't care that you are a human being...but there wasn't, there didn't feel like there was any relation of authority, as like an unequal one, it didn't feel like there was an unequal relationship because you were taking part with us and you were leading them but you'd never force anyone to do something or if someone really didn't like something you would be like OK that is OK um and nobody really felt pressured to go to the workshops if they didn't have to we want to go because we wanted to support your research. But there is a lot of I guess things in the community and maybe I am aware of this more now than a year ago. Is that people, especially self-advocacy groups, it was about, nothing about us without us, that quote has been like everywhere. and I am like, 'that makes it a lot better because it was not without us'” (P1)

From a pilot performance piece entitled *Adventures of Super Aspie Grrl* (2017), I discovered it was important to make the text visually overwhelming with each letter being a different pattern and colour to the point that many people found it hard to read. This was intended to: 1.) Overwhelm neurotypical audiences in order to give them the feeling of what was like for many people on the spectrum when trying to read or communicate with the neurotypical world; 2.) frustrate neurotypical audiences - as a dyslexic, dyspraxic and autistic person I wanted neurotypicals to

feel a bit of the frustration of not being able to read a word or understand something (For examples of my creative Appliques created before workshops please see Figures 59 – 61). I also made positive appliqués of important words to promote the neurodiversity paradigm such as *Neurodivergent* and *Super Aspie Grrl*. This gave physical presence and ownership to these words in a different way than just saying or writing them down. I could hold these words in my hands, I could touch them, feel them, look at them, smell them, manipulate them, roll the words up into a little ball- it took away the power of these negative words and empowered me. This also gave me, as an autistic person who feels much more at home in the sensorial world and the language of vision, touch, smell, and sound, a proprietary way to ‘feel’ the language of the pathological paradigm in a more ‘wholistic’, and I would say autistic way. I wanted to see if this was experienced by my participants as well or if this was part of my own subjective experience or ‘qualia’. Did this give the attendees more ‘agency’ as autistic people



Figure 59 Life Hacker Applique by Annette Foster (2015)



Figure 60 Non Neurotypical (spelled wrong) Applique by Annette Foster (2015)



Figure 61 Overwhelm Applique by Annette Foster (2015)

Applique specific tasks:

The participants were asked to create a word or phrase that articulated their experience of being autistic that we would then applique onto a piece of clothing or fabric. With the idea that the participant could wear this or display this item in their home to remind themselves of a new perspective that was a positive experience of being autistic, showing their pride in identifying as autistic and being part of the autistic community. This was inspired by my own creative practice of making appliques in response to my experience of being autistic. Participants were asked to make something physical that they could hold, that articulated their experience of

being autistic from their perspective (Table 5). Some participants usually awaiting diagnosis or had a complicated experience of their identity as autistic and found it hard to come up with something positive to say about their experience.

During the three introductory workshops participants were encouraged to talk about their general experience of being autistic especially how they discovered they were autistic and about their experience of being diagnosed. This was while they continued to create their positive label or slogan about their experience of being autistic. Many participants spoke of knowing that they were 'weird' but not really knowing why and looking back now after their autistic discovery and/ or diagnosis with disbelief or realisation that their parents, GP's and teachers either didn't seek diagnosis for the participants due to stigma around the diagnosis of Autism or the stereotypes about autistic people. Note that throughout the workshops and interviews the use of the word or label 'weird' was chosen in particular by clinicians, psychologists, parents and participants to describe their undiagnosed autistic experiences and '*autisticness*' instead of the label autistic. Possibly as this was a more desirable way to think that this child/teenager/ young adult was not autistic but just weird. P3 states that they were "*heavily hinted at being on the spectrum from about 16 so that is what? Spending three years being self-diagnosed and then being diagnosed. Yeah, before that I just thought I was weird and unlikeable*" (P3).

The other aim of these workshops was to create a sewing circle like atmosphere where participants could be busy with their hands and not have to make eye contact, or do the usual neurotypical social thing of looking like you are paying attention to

the speaker, and relax into the conversation which was directed to explore their experience of being autistic.

Some of the phrases that participants came up with were words that previously might have been used to label participants negatively as a nerd, alien, weird. Others were newly created words that expressed their experience of being autistic, like participant 8 who developed 'Anti-Fem' to express their identification as a Lesbian and Autistic.

Table 5- Photographic Documentation of Appliques made at the Super Autie Gang Workshops 1, 2, and 3

Super Autie Gang Appliques 2018 Canterbury	Text and creator
	WHOLESOME AUTISTIC by P1
	NERD by P2



WEIRD AS HECK by P3

Super Autie Gang Appliques 2018 Canterbury	Text and creator
	ALIEN BRAIN BY P5
Not completed	AUTISTIC ASEXUAL AWESOME BY P6
<p style="text-align: center;">[REDACTED]</p>	AUTI-FEM by P8

Super Autie Gang Appliques 2018 Canterbury

Text and creator



AUTISTIC
SAPIEN
SELF WISE
P9



AUQUPI- Autistic
Queer Pioneer
By P10



AUTISTI-QUEER
by P11

Super Autie Gang Appliques 2018 Canterbury

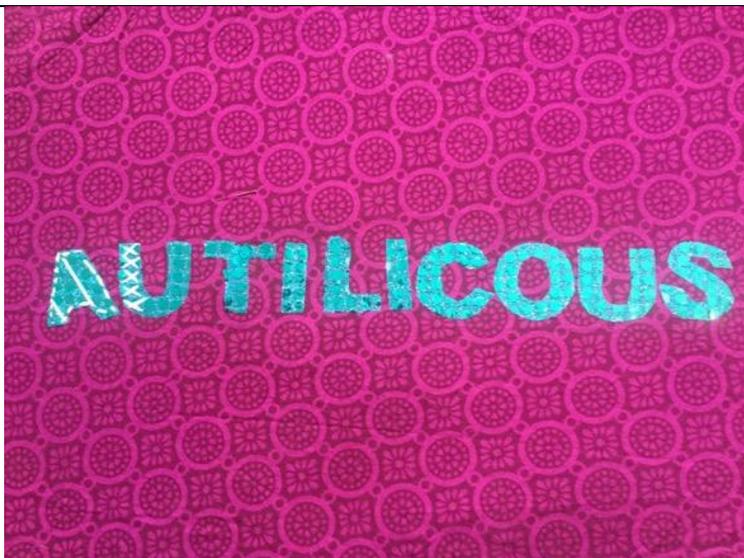
Text and creator



DON'T TOUCH
ME with a heart
underneath BY
P12



STATIC MIND! BY
P13



Autilicious
(Autielicious-
participants
realised their
spelling mistake
after making it) BY
P15

Super Autie Gang Appliques 2018 Canterbury	Text and creator
	<p>I FOUND MY WEIRD by P16</p>
	<p>FIND YOUR WEIRD BY P16 (They made two appliques.)</p>

Participant 6 was only able to come to the last of the three applique workshops and wasn't able to complete their applique which was 'Autistic Asexual Awesome', but when asked what it was like to create a positive statement about being Autistic they replied,

"Empowering. It was still so much stigma around it (being Autistic) and just taking that statement being like, 'no, that's BS'. It's something that's really awesome. We should be proud of it and just taking that and putting it into something creative was really cool" (P6).

The aim of the Applique workshop was that it brought autistic people together to confront stigma and labels from a neurotypical world and re-appropriate these words or create new words as positive affirmations about being autistic and bring positivity to an isolated, negative group identity ('people with autism', pathologised) and stated to change that group identity to a positive autistic identity, celebrating autistic culture and community (Cooper, Smith & Russell, 2017; Cooper et al., 2020).

Another participant commented on their experience and interpretation of the aim of the applique workshops, *"You were meant to come up with a positive affirmation or statement to do with being a person on the spectrum"* (P3).

This participant's applique stating, *'Weird as Heck'*, could be representing their experience of being not only weird in a neurotypical society but atypical or not normal, strange, alien.

It could be said that a late AWCTN+ person might feel like they are in a constant state of 'annoyance' and 'surprise' when thinking about how they are treated by a neurotypical society. Many autistic people are told continually that they are 'weird' to the point that they begin to believe it themselves. They may be aware of their difference even though they might not even know they are Autistic. As Penni Winter states, "Even if they don't have a formal diagnosis, it's still possible they will hate their 'weirdness' or 'difference' anyway, and will likely feel almost as much pressure to be 'normal'" (Winter, 2012, pp.116–117). This feels like the genesis of autistic masking. The participant comments on this when talking about their general experience of being late diagnosed Autistic.

"I was diagnosed at 19 formally I was heavily hinted at being on the spectrum from about 16 so that is what spending three years being self-diagnosed and

being diagnosed. Yeah, before that I just thought I was kinda weird and unlikeable. I still think I am weird but hopefully less unlikable” (P3).

The act of using this as a positive statement reappropriates the word ‘weird’ to be a statement of pride in being autistic. That is in the context of words like ‘queer’ and ‘crip’ being reclaimed by LGBTQIA+ and disabled activists and scholars. I have seen examples of this when I piloted the ‘*Autistic Actions: Feminist Art Activism: a crafty practical workshop*’ later renamed the ‘*Autistic Queering Pride Applique Project*’ at Autscope in August 2017. Several participants from the 2017 pilot project created appliques that used the word ‘weird’ as an affirming positive autistic attribute. Such as ‘weird pride’ or ‘proud to be weird’ (Figures 62 and 63). It was interesting that the idea that ‘weird’ was an autistic attribute that could be reappropriated to a positive characteristic was shared by a large age group, the two participants that created these appliques were very different in age one participant was over 50 and the other participant aged 13.

[REDACTED]

Figure 62: Examples of Applique ‘Proud to be Weird’ from Autistic Action: Feminist Art Activism: a crafty practical workshop at Autscope 2017

[REDACTED]

Figure 63 :Examples of Applique 'weird Pride' from Autistic Action: Feminist Art Activism: a crafty practical workshop at Autscope, 2017

There was another T-shirt from the pilot 'Autistic Actions workshop' at Autscope 2017 that was similar to this 'weird as heck' statement and its reappropriation of words that are used by the Neurotypicals world to stigmatise and negatively describe autistic people. This 2017 pilot participant was perhaps audacious and used the word 'autistic' itself (as there is so much stigma around the word) in their applique statement, 'Autistic as F*ck' showing the participants unapologetic pride in their autisticness (Figure 64).

From my experience, many autistic people, including myself, who are discovered later in life report that they are seen as 'strange' or 'weird' by neurotypical people

[REDACTED]

*Figure 64: Applique Example 'Autistic as F*ck' Autistic Actions: Feminist Art Activism: a crafty practical workshop, Autscape, 2017*

including seeing themselves as 'aliens'. I think that the cultural notions of weird connect to stigma and to the way the biomedical model codify 'typical' and 'atypical'. Goffman (2016), a prominent sociologist and social psychologist from Canada, suggests that stigma is a characteristic that makes a person different from others in a societal classification that diminishes this person's status in society. He suggests that stigma is relational between the characteristic and the 'discrediting' of a person by other people without this trait. He suggests that a person with a stigma is not considered by society on some levels to be human, and grounded on this notion non-stigmatised people carries out an assortment of discriminate on the stigmatised person which greatly diminishes their life changes (Goffman, 2016).

However, in many instances when late discovered people point this out to people they trust, they are not weird enough to be seen as possibly autistic therefore are not give an opportunity to discover they are autistic or be diagnosed. From my experience I knew I was seen as 'weird' but when I asked people in positions of power (such as a teacher, parent or doctor), and say, 'Ok, I know I am seen as weird,' they say, however well meaning, 'No, you are not weird, you are 'normal', everyone feels this way sometimes'. This is an example of. however unintentional, invalidation or gas lighting. These different forms of stigma and invalidation that

autistic people experience daily throughout their lives can lead to ‘chronic invalidation’ (Gates, 2019). In turn ‘chronic invalidation’ leads to ‘toxic’ shame from stigma, which is ‘acquired through experiences of abandonment, rejection, blame and abuse that oppress us into believing our fundamental humanity or true self is ‘defective and flawed’” (Gates, 2019, p.23). Gates (2019) sees this as the ‘Stigma of Autism’. Gates (2019) sees the stigma of autism as unique because stigma and invalidation are complex and can come from many grounds such as ‘*overt stigma*’, which can be associated with stereotypes or observable differences, such as an ‘autistic gait’ or stimming (Gates, 2019).

Another form of stigma autistic people can be affected by is *concealable stigma*, the energy and agony associated with, undervaluing yourself and hiding who you truly are, to even yourself sometimes, as the pressure to conform to neurotypical social norms and conduct can be immense (Gates 2019). Autistic people can also be affected by *Conduct stigma*, any slight deviation from Neurotypical behaviour is picked up and constantly commented on, pointing out all the ways that they don’t fit in or adhere to neurotypical social norms and conduct (Gates 2019). Many AWCTN+ people from this project reported that they were aware that they ‘self-police themselves’ to avoid the humiliation of getting it wrong, over and over again. There are also forms of *presence stigma* which is much harder to define, but essentially means that neurotypical people can just sense that autistic people are different and treat them adversely due to this (Gates, 2019).

Adding the word ‘Heck’ adds emphasis to the presence of this stigma, the participant is not only weird, but extremely weird, ‘Weird as Heck,’ however by ‘cripping and

queering' or autisticizing this term as a positive statement and a declaration of pride they participants is stating, the weirder, the better. The term weird after self-diagnosis becomes a useful term to describe yourself positively by reappropriating the word instead of a word of label that is used to stigmatise you, or to infer that something is wrong with you. The participant also explained why they felt that they were 'weird' and why it was a positive autistic attribute or 'not boring'. P3 states, "*and because also I think that my personality and my interests are very shaped by being an autistic person. Um I have like very obsessive niche interests, special interests and ahh I think they do make me weird but that is a good thing because I would be really boring otherwise ...*" (P3).

It is interesting that they also commented on the fact that the word they used; 'heck' is also a word that they have enjoyed repeating for echolalia and was one of the reasons that they chose the word. "*And mine was 'Weird As Heck' because at the time heck was one of my echolalia words that I would say a lot, I still do, I kind of go through cycles of saying the same words um over and over especially depending what TV I have been watching. It's definitely a mirroring behaviour*" (P3). Which is also identifying with autistic culture mannerism such as stimming. It is hard to get a definition of this word without it being pathologized. What the participant is describing above is delayed echolalia, when a person repeats a word or phrase that they hear from someone else, a TV program, a film or pod cast/social media meme, from any source. Many autistic people do it as expression, to express themselves creatively or just for the enjoyment the word. The autistic community also identifies echolalia as a verbal stim, a repetitive action you do to express yourself.

Several participants used words they have repeated as delayed echolalia in their appliques. Another participant created an applique reading 'Wholesome Autistic' and commented on their use of the word wholesome as 'a verbal stim', or verbal tic, which the autistic community would describe as echolalia as it was an word they repeated over and over.

"I kind of struggled to think of something. But then I was like, you know, I just want it to be wholesome and autistic or something you know, wholesome autistic. Um, it's because I didn't want to be overly negative... I felt like the workshops were there to bring positivity to us... I go through verbal tic's like, I use the same word over and over for a while and I think wholesome was it. Yeah. I think it was inspired by Captain America. Cuz he's very wholesome. I don't actually like him. I don't like him as a character. He's very wholesome. Yeah. Yeah. it is like um, it's like white bread. Do you know what I mean? It's not wholesome... Yeah... Because white bread like just plain slice of a buttered white bread feels like the typical nuclear American family. That's like Wonder Bread... I really like the way it sounds. It's a bit of a verb. It was a verbal stim as well" (P1).

I am very interested in P1's choice of the word 'Wholesome' and how they identify this with 'Captain America', the nuclear family and white bread. 'Wholesome' person meaning, good health, physical and moral well-being. This could be interpreted as; white, male, straight, and western. Which they state they don't necessarily fit into or identify with (P1's ethnicity is Irish and Saudi, they also identify as LGBTQI+, non-binary and without superpowers). P1 states they don't like Captain America and that they don't think that these labels for wholesome particularly fit. Could they be

reappropriating the word Wholesome to incorporate themselves despite the stereotypes around this word are more in line with male, white, straight, American superheroes like Captain America? The antonyms of Wholesome are: unhealthy, unhygienic, bad, sickly. Could it be that the participant wants to identify as a healthy, wholesome autistic person who would not be in line with the stereotypes and stigma about autistic people, let alone their multiple intersectional identities?

Participants used labels/ words such as Nerd, Geek, Alien, Weird, Wholesome, ACE Autistic Awesome, Anti-femme to describe their experience of being autistic - a reappropriation of these negative stigmatised labels into positive affirmations and autistic identity.

Participant 5 used the words 'Alien Brain' to describe their experience of being autistic:

"I did like the applique ones. Yeah, I'm really proud of the one I did last year, because it's really tidy. And the colors are good. [I]t's silly, but like I was trying to figure out like, an identity kind of label. And I settled on alien for some reason because it just, it fit... I like the way he [Spock from Star Trek] talks. I always really liked the way he talked..." (P5).

This participant used the words 'alien brain' to describe their experience of being autistic. They identified with characters like Spock from *Star Trek*, he was viewed as different, he had an overt stigma which was symbolized by his ears, and he was known for being without emotion which relates to some stigma and stereotypes about autistic people and social communication and emotional expression. Also,

from my experience with this participant they have expressed an inability to understand and describe their own emotions (alexithymia) which would be another why that they may have identified with aliens like Spock.

There is a cultural association of autism with the figure of the alien. Hacking (2009) sites several cultural instances that autistic people have been referred to as Aliens and Autists themselves referred to themselves as Aliens. Notably by Oliver Sacks who wrote an article about autism that was later became a book, *An Anthropologist on Mars: Seven Paradoxical Tales* (Sacks, 1995) after a comment by Temple Grandin, an early autistic author, when she stated “Much of the time I feel like an anthropologist on Mars” This described her confusion when interacting with non-autistic people. (Sacks 1995) Hacking also points out a ‘autism awareness’ campaign run by CAN: Cure Autism in the early 1990’s, now a parent run organization, that shows a father talking to the camera stating, “Imagine that Aliens are stealing one in every two hundred children. ...that is what is happening in America today. It is called Autism” (Hacking, 2009, p.44). Many autistic authors and referred to themselves as Aliens using this in the titles of their books such as: *Through the eyes of Aliens* (O’Neill, 1998); or *Women from another Planet* (Miller, 2003) and adopted this as a positive word. As Hacking (2009) states, “An Alien is a second order metaphor...an alien is a foreigner... a rational and sentient being from outer space. At the second order, the word is used as a metaphor for the strangeness of autistic people” (Hacking, 2009, p.46).

When asked to describe their feelings while in the stim circle, while being interviewed this participant answered, “*AHH I don't. I'm not good at that*”. I replied, “*you're not*

good at describing feelings. Are you?" Participant 5 replied, " Yeah". Many autistic people have related to, *'feeling like an Alien.'* Other participants from the pilot project in 2017 created another applique in reference to feeling like an alien *'Autistic Ace from Outerspace'*.

[REDACTED]

Figure 65: Applique Example 'Autistic Ace from Outer Space' Autistic Actions: Feminist Art Activism: a crafty practical workshop, Autscape, 2017

This pilot participant didn't directly call themselves an Alien, they implied this by stating they were from outer space. The participant refers to themselves as being an, *'Autistic ACE from Outer Space'*, this referred to their sexuality and identifying as ACE: Asexual (Figure 65). You could also interpret the word Ace to mean first rate, top, or world class. It is important to note that many AWCTN+ participants in the pilot and SAG workshops referred to their multiple intersectionalities as an autistic person through their applique, such as (P6) *'Autistic ACE Awesome'* and (P8) *'Autistic*

Femme'. Referring to P6's, their identification at the time was as a Femme Lesbian. Throughout the process of the workshop, P6 decided to identify as a more gender-neutral name within the safety of the workshops autistic space and now identify as non-binary.

"...think with non-binary people and stuff in the group made it easier, you know, to explain that... I think it's nice in a way that I called myself (new gender-neutral name) in the workshops and stuff because it's kind of like a bit of a - not really a secret identity - but it's like the right one really, in a way. Yeah, it is the right name" (P6).

This connects with the 'dynamics of passing' common to both autistic and gender identities. By carrying out this exercise, they reappropriated the things that make them 'different' or 'stereotyped' and marginalised as positive attributes this allowed participants to explore their own identities as intersectional autistic people in a safe accepting environment without the fear of stigma.

19.3 Workshop 4 Stimming 1:

Activity: Creating videos of stimming and audio recordings of stimming sounds and Night Lights Activity. The Senses focused on in this session was touch and visual.

- I. **Sense Diary Assignment** In the journal assignment, in the last session of the applique workshops participants were asked to keep a stim diary for that week in their sense diary. They were asked to notice when and how they stim and with what did they stim with. Participants were encouraged to take pictures of this if easier or they could just write a collection of words as a response. It was emphasised there was no right or wrong way of documenting a stim diary.

Participants were also asked to bring in any favourite stim toys they wanted to share with the group.

The original Super Autie Gang schedule stated, *“This workshop was developed to explore the pleasures and/or agony of stimming and the negative stereotypes of stimming for autistic people”* (Foster, 2018). Participants were asked to bring stimming objects to the workshop to share if they had any. Participants were given the opportunity to talk about stimming and what they discovered from the stimming diaries, we then worked with video and movement to film participants stimming and playing with stim toys. This was to determine what kind of stims people did and when and why they did it.

II. **Sharing Sense Diary Entries on Stimming**

The workshop started with participants sharing their stim diaries and stim objects one person at a time so each person could be heard. Some participants did not have stim diaries but were easily able to describe their stims, it was a consensus that many people do small things with their fingers that can be hidden. Many people had similar stimming objects blankets, pieces of fabric, stim toys that have interesting patterns or light up (although some people are overwhelmed by flashing lights or bright lights in general). Also, many people as children did typical autistic stimming hand flapping, rocking, spinning but were either told by their parents that their stimming in general was not appropriate and were repeatedly told to stop these behaviours as they were not normal and *‘weird’*. Many of the participants talked about how their parents are very aware of what other people think- and cared too

much about us *'fitting in'* or *'appearing normal'*. There were some people like P9 who were never told to stop their autistic stimming and slept with a teddy until they were 30 years old, until their boyfriend became a substitute for this. They also had a blanket that had a satin outer lining that became tattered and eventually was just a small piece of fabric with satin, they loved how the satin felt and like to rub the two layered lining together. They had this until their twenties and still keeps this safe in their home for sentimental reasons. P9 feels this is because their grandfather, whom they suspect was undiagnosed autistic and saw this behaviour as *'undiagnosed autistic normal'*, raised them and their sister who is self-diagnosed autistic. Many participants said they still slept with a teddy with their partners. We were all in agreement that we also self-police ourselves, that we observe what is going on from a distance in society and then decided to not do certain things to try and fit in or be *'normal'*.

III. Stimming and Stim Tool/ Toy Videos

The next activity participants were asked to get into small groups and to have a play with the stim toys and film each other stimming. This was filmed very close up, mostly on the stim tool and the participants hands. This was to document the variety of stimming and stim tools that participants used and took part in. Documentation for some of this activity is in the table below (Table 6). This footage was not used in the final performance of Super Autie Gang; however, this footage could be developed in the future into a further into a piece of collaborative art. In future work, I would like to explore developing a catalogue or dictionary of stims and the emotions they could

express. There is little research on stimming as a form of communication and I would be interested in exploring this.

Table 6 Examples of video filmed by participants of stimming

Examples of video filmed by participants of stimming	Links to private videos on youtube
Stimming with coffee mug by P7	[REDACTED]
Stimming ball rolling by P11 and P15	[REDACTED]
Stimming with a plastic spring by P8	[REDACTED]
Stimming with bicycle chain by P15	[REDACTED]
Stimmy fingers by P9	[REDACTED]
Two hourglass stim play videos by P11 and P15	[REDACTED]

Participants were introduced to new stim toys and shared their own stim toys which allowed participants to explore, engage with and recognise and learn about those aspects of their sensoria that they enjoy. Adopting new stim objects and possibly new stim routines that are calming, that fascinate, that help them to become absorbed in the sensorial world in a way that is pleasurable instead of being overwhelmed. By creating video footage of them playing with stim toys, creating stimmy sounds and playing with stim lights and light stim toys in the dark reinforced the celebration of stimming and play as a positive thing that should be experienced and enjoyed by the autistic community.

IV. Night Light Activity

One participant describes the Night Light activity, *“A lot of the workshops were about the five senses, and I brought one of my lights. I think one of them was the one with*

the lights. Sophie brought her cat (light up cat that is soft to touch and cycles thorough different colours) and we were just like, oh gosh” (P2). Participants were fascinated with this cat in particular and many went home and bought one for themselves (Table 7).

“Yeah, so like at the end of the session...Annette turned off the lights and we played with different lights in the dark... it was just fun, and it was really seeing how...umm people’s moments of sensitivity or well enjoyment of sensitivity ahh amongst autistic people... I think I just got attracted to the lights, I think it was something about the objects we brought that day they were just fascinating. For some of us like Gab, lights can be a bit, well you know overwhelming. The senses can be a bit (sucks teeth in), well really a bit too much, uncomfortable for some. there are just some colours and light tones that we just can’t stop.... [looking at] the light one... and um yeah and I think we just really enjoyed it. when it is completely dark, and the only light source was the ones that we [have] got” (P2).

Table 7 Video documentation of participants taking part in light night visual and bodily stimming activity

Video documentation of light Night activity	Private YouTube links
Light night video documentation 1	[REDACTED]
Light night video documentation 2	[REDACTED]

This activity was inspired by my experience of a ‘night light’ activity at Autscope¹²⁷ 2017. I tried to recreate ‘night light’ for the participants. I was so moved by my

¹²⁷ Autscope is a three-day conference and retreat for autistic people by autistic people. ‘The environment and content of the event are centred around autistic people’s needs, interests and sensitivities’. Autistic allies are also welcome, and the event holds workshops, academic lectures, social activities and more. Autscope has been running in the UK since 2005 and was inspired by Autreat which was held in the US by Autistic Network international since 1996. <http://www.autscope.org/about/concept>

experience to see the joy on autistic people's faces, experiencing fascination and enjoyment of sensorial sensitivities I wanted to share this with the workshop participants. Participants were asked to bring in any sensory objects that light up if they had them (several participants did bring in objects including a light up wand, a lava lamp and the glowing cat mentioned earlier), and I collected different things that could light up in the dark, finger laser, glowing fingered gloves, wand projectors, glowing glasses¹²⁸ and encouraged participants to play with these objects. One of the participants, P15, had a problem with lights and flashing light so P15 sat in the OWAD tent while we played with lights in the dark. P15 seemed perfectly happy to sit in the tent as it shielded them from the flashing light but allowed them to still take part in the activity and experience the enjoyment of sensorial experience as a group. P15 stimmed inside the OWAD tent, they were rubbing the walls of the tent up and down. After 30 minutes of exploring the 'night light' I realised that we needed to finish for the evening as that was the time I had given to this activity and the two hours were up. Participants were having so much fun they protested and wanted to continue the activity. We continued to play with the lights in the dark for another 15-25 minutes. One participant commented "*We turned on the lights and many of us realised that we were over stimulated/ overwhelmed and felt; dizziness, had a feeling that we need to eat- like low blood sugar, many people had a headache and a glazed over look in their eyes, or a looks of confusion and being 'out of it'*" (P13). Many of us commented that we had never experienced this feeling of overwhelm with such a large autistic group of people. It was also interesting that the participants

¹²⁸ The light up glasses were problematic as the battery pack made a high pitch noise that was annoying to most of us.

can be overwhelmed by sensorial experiences that we enjoy as well as things we find challenging like open plan offices or a loud pub on a Friday night.

19.4 Workshop 5: Sound

Participants were asked to write in their sense diaries about sounds that they liked and sounds that they disliked.

It is important to note that what I noticed about the sound workshops before it even began was that several participants contacted me and said they would not attend the workshops because, “sound [was] *a real trigger for [them]*” (P12). I interpret this as a reaction to the trauma of being repeatedly overwhelmed by sounds. From my experience with the group, this is a common autistic experience. When developing future workshops about a sense that many people find overwhelming this needs to be acknowledged and addressed with the group in advance that you will have participants that will not want to attend due to the fear of being overwhelmed by sound and talk to the group about how this can be minimised. Many of the group members wear headphones or ear defenders around their neck as a precaution and/or over their ears all day long, in the session to muffle sound as most neurotypical spaces and even ‘autistic spaces’ can be overwhelming due to sound.

In the first workshop, I asked participants on Facebook and in the *Fantasy Safe Space Workshop* if they could invent, modify, or create something that would help your experience of the neurotypical world and what would it be?

- I. Many of the participants find it hard to filter sounds. Participants spoke of their experience of sound as chaotic and overwhelming, several participants described

not being able to hear what someone is saying to them because too many other sounds are being heard at the same time, or it might take them longer to process all that information. Many of the participants use subtitles for English spoken films and streaming/tv programs because they find it hard to filter sound and process it quick enough to keep up with dialog, let alone conversations. (P8) takes this a step further and wants to subtitle life, “[I would invent] *glasses I wear that show subtitles for people speaking in front of them like on a screen. I suppose they'd be like sunglasses. a bit like those sci-fi movie ones where they have a screen in front of them when they wear them, and they'd work just like normal subtitles so they pretty much just appear when sound is on*” (P8). Another participant, P15, wanted to design, “*Meeting/social places where one sense is restricted i.e. in totally dark place or a place where all noises are silenced(/white noised) to better focus on the other senses/other forms of communication, when you've run out of one*” (P15). Many autistic people find it helpful sometimes to block out one sense, such as eyesight, this might make it better for them to hear someone. This blocks the overwhelming visual stimuli out of their sensory processing to allow more focus to concentrate on sound for instance. And (P15) also would like to invent a “*Directional hearing device to isolate conversations and switch between them (that maybe probably exists already)*” (P15). This device could help with the experience of many participants, hearing everything at the same time, but not being able to distinguish any of it.

- II. I asked participants to listen to the ‘silence’ in the room and identify what they could hear. The participants gave a very detailed description of minute sounds they heard in the room. We went around the group sharing what they heard, and

many people heard different and similar things such as the buzz from the fluorescent lighting and the creaking of the vents that were constantly moving in the building depending on the temperature of the room. People on different sides of the room heard different things. Students closer to the road heard sounds of cars and people talking, as well as wind, leaves rustling, where people on the other side of the room were more interested in the subtle creaking of the windows automatically opening, their own breath, people sighing, rustling, slight movements, lips parting, an overall electronic buzz, and distant footsteps. It was interesting how a 'quiet room' became a very loud room, very quickly.

- III. We began by talking about sounds that participants liked, I brought a few quiet instruments to the session and one of them was a rain stick. Due to several participants' apprehension about going to the sound workshops, I decided to only bring a few instruments that were calming and talk about sound much more than I envisioned. I felt it was important for students not to be overwhelmed by sound and feel they were in an autistic space that provided a safety net from the outside world that sometimes could feel like onslaught of sound from all directions. Due to this, much of the planned activities were not carried out. At the end of the session, I had planned a walk-through campus with headphones or ear defenders on as a group to show pride as autistic people, highlighting our sensory differences. Many of the participants felt too exposed and already overwhelmed by a normal day on campus to subject themselves to the possibility of becoming more overwhelmed. I had to modify the workshop.

Several participants approached me before workshop three to express their concern about being overwhelmed by too many sounds happening at once. However, surprisingly one of the instruments, a rain stick, was one of the first sounds P9 said they liked and shared that with the group. Other pleasurable sounds that participants shared were the sound of rain on a flat roof, P5 shared a YouTube video of ice skating on black ice on her laptop. After this I set up the video projector so that people could share sounds on YouTube or off the internet. I strived to work flexibly with the group, to change and adapt quite quickly to participants suggestions and needs. At first, I was reluctant to do anything but talk about sounds as several participants showed a real fear of being overwhelmed in the session. However, I realised quite quickly as long as it was controlled it was important for participants to share the actual sound of things they enjoyed.

Many participants liked the sound of the ocean, streams, running water, crinkles/crunches, clocks ticking, glockenspiel, popping sounds, metal sounds, humming, cats purring, whale songs, birdsong (many people said this could go either way as some birds can be really annoying and stop you from sleeping or concentrating). Another loved sound was skipping stones on a frozen lake. Many of these videos were also posted to the Facebook SAG page.

One participant, P7, is a soprano opera singer and loves opera music. Other participants hate high pitched singing – it is interesting the variety of sounds that some people like and others cannot stand within the group.

Many of the participants really liked music - classical music, cello music, many participants played music videos on the big screen and they felt very moved by that music. P13 said, *"I could feel the music all the way down my spine and throughout my body"*, as if P13 had a kinaesthetic reaction or bodily reaction to the music. P13 stated, *"sounds like that, [cello music] it reverberates in my body"*. P4 states why she likes cello music, *"Cello music is my thing. I think it's just, very harmonious. Like, it's Sound, the tone of it. It's not too low, and it's not too high. It's right bang in the middle, which I really appreciate. It's like a very well-rounded sound"* (P4).

Other participants enjoyed video game music and anime music. P7 explains why they like this type of music, *"...at work if I have to sort of like get my head in gear I'd usually play like video game music cuz you, usually it's like quite relaxing music, but it's also been designed to keep your brain focused"* (P7).

One participant said, *"the sound of silence is the only positive sound I could think of"* (P8).

Another participant, P15, who was very musical, played the guitar and the piano. They spoke about how they really like 'major 7'. They were interested in where mathematics and music meet and showed a video titled, *What Tau Sounds Like*, where musicians apply numbers to all the notes in a major scale and calculate the mathematical constant 'Tau' to 126 decimal places.

IV. Participants shared sound they disliked. Here were many sound people disliked; first of all, participants stressed their dislike of any loud noises such as sirens, alarms, loud voices, screams, loud car engines or motorbikes any deafening

sounds like chain saws, sounds of construction, were disliked by all the participants and many participants expressed physical distress from sound. One participant, P1, commented, “loud noises are like a slap in the face”. Other sounds disliked included Velcro ripping, nails on a chalk board, markers against paper, marker pens on whiteboards, the sound of ripping paper was disliked by many, the high-pitched sound of florescent lights, electric buzzing, polystyrene breaking or rubbing, scrapping a bowl, the sound of people eating, chewing, especially eating crisps, murmuring through walls, wet/sticky sounds, dogs barking.

The session ended with participants recording sounds that they make that they find appealing and make such as a popping noise with your mouth, raspberries, a clicking sound with your mouth. P4 did this sound while they are in lectures, they weren’t aware they were doing it and “you can just hear me in the background clicking” (P4). Words that sound nice and people like to repeat such as: Nostalgia, pernickety, facetious and a Chinese Mandarin phrase. The link to the audio recordings is in the Table 8 below. The more we explored the senses, it was becoming apparent how multifaceted AWNBT+ people’s sensory world was, that with sensory differences came expressions of emotions, from agony to intense joy from AWNBT+ peoples experience of the senses.

Table 8 Recorded autistic (stimmy) sounds documentation links

Sound	Participant	[REDACTED]
Rainstick	P11	[REDACTED]
Echolalia words: Nostalgia, Persnicketic,	P4, P8, P7, P4	[REDACTED]

Facetious, Chinese phrase		
Popping sound, Brrrp sound, clicking noise, a sigh, a belly pat, leg pat	P8, P7, P4, Annette, P11, P11	[REDACTED]

I was beginning to see that stimming was an under recognised, unique, and Autistic expression which came in many different sensorial forms. This unique autistic expression needs further study to understand the importance of stimming for autistic expressions and the interconnective nature of all autistic experience with the senses.

Participants also enjoyed making sounds such as clicking with fingers, belly taps. Participants also commented on how they enjoyed sounds they could make with their own mouth including focal stims, saying words that they like over and over, clicking with their tongue, whistling, humming, some people like the sound of whispering which is officially called ASMR¹²⁹. One participant felt that humming was like an Autistic trill- inspired by a Pokémon Trill; a little repetitive tune that played whenever you entered the room. *“Yeah, I do, I find myself humming along. Yeah, I feel like most autistic people do that, like, no particular tune or anything, to just be like, washing the dishes only you're just going hm, hm, hm, hm, hm, almost like a Pokémon trill, you know? An Autistic trill!” (P7).*

¹²⁹ ASMR stands for Autonomous Sensory Meridian Response and is the experience of a tingling sensation up your neck and to the top of your head which is auditorily or visually stimulated by specific things such as whispering, chewing, or tapping. The person who came up with the term in 2010, Jenifer Allen, calls it a 'brain orgasm'. This had become a huge phenomenon on YouTube and some autistic people find it very soothing, others do not.

<https://www.nytimes.com/2019/04/04/magazine/how-asmr-videos-became-a-sensation-youtube.html>

Some of the sounds people could make with their mouths was recorded at the end in the session. Many participants commented that these were focal stims or 'stimmy sounds' and that making sounds like these was just another form of stimming and echolalia.

Halfway through the workshops, I decided to have a few minutes of silence, just a reset for participants as its can be very overwhelming in a group of 12 autistic people as several conversation tend to go on at once. I brought in 10 pairs of ear defenders I borrowed from a friend and asked participants to try them on. I was very curious about ear defenders and several of the group were as well. Many participants wear their own noise cancelling headphones, but many had not tried ear defenders, possibly because they are seen as something autistic children wear or something that is stereotypical for autistic people, and we were all late diagnosed and were not aware of how much sound affects us. I ask the participants to do two minutes silence in the room- so they found a space in the room that they felt comfortable in and sat or laid down. I lowered the lights down and we just sat in silence. After this exercise participants described the things that they could hear; bodily functions including: their heartbeat, breathing, stomach gurgling, and many participants just felt the sound of silence was quite lovely and freeing. Some participants enjoyed the pressure of the ear defenders and others could not tolerate this pressure and had to take them off early. This became common practice for the beginning and halfway point for the remaining sessions to have a 'sensory break,' short three minutes of silence, with the lights down very low as many participants were sensitive to light. Participants could sit and listen to the silence of the room with their eyes closed, wear ear defenders provided or their own headphones, they could listen to quiet music or play games on

their phones/ tablets as long as it doesn't disturb anyone, it was important for participants to be able to do whatever they need to do to relax and rest themselves.

19.5 Workshop 6: Stimming 2

Exercise: Smell based on participants homework to use their journal to record their experiences of smell.

I. Discussion of Sense Diary Entries on Smell

This workshop started with a 'sensory break' for three minutes in silence with the lights down low which been really helpful for me as well as the group. We began the session by talking about smell and participants likes and dislikes in relation to smell. Many participants liked perfume such as Jasmine or other floral scents, others did not like perfume at all and could only tolerate more subtle scents on their own bodies like cucumber or vanilla. Some participants were so sensitive to perfumes, their wrists would itch where they sprayed it. Many participants were very sensitive to scented laundry detergents and soap and tried to buy non-scented and non-biological laundry detergent or they would be overwhelmed by the scent, or their skin would become irritated from it.

Some of the smells participants loved: lavender, laundry, farm, garlic, coffee, pastry, baking bread, petrol, teabags, musty, orange, pine. However, participants varied wildly with their one person's favourite smell could be something another participant could not stand. Some people really liked the smell of their mother and grandmother while others could not stand their parents' smell. Some of the smell's participants did not like were: body odour, the smell of food on clothing, strawberry, rose, lip balms, spicy food, barbeque/bacon flavours, food cooking, chocolate, bleach and all cleaning products, plastic/rubber, saliva, and sweat to name a few. Yet other people

had the opposite reaction to these smells and loved them. Many participants experience was heightened when they were unwell, stressed or overwhelmed. Participants also talked about their smell of their own body and hair and that some participants washed more regularly than other people because of this where others said that when they are having a hard time, they find it hard to take care of themselves at all including personal hygiene.

II. Sliding Scale Warm-up Exercise

I was very keen to do some movement work with the group around stimulating however many of the group expressed concern that they were not really movement people and that this could cause anxiety to many of the group just because it was something new and out of their comfort zone. I wanted this to be a positive experience for them. The first exercise that the participants took part in was sliding scale exercise where all participants stand in a group and one participant volunteers to walk a short distance from the group and make a statement such as: *'I have a dog'*. All participants who have a dog walk over to stand with that person. This continues, another person walks away from the group and says, *'I have a tattoo'* and whomever has a tattoo will walk over to that person creating a small group. Another person might walk away from the original group and say, *'I would like to get a tattoo'* and others will join them if they agree. This is repeated allowing participants to get to know each other and make connections as the questions became more revealing. With statement such as, *'I am non-binary'* they also showed the intersectionality of the group and how many times the answers to the questions were not black and white. It was important that the participants could also stand in the middle of the group if they only agreed with the statement partially. One participant was struck by

the way this exercise allowed them to embody the experience of intersectionality and heterogeneity of the group which in turn helped them to understand the autistic community and themselves, *“It’s that finding, finding the differences and finding the similarities at the same time that was really cool. I think one thing I remember was basically splitting the room, then moving in one direction or another based on how we, I think, agree with the statement. or if that statement applies to us or something like that. And just, just seeing all the people just running back and forth again, some people standing in the middle because it was just still some grey areas and that Yeah, and that was cool”* (P6)

III. **Exercise: Stim Circle**

I had already created a stimming seminar for neurotypical people to help them better understand why autistic people stim and how this is a natural human action that every neurotypical person also does. I then revamped this workshop for the AWCTN+ community and my PaR workshops to make it autistic friendly. The workshop explored positive stims, to promote wellbeing and to combat the negative view of stimming as ‘weird’. I also addressed the anxiety and trauma associated with being stopped from stimming because it was considered not ‘normal’ or appropriate in the neurotypical world or within the pathological paradigm/medical model of autism.

For the physical part of the workshop, I had all the participants stand in a circle. Normally, with my neurotypical participants, I would ask them to share something that they do when they are anxious. At the time, I was just becoming aware that stimming could be a positive activity, as from my experience and research it had

always been referred to by clinicians, researchers and many autistic people as a negative behaviour that should be stopped or an indicator of anxiety or stress. We were all standing in a circle, and I realised as we were all just looking at each other awkwardly that I didn't want to ask them to talk about and embody negative stims as we inherently did at the beginning of the other stimming workshop due to the pathologisation of stimming as a symptom of autistic anxiety. However, the joy that the participants experienced during the second half of the workshop, the Light Night activity, completely countered the stories participants shared of the shame and guilt they felt about stimming at the beginning of the workshop. This was so strong that one participant broke down a week later in the autistic social group when we were talking about the possible correlation between stopping autistic children from doing harmless stimming because it is seen as 'weird' seems to correlate to especially non-diagnosed AWCTN+ people to sublimate their stims into more neurotypically normal gestures that become obsessive more harmful stims such as picking, scratching, or biting the inside of your lip. P1 broke down in tears and was upset because they felt they, "*only had negative stims to share*" with the group (P1). I felt that it could be just another way for participants to experience the shame and guilt that pathologisation of stimming and the stereotypes and stigma about autistic culture. It was apparent for most of the participants their understanding of stimming was a negative experience. I understood as I had developed a picking stim as a teenager that had left me scarred physically and emotionally and so, I thought the last thing needed was for us to concentrate on the negative interpretation of stimming.

All the participants knew that there were positive stims, but for many they just had not been recognised yet as stims as the only definition we have of stimming is from a very pathological idea that stimming was an autistic behaviour that should be stopped, eliminated, to allow them to fit more easily into neurotypical society. I suggested we needed to develop our own language together to talk about stimming from our own experience exploring the happy stim.

Many Participants commented on this in their interviews.

“I liked the circle... we went in a circle and did our stims. It was fun... maybe if I was like super tired I might not [have] been in the mood but you know sometimes when you get high off each other? Good emotions? Yeah it was fun in a way that let us be like kind of silly but didn't feel patronising because you were also being silly” (P1).

P2 felt more connected to the group and, by actually seeing other participants physically sharing stims, they felt they felt less alone and stated, *“It was fun... having other people to do the same stim you know to get a connection as well. It felt quite connected with people and it was nice listening to other people's experiences... but it was nice to see that... ah well... I am not the only one [that stims] ...at least... And there is a lot of variance” (P2).*

P4's happy stim was a waving of their hands close to their face as if they were fanning themselves however, due to the contagiousness of the happy stim in the room and the sheer happiness that was genuinely felt about the discovery or the unmasking of the joy of stimming, P4 comments *“And I, I added my own jumping because I got really excited about it [when I did my stim in the stim circle]. And I don't*

know, I can't remember the word for it in English, it is that word where like, everyone one is doing it, [in unison – spoken in Mandarin]. It made me happier to see everyone do that, completely without, you know, to not be judged for that. And I was really happy that and it made me jump with my stim” (P4).

Many stims are unconscious, especially when there is no awareness of what a stim is as a late diagnosed AWCTN+ person, and how it is a part of autistic culture. As one participant stated, *“I am not going to lie I made that one up on the spot [their happy stim in the stim circle]. It was a Dad dance¹³⁰. To be honest I think I actually do, do that, I sway from side to side in daily life” (P1).* Even as they spoke about their ‘happy stim’ they refer to it as ‘made up on the spot’, however in the next sentence they state *“I actually do, do that” (P1).* This is important, as participants and I were really exploring, almost conducting an experiment in happy stimming, trying to recover or discover stim movements that we have always done but was labelled *just another weird thing that individual (undiscovered autistic) person does*, especially as late diagnosed AWCTN+ people. To know what a stim was, and what emotion was attached to it. Many participants describe themselves as energetic, and P4 talks about their urge to move, *“I feel the urge to rock. Not even just to move. Just rock, I have a tendency just to rock. Like, if I'm standing still. I will rock. So, I didn't realise that was an autistic thing as well. And [I find it hard to keep still] I just felt my fingers keep moving” (P4).*

¹³⁰ P1 happy stim they titled a, ‘Dad dance’ was where the P1 swayed from side to side while they moved their arms and shoulders in a choo choo motion running like motion.

I used a basic drama exercise: one by one, each person shares a gesture/movement, a 'happy stim' with the group within the 'stim circle' and then all the participants did this happy stim together and finally repeating each stim one after another into a series of stim gestures or stim dances (Table 9). We went around the circle clockwise, however this circle was not a typical neurotypical circle - participants were not expected to make eye contact and had plenty of personal space around them. If participants did not want to partake, they could leave the circle and observe, if that is what they wanted, or they were able to use the OWAD tent or the chill out room if needed. Participants were also told it was okay to pass on an exercise if it was causing them anxiety.

I began the exercise sharing my own happy stim, which I thought of on the spot as I was (like many of the other participants) unaware if I actually had a happy stim. I instinctively rocked back and forth on my heels while swinging my arms. Then the whole group mimicked back this happy stim movement with me.

As each person shared their happy stim, the group would mimic this back to the participants and then repeat the other happy stims that came before, creating a quick choreography of stims put together that participants stim danced together.

The happy stim that P9 shared interestingly involved another person. This was very subtle and minimal, and also repetitive. P9 asked the person next to them to hold their hands out in front of them with their palms up flat, as if you are about to be handed something.

Table 9 Descriptions of Happy Stims Discovered in Stim Circle Exercise

Participants	Description of Happy Stims and notes	Name given to stim	Emotions associated with stim
P1	P1 swayed from side to side while they moved their arms and shoulders in a choo choo, running like motion.	Dad dance	Happiness
P9	Interestingly involved another person. P9 asked the participant next to them to with their hand hold their hands out palms up with fingers tightly together. Then P9 held with all five fingers tightly together lightly tapped the inside of the other participants palm with her fingertips three times. P9 then put their hands out, palms up and encouraged the other participant nonverbally to do the same to them.	Hand tapping stim	Distracting stim/ happy/ fun game/ stim
P2	P2's happy stim was energetically moving their hands in fists around their head as if they were a human interpretation of an ever-moving atom while making the sound 'heahhhahahahaha'.		exuberant expression of joy and excitement
P12	P12's happy stim was to jump up and down while clapping their hands quickly together quietly, their hands were held tightly to their chest as if in a position of prayer, and the clapping was small and controlled only moving their hands a few cms away from each other before bringing them together to create a quiet clap. Their body was quite rigid or straight up and down.	Hand clapping with a jump	Happiness
P4	Waving of their hands close to their face as if they were fanning themselves and an added jump for extra excitement.	Fanning or waving (hand flapping variety) stim with a jump to	Sheer happiness

		add extra excitement.	
P14 and P11	The next participants happy stim was a stimming hug that P14 shared with the group. A stimmy hug incorporated rocking from side to side or swaying back and forth while in a hug with another autistic person. P11 and P14 demonstrated this for the group.	Stimming Hug	
P14	P14 provided an alternative happy stim. Their alternative stim was a 'shaky leg' or bouncing their foot and leg up and down with the foot balance on the ball of the foot and the heel off the floor.	Alternative happy stim or Shaky leg	happy
P5	Hands in pockets stimming with small everyday objects in their pockets, or stimmed with the fabric in their pockets creating holes she had to repeatedly sew up.	Hand in pockets stimming with small object or pulling apart fabric in pocket.	Neutral stim

Then P9, with their hand held with all five fingers tightly together, lightly tapped the inside of the other participants palm with their fingertips three times. P9 then put their hands out palms up and encouraged the other participant nonverbally to do the same to them. It was specifically three taps, very precise, as if you are pressing the space bar on a keyboard with all your fingers, but the keyboard was another person's outstretched palm. P9 told a story about their stim while they shared it; they remembered doing this with someone that was really stressed at work before P9 was diagnosed, they was aware this person was experiencing temporary mutism, so they did this happy stim with them and it seemed to calmed that person. Not everyone was able to do this as many people in the group don't like to be touched as its painful

and uncomfortable for them (this was exemplified in the applied t-shirt P12 created stating, *'Don't touch me'*). So, some people did the tapping to the air and then holding their hands out to the air to recreate the happy stim as closely as possible. All participants were engaged at this point and having fun together.

I interpret this 'happy stim' as a 'playful' repetitive action that creates a connection with another person and keeps your mind off of other things because you have to concentrate on the tapping ritual, like an autistic partner stim meditation. P2's happy stim was an exuberant expression of joy and excitement. P2 energetically moved their hands in fists around their head as if they were a human interpretation of an ever-moving atom while making the sound 'heahhhahahahaha'. It was interesting to see each participants personality be expressed in the way that they articulated their happy stim. P12 is much more reserved and precise, hence, the hand tapping stim. Where P2 was much more excitable and over the top with the expression of their emotions. The whole group mimicked P2's happy stim together and they also repeated my happy stim.

P12's happy stim was to jump up and down while clapping their hands quickly together quietly, their hands were held tightly to their chest as if in a position of prayer, and the clapping was small and controlled only moving their hands a few centimeters away from each, other before bringing them together to create a quiet clap. Their body was quite rigid or straight up and down. This was in one way controlled and contained (the tightly held hands and body and light hand clapping) and in another way an energetic expression of joy (the jumping up and down).

At this point, I could tell that our experiment was starting to become quite a meaningful moment in the workshops, the group was really actively engaging with this exercise and the idea of investigating and reveling in the happy stim. That moment was quite significant as the whole group broke out into a very energetic group stim for the first time, an amazing happy, clapping, jumping, dance together and it was beautiful to see. The emotional temperature seemed to go up in the room, you could feel the excitement and see the sheer joy on people's faces, we had discovered something together, happy stimming was fun, even more so with other autistic people, a group of autistic people, a community. It also seemed to be contagious like laughter, the more happy stims we discovered and shared, the more delighted the participants were, which encouraged more happy stimming. As P6 commented about the workshop, "*...the stim circle, which was really, really fun... Because we were doing happy stims and then everyone was just making happy stims which was just making me happier, which makes more [happy] stimming. And then that would kind of like, also went in a circle.* [So, people were sharing happy stims, but it was actually creating more happy energy. Is that what you're saying?] *Yeah!*" (P6).

I also remember seeing the joy on P12's face when they saw the whole group jump up and down with them, this was observable, the participants excitement was electrifying. For most participants, this was the first time that they were sharing their unique happy stims with a group of autistic people and also the first time many participants consciously took part in collective stimming.

The next participants happy stim was a stimming hug that P14 shared with the group. A stimmy hug incorporated rocking from side to side or swaying back and forth while in a hug with another autistic person. P11 and P14 demonstrated this for the group. P14 was very conscious that not everyone was ok with hugging or touching another person in general, so they also provided an alternative happy stim. Their alternative stim was a 'shaky leg' or bouncing their foot and leg up and down with the foot balance on the ball of the foot and the heel off the floor. I found this quite noteworthy as I had a misconception that a shaky leg was an expression of anxiety. However, P14 said that they do it when they are happy. This made me think back to the first workshop P14 attended (the first Stim workshop) and I noticed they were shaking their leg quite vigorously during the sessions and I was worried that they were anxious, I now know they were actually enjoying themselves and expressing this through their bodies in a 'shaky leg'.

Each movement would be repeated, one after another around the circle adding the new movement when someone would share it and we did it all along the circle so by the end we had this vocabulary of movement that we did a type of stimmy dancing choreography. It really felt like it was a vocabulary, a language, that we were speaking/sharing with each other. This was also a shared language.

While going clockwise around the circle, we came to one of the quieter members of the group, P5, someone that was not as verbal as some of the others in the group and seemed to have high levels of anxiety in relation to other people. We came to P5, and they were having trouble figuring out what their happy stim was. When I interviewed P5, they commented about their experience participating in the stim

circle, *“I don't like stimming around other people. So, it's kind of weird. to do that, I guess. Yeah. [that was the first time I stimmed around other people]. Yeah, it was nice. It's always really nice seeing other people happy. I mean, most of mine are anxiety-based ones... I knew, I know there's healthy ones... with the flapping everyone talks about that being a happy one”* (P5).

P5 didn't ask to be passed over and she just stood there with their hands in their pockets, and I suggested that perhaps that was their stim. P5 agreed with this and so the whole group placed their hands in their pockets and just stood there in silence for a moment. This was striking because it was in contrast to the other stims. There was silence and stillness in this gesture. Later in the session, we were doing some other movement exercises based on, *‘How do Neurotypicals walk?’* and P5 voiced to us that she was told by her parents and a teacher to take her hands out of her pockets because *“‘normal’ people don't stand with their hands in their pockets all the time, it wasn't normal”* (P5). I also found out later in the following session from P5 that they stimmed with small everyday objects in their pockets or stimmed with the fabric in their pockets, creating holes they had to repeatedly sew up, most of the time. So, in fact, having their hands in their pockets was liberating for them as they were stimming, they were just hidden stims. But it seems even these masked stims, within pockets, were still seen as ‘unacceptable behaviour’ to a neurotypical society.

IV. Exercise: Simple Stimming Dance Choreography

Participants were asked to create short choreography based on their stim from the Stim Circle. I asked participants to find a space in the room where they felt comfortable and to spend some time just stimming working with their stim from the

stim circle, or another stim, they do or put several stims together. Participants were asked to really explore their stim and see if they could discover varieties of their stims that could be performed as well. They are asked to think about how their stim could be like a dance, how stimming could be celebrated. Participants were asked to then carry out their stim, or a series of stim varieties, for one-minute intervals, each time changing some element such as time/speed/tempo, position/shape, adding sound, adding text, different sounds.

First, participants were asked to change the speed of the movements; first speeding up their movement for 30 seconds, then speeding it up more, participants were prompted to then slowing down their movement for 30 seconds and then really slow down their stim even further. Participants were then asked to change their position when doing their stim i.e. moving into another position or shape; laying down or standing up, moving in space, walking while stimming. I also asked participants to try to narrate their stimming - just tell people what they were doing or talk about what they are thinking while they are stimming for 1 minute.

The participants were asked to think about what sounds their stimming might make if they made a sound (this could be actual sound or a sound interpretation of their stim) and participants were asked to stim for 1 min while making these sounds.

Participants then were asked to pair up and perform their favourite version of their stim for one other person - I wanted to make sure that participants did not feel too vulnerable doing this. I then asked participants to get into groups of three or four to develop a small dance that incorporated all their stims together. Participants could

use any version of their stim, or a variety of versions of their stims, to create a choreographed stim dance together. I asked participants to think about how they would begin the dance and end the dance. To think about making sure they were incorporating different speeds, levels sound and stillness in their very short (1-2 minute) choreographies. Then each group performed their choreography for the group. This was a successful exercise, and I would like to develop this further in future workshops to think about creating stim choreography form this exercise.

Participants were very keen on creating these dances and showed some really interesting beginnings of stim movement choreography. Participants also asked to choose songs to go with some of their movements such as P1's Dad Dance which was recreated by their whole group in response to music playing. I feel, looking back now, that this part of the workshop was overlooked as the stim circle was such a realisation and the next exercise *Pretending to be Neurotypical* were more useful for participants to explore their autistic experience. I feel that this part of the workshop would need to be explored further and it made clear by exploring stimming participants are getting to know themselves better and celebrating a part of themselves is important to their own experience of being autistic, but also to the development of autistic culture. I feel stimming is like a lost language that needs to be learned by autistic people again, there needs to be detailed explorations into how autistic people stim and the experience of it as communication. Also, the expression of stimming is so unique to each individual person and this needs to be stressed, and each stim can be interpreted differently depending on autistic people's sensory experience.

V. Pretending to be Neurotypical Exercise

Please see a video documentation of this exercise at:

[REDACTED]

This was a practical movement-based exercise based on the question what do 'neurotypical people walk like?'. Participants were asked to try to think about the difference between an 'autistic walk' and a 'neurotypical walk'. This was in a response to a workshop I attended which asked people to try and walk like autistic people or, more specifically, to practice toe walking, heel walking and walking in shoes that were on the wrong foot. I thought it would be really interesting to turn that around on its head and to crip and queer this exercise by asking autistic people to walk like neurotypicals.

The participant's responded to this exercise well and this went way beyond a simple mimicking of a physical walk. Participants started to just pretend that they were neurotypical. This was not hard for participants as they masked or pretended to be neurotypical most of the time before their autistic discovery, however this time they were able to make fun of all the things neurotypicals do that they actually find annoying and weird.

19.6: Workshop 7 and 8 Object Description Workshops

IV. Object Description Workshops Background

Stemming from my practical performance research into articulating my own experience of being an autistic person (Adventurers of Super Autie Grrl performance 2017 and 2018), I constructed another SAG workshop using objects. I asked the

individuals to bring in three 'favourite' objects and to tell the story of that object and how it represented them as an autistic person.

Participants were asked to first write down some responses to several questions about their objects to make it easier when we did go around the group to tell a story about the object. This was a technique employed to make the activity more accessible, giving the participants time to think about the questions first and write/type responses to the question, that they could use when telling their story. As always, if participants did not want to write/type down anything that was perfectly fine. I was particularly interested in why they chose these specific objects to represent their experience of being autistic. If there was a story behind each object, as well as how the objects represent their experience specifically, is it practical, sensorial, intellectual, and/or metaphorical and why.

Participants all sat around a table and told their stories about each object one at a time. These stories were audio recorded in hope they could be used as material for future performance work. These workshops were designed for an autistic culture and neurotypical workshop methods were not always helpful or affective. Rules such as only one speaker at time was helpful to allow everyone in the group a voice, but this was also very flexible in presentation and many times the story telling broke into conversations. Most of the time, the conversations were about how they related to each other's stories, the commonalities of their autistic experiences. I felt it was important for this kind of dialog to happen, for participants to relate to and validate each other by acknowledging similar experiences. When the topic drifted away from this, I facilitated the group back to the speaker and the topic at hand.

The first thing I observed was that most of the objects related to exploring the senses in some way. There was a representation of all senses when participants were referring to why these objects symbolise their experience. Touch, sight, smell were the most referred to, however taste and hearing were also elements of participants experience of their objects.

The object descriptions were very rich with materials describing participants everyday lives and experiences and how these objects were symbols representing their autisticness or difference. Some participants found it hard to know what is attributed to being autistic and what was just them. As P5 state, *“I couldn't figure out how I could separate it from like, who I am. Because I only found out about it a couple months ago and I didn't discover it. I was told. Yeah, so I'm not really sure what is that and what part, what's just me. So, I just brought some stuff that was just important to me”* (P5). Excerpts from transcripts of the object descriptions and group discussion around these descriptions by workshop participants are in Table 10 below.

The first theme observed was that most of the objects related to exploring the senses in some way. There was a representation of all senses when participants were referring to why these objects symbolise their experience. Touch, sight, smell were the most referred to however taste and hearing were also elements of participants experience of their object

Table 10 Object Description Information

Object	Sensory Modality						Proprioc eptor (body in space)	emotio ns	Notes
	Sight	Sound	Touch	Smell	Taste				
Objects referring to the senses and emotions									
yellow purse (P7)	Y	N	N	N	N	N	Happy, calm	<i>'... I found that yellow actually kind of made my mood higher... when I was little...I would refuse to leave the house unless I was wearing an item of yellow.'</i> (P7)	
USB stick (P2)	N	Y	Y	N	N	N	calm	<i>'...And the thing with this USB stick I really like to just go click, clack click, clack. Yeah. It's almost always a masking thing when we were talking about my USB stick.'</i> (P2)	
Objects where Participants commented on sensory seeking but also sensory avoiding others they found overwhelming or disgust towards.									
Body Butter (P8)	N	N	Y	Y	N	N	calm	<i>'So, it's like green tea and it's really nice. I just like the feel of the actual you know, soothing and just nice to put on...I've always been kind of like very sensitive to smells, say like, if someone's wearing perfume, like too much in the street, it will cause me to like, kind of, stall and pause, I and like kind of - not really recalibrate - but like get my gatherings together. And that was always like a big thing, I mean, it's always sensory issues with me.'</i> (P8)	
P1 headscarf	N	N	Y	N	N	Y	calm	<i>'I liked the feeling of being wrapped the only problem is...it gave me a lot of headaches, but I did like the feel of being wrapped up in something. and also, I just like the swish when you go like this (swishes fabric over and over as a stim), it's like swish, scarfs are swishy.'</i> And they refer to themselves as a 'Fabric molester' (P1)	

								when they visited certain shops: <i>'...especially clothing stores, Primark has so many soft things. The softness goes really quickly when you buy it ... but in the store... it's like perfectly.... its heaven... soft' (P1)...</i>
Plush Toy Octopus (P7)	Y	N	Y	N	N	N	calm	<i>'I like it ...because it's really soft.. But yeah, it's like, it's quite soothing. Like, I just sort of got it to relax me in my room. Like you can spin this octopus.'</i> P7 calls him, <i>'Stropopus because he's very stroppy and he is reversable to having a smile on one face and a frown on the other.'</i> (Participant commenting on their sensitivity to touch in relation to other fabrics they don't like) <i>'...I've learned from my mistakes because I bought stuff that the material triggers me so much I've actually thrown it at full force back at the bag. Like, no get away from me.'</i> P7 also refer to themselves as a <i>'Fabric messer'</i> in relation to P1 story about their object. (P7)
Fabric or clothing Object's participants used as soothing/ calming sensory symbols of other people in their life or their past.								
My grandma's cardigan (P4)	N	N	Y	Y	N	N	Comforting/calm	<i>'....it smelled a lot like my grandma. And it's not very heavy, but it's a really comforting thing to just, like, hold, like just to put near your face... it's just something really comforting knowing that it's my grandmother's.'</i>
Mothers scarf (P1)	N	N	Y	Y	N	N	Comforting/ calm	<i>'it used to smell a lot like my mother. I can't really explain what the smell was but it's like a really nice, warm, comforting smell that made me really want to hug her all the time.'</i>
Jacket from when they were a Teenager (P1)	N	N	Y	N	N	Y	Comforting/calm	<i>P1 talks about a jacket they loved and wore as a teenager, <i>'...I have clothes I am never going to wear, and I just have them but I don't know what to do with them. It's a sensory thing and a fabric thing. A hoarding thing and a swishy thing.'</i></i>

Assistive Sensory Tools participants used to stim and as preventative of overwhelm or to replace a stim that annoyed others around them.								
Noise Canceling headphones (P11)	N	Y	N	N	N	N	calming	P11 experiences temporary mutism often so they asked P1 to read their response. <i>"The headphones are the best assistive items that Gab has and it helps them survive and is both practical and sensational (Sensorial-Gab corrected them) - as in, to do with the senses"</i> .
Fidget cube (P8)	Y	Y	Y	N	N	N	comforting	<i>"...it's ocean patterned because I love the ocean. It's always quite comforting and stuff... I just like, just clicking it and everything and rolling the rolling part around, because I always used to break off the backs of like remotes and stuff. And it used to frustrate my dad because, you know, just like clicking as I'm watching TV or whatever, it's always nice, I still do it now"</i> .
Rubber Tangle (P11)	N	N	Y	N	N	Y	calming	<i>"(this) item is the tangle, a rubber one that is better than the plastic one because you can bite it"</i> . P11 objects is involving, touch and smell, and biting stim. They also use it as a stim toy moving it around with their hands which helps them self-regulate their sensorial experiences and mood.
Hourglass timer (P7)	Y	N	N	N	N	N	calming	<i>"...one of my main issues was the picture was too big like with like work and stuff and I've never know where to start. And I just get overwhelmed and stuff...I like watching it (the sand) like go like trickling"</i> .
Keys (P2)	N	Y	Y	N	N	N	calming	<i>"These are the keys to my university accommodation like putting in a pocket and just stimming inside it... (it is) a safety mechanism to make sure I have not lost my keys..."</i>

Objects that represented participants passions or fascinations (i.e. sometimes referred to as 'Special interests')								
Plush toy Donkey (P5)	Y	N	Y	N	N	N		P5 had several plush toys that were very important to them and represented their passion and fascination with donkeys and sharks... (P5 had a plush toy Donkey named) Corduroy, <i>"I took him literally everywhere. Like in every picture of me as a kid, he's just there...He is really important to me."</i>
Plush toy Shark (P5)	Y	N	Y	N	N	N		P5 also had a plush SawFish and P5 talks about their fascination with Sharks, <i>"I just, I just, love them. There's so many of them and they're just they're really interesting...Yeah, I used to have this big...shark Almanac and it's just every shark that's been discovered so far. And it's just fantastic... I was just thinking about sharks. and like how shark's kind of have a bad name but actually they're quite lovely creatures"</i> .
Phrase book of languages (P6)	N	Y	N	N	N	N	excit eme nt	<i>"I am Interested in basically, languages so I thought that as really fitting it's like a long term passion of mine, It's the reason I'm studying here because I love languages..."</i>
Sketchbook (P6)	Y	N	Y	N	N		calm	<i>"Because that's also a long-time passion of mine, helped me through some um dark times in middle school and just started drawing". P5 describes why drawing is important to them as a coping mechanism or meditation, "And [it] really helps me to just calm down sometimes because if there's one thing I can completely focus on, and everything else ceases to exist, and then the only struggles are like, Oh, no, that one eye isn't completely symmetric..."</i> .P6 explains why touch affect why they only draw on one corner or a page <i>"I'm left handed so I can't use the ring book the normal way around"</i> .
Skateboard (P11)	Y	N	N	N	N	Y	happ y	P11 representing their new fascination or special interest. <i>"It's their first special interest since diagnosis, its super fun, they</i>

								<i>bought it themselves and it's probably going to take over their live a bit".</i>
Many of these objects have are very significant to the participants, these objects went everywhere with several participants as children, and some continue to do this as adults. Participants also in some cases anthropomorphised or personified these objects.								
Push toy Dog 'Honey' (P6)								P6 still takes their stuffed dog on holiday with them and sleeps with it. P6 only takes him away if it's not 'dangerous' to do so as, <i>"I don't want to, Honey to get lost. and we also moved around in the country a lot. So, we spent nights in different places and I was like, he can't get los".</i> It represents their love of Roman history and is named after a famous historical figure <i>Hanniba l Baraq</i> . P6 saved the first 'Honey by Barca' plush dog in a <i>"glass box. So, it could still survive, and we didn't have to throw it away"</i> .
Blanket with satin trim (P9)	N	N	Y	Y	N	N	calm	<i>"This bit of satin that I had, originally it was like a whole blanket and I loved it so much that I wore it out".</i> P1 liked the 'cold satin' lining of the blanket. participant wrapped the remaining satin strip of their beloved blanket <i>"to keep it safe"</i> . P6 also had empathy for their blanket when it was thrown away. <i>"and my granny cut off most of it and just let me have the side satin bit which actually devastated me, and I was only like four. And It devastated me because I imaged this big other bit of blanket waiting at the dump to be rescued because I had personified it and um anthropomorphised"</i> (P9).
Plush toy Donkey 'Corduroy' (P5)	N	N						P5 had several plush toys that were very important to them and represented their passion and fascination with donkeys and sharks. (P5 had a plush toy Donkey named) Corduroy, <i>"I took him literally everywhere. Like in every picture of me as a kid, he's just there...He is really important to me"</i> . P5 made an observation about Corduroy the donkey that he was misunderstood or mistakenly labelled a rabbit, <i>"the people who had had corduroy before me thought he was a rabbit because they've done the ears, like, drawing on paws with marker. and like a crisscross nose. So I guess they thought he was a rabbit but he has a tail, is like...this seems like he is clearly a donkey"</i> .

								and their plush toy was recreated by parents, <i>"I missed him so much that my mom just took him apart and got like a pattern and made him out of some material"</i> (P5) as they were loved so much. One participant actually went to the store where their beloved 'Cordouroy' was made.
Plush Toy Octopus (P7)	Y	N	Y	N	N	N	Y	P7 likes the colours of the octopus, <i>"because the grey and the black was more my aesthetic"</i> , which is very important to them. <i>"I like it ...because it's really soft.. But yeah, it's like, it's quite soothing. Like, I just sort of got it to relax me in my room. Like you can spin this octopus"</i> . P7 calls him, <i>"Stropopus because he's very stropy"</i> and he is reversable to having a smile on one face and a frown on the other.
Objects and foods and taste								
Milk Jug (P2) /Gravy								<i>"I bought it in Marks and Spencer's and originally the label said milk jug and I used it as a gravy jug instead and then to say that well I just don't care about labels sometimes"</i> . When P2 motioned drinking gravy out of a milk jug after saying, <i>"it is a jug and I bought it in Marks and Spencer's but I actually use it for gravy"</i> . P2 elaborated, <i>"...the first time I had a traditional British roast dinner...I actually licked the plate inside the room... usually when I have had dinner, I just go back to my room, my bedroom and I have dinner there and I just lick the plate and I just chug on that"</i> . Several participants admitted to doing similar things such as 'plate licking,' 'licking your fingers' P8 stated, <i>"I think this is a room full of plate lickers"</i> .
Ice cream and ?/ plate licking (P9)	Y	N	N	N	Y	N	calm	P9 reference to having to eat the same two foods and a plate licking action they carried out every day after school, <i>"I did used to do the plate licking thing when I was younger where I had to have two of them, the same food when I would come home from school but I would have to lick the plate in a proper pattern then you do like asterisks. Then you get the little bits that were left and it had to be in the same way..."</i>
Note Objects represent autistic imagination								

Plush toy Rabbit (P5)							<p>One participant felt that their childhood plush toy a rabbit, <i>“It’s something I always used to carry around with me when I was younger along with a childhood blanket. It kind of represents my imagination because I always use to imagine, it’s called Tiki, and I used to, I imagine playing with it in like Tiki Land... it’s a nice weight and kind of material... I used to swing it around by the ears and everything just... Yeah, that’s why one of its ears is actually stitched up because I was on the trampoline and swung it into the neighbor’s garden”</i> (P5)</p>
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19.7 Fantasy Safe Space Workshop

The fantasy safe space workshop took place June 5th, 2017. Seven participants took part in the two-hour workshop. It was developed as a creative and active way for participants to explore what was their own personal safe space (see Figure 66). This workshop included several activities. It took the same structure as the other workshops starting with a chillout silent time at the beginning of the workshop with the lights down.

Contributors were asked to design their safe space based on several questions. I asked participants to walk around the room and find some where they felt comfortable. Workshop members were asked to make sure they had their sense diary or something to write on and a pen or something to type their answers.

Participants were asked to make themselves comfortable they could sit or lie down however they needed to (chairs were available if needed) and to close their eyes (if they felt comfortable doing so). Participants were asked to try to remember a time where they felt completely calm or safe, or to imagine a place where they could be happy and safe. What does your safe space look like? Is it in or outdoors?

The first activity was participants responses to a question I asked participants to think about last week and on the Facebook group. The question asked was, *'If you could say anything to a neurotypical audience about your experience (as an autistic person) what would it be and why?'* two participants responded online to this question:

"Dear NTs: I've realised lots of things I do you don't, and that this is ok. I have abilities you don't and lack abilities you do. I've realised my very visual memory

*means I see and remember more than you: when I need to remember an idea, I close my eyes and see the piece of paper where it was written; I know where every little thing is - it's all up here *points to head*. the downside is I remember ALOT. I remember when you were mean to me, what you said ('odd', 'standoffish', 'unapproachable', 'cold'), how you looked at me (though not your eyes: that level of being seen and seeing is painful). You make me lonely in crowded, social places -*

[REDACTED]

Figure 66: Participants sitting in their Fantasy Safe Spaces created with electrical tape, Fantasy Safe Space Workshop 2018

you ignore and exclude me. But I want you to know it's ok now, I found my group of weird, I like who I am. I lie by accident with mimicking to be like you, but I am starting to tell my truth: and I like me. I don't lie; I see things in such detail you can't imagine; I love and fight for others - including you. I am not less, I am more: I am autistic sapien - self wise" (P9).

This message points to many of the things explored during the workshops as this participant realised that their experience of *'very visual memory'* is different to others and has made them realise the significance and downside of this experience. To be able to be a part of an autistic community is so important for this group of AWCTN+ people as they are allowed to, 'tell the truth' about themselves instead of, *'lie[in] by accident with mimicking to be like you'* or masking their true nature subconsciously to fit into a dominant neurotypical culture.

Another participant, P15, responds to this question on the Facebook group,

"What I want neurotypicals to know: autistic people have needs and value, both of these might just differ to yours. I am generally engaged in the activity or conversation. Please don't make me smile, nod, respond or look at you to prove this. Stimming feels good!! It soothes, distracts, focuses, stimulates, expresses feelings, etc. And can be great communication if you learn an individual's language. And there are SO many forms of communication!!" (P15).

This participant came to the group at the beginning of their discovery that they were autistic. They spoke to me about the positive affect the workshops have had on their daily life, especially the stimming workshop as this participant reported that they began to stim for pleasure and in public for the first time due to the workshops. You can see this in their acknowledgement that, *"stimming feels good!"* (P15), and that it has many different purposes for autistic people.

Some of the other responses from the workshop include,

P2: *"Please stop using so many bright lights"*

P4: *"Say what you mean, rather than what you think you want to mean"*

P15 added, *"All of the neurotypicals and us have individual needs, individual ways of doing things and just because ours are slightly different, it doesn't mean that they should be viewed in a different way. They are just our needs, just like your needs are your needs... Yes I am perfectly normal, I am very normal and very autistic!!"* (P15).

I felt these were insightful and really represented a very real need for autistic people to feel they have value and are equal to neurotypical people. I think it points to the need for the recognition of autistic culture and communication styles. I am also interested in the idea that there is 'an autistic normal' this has been talked about since the beginning of the workshops and though the group recognises there are many similarities and differences in all the participants experiences there is also a recognition of a way of being that is intrinsically autistic and when this is recognised by participants of themselves and others within an autistic space it is celebrated as a part of autistic culture. This includes the recognition, 'that stimming feels good'. And it has various functions for an autistic person including communication. Also, that autistic people have different communication styles and that means they will not always have eye contact or look like they are engaged but this does not mean that they are not paying attention. This group of late diagnosed AWCTN+ people feel, 'they have found their group of weird', many time for the first time and, participants feel, *'I like who I am'*. Participants acknowledge their struggle but also have hope

and feel that it is okay to be autistic, *“I lie by accident with mimicking to be like you, but I am starting to tell my truth: and I like me”* (Participant).

The next part of the workshop was quite practical and was inspired by *Adventures of Super Autie Grrl* and the techniques I used to illustrate alternative autistic spaces such as the drawing of my autistic, dyslexic, dyspraxic brain in particular the reticular formation; the part of the brain that controls the sensory input and defines my experience of the world on the floor with electrical tape (see Figure 67). I wanted participants to create their own autistic spaces if only with electrical tape to imagine what their autistic space might be like.



Figure 67: Projection of the reticular formation diagram and a recreation of this in applique. *Adventures of Super Autie Grrl* (2017) *Also note drawing of reticular formation with electrical tape on the ground.

I wanted participants to do something practical that allowed participants to explore their experiences of being autistic in a more embodied way, by asking workshop members to physically create their own fantasy safe space and inhabit it (see Figure 69). I asked participants to think about their fantasy safe space, this could be anything - they were not limited by reality. Participants were asked to get their notepads out and write down the answer. Workshop members were asked to describe what this place smelled like, what did it sound like, were there any sounds? How did you control the sound in the space? What type of objects are in the space, including furniture, stim toys etc.? What are the textures of these objects? What was the lighting like? If there are objects, how are they organised in the space or what was visually in this space? Once again, I asked participants to write down the answers to these questions. Making sure to ask one question at a time and giving participants plenty of time to respond in their sense diaries or on their phones.

The next part of the exercise was for participants to create a rendition of this space with electrical tape on the floor, this was a chance for participants to think about this activity in a different way spatially and creatively. I reassured participants that this could be very simple, and I wasn't expecting Mona Lisa's, just a rendition of the space they were thinking of so that they could inhabit the space. It needed to be big enough for them to fit into and a way for them to describe their space to the group.

Participants seemed to catch on to this exercise quickly and they created their spaces in the room out of electrical tape. P1 talks about their experience of the safe space workshop and the safe spaces that stuck out for them,

“You create a picture it’s for your safe space and I made my bed, I love beds. So, everyone got coloured electrical tape and you had to go somewhere in the room and made a representation of your safe space. I made a bed I think someone else made a bed and a couch. P16 made like a small enclave that was supposed to be full of stuff which is cool... very particular stuff. P15 did either a camper van or a hammock or maybe both, (so they could bring the forest with them), with a hammock inside of it, that is really good”.



Figure 68: Participant Fantasy Safe Space made with electrical tape, Fantasy Safe Space Workshop, 2018

I asked P1 to describe what it was about their bed they liked- in relation to their safe space:

“It’s soft and warm. Yes, sensations are very important and obviously... sometimes it sucks if they... they [landlord] have given me a spring mattress

and I hate it, but I am too anxious to go over there and say, 'hello this hurts me a lot'". P1 is very sensitive to textures and sensations including the sensation of a spring mattress which "hurts [them] a lot" (P1) (Figure 69).

P1 was asked, 'what is important about having a safe space for an autistic person?'

"You have the control of it, and it can't be entered by someone especially without permission. So, before I had my bed, I retreated to, I needed to use a blanket because the room wasn't my own and also, anyone could come in if they wanted to? [Family home]. Sometimes I needed to go somewhere so I could cocoon myself away from the world and a bed was good for that, especially when my clothes were messing me up [sensitivity to fabrics- touch etc.]. I could take them all off and go in a blanket and still be warm and I can pull it as far up on my head as I wanted to, but I have to pull it back down because I want to breath. and ... its dark and soft and like quiet and that makes it all about... I mean yeah it's all a big cocoon from the senses ..." (P1)

This is interesting as this is an example of the need for many autistic people to have a space that can be completely controlled in terms of the senses, usually to recover from autistic sensory overwhelm and/or burnout from masking. "[S]omewhere so I could cocoon myself away from the world" (P1), and in many instances the only place this can happen is a personal bed/ bedroom. However, P1 shared a room as a child, and even as a young adult, so a blanket was their only safe space as,"...anyone could come in if they wanted to [in their room]" (P1).

This seems to suggest a need for autistic people to identify their sensory needs in a safe space and how this needs to be available whenever needed to help autistic people shelter themselves from the senses regularly to combat against autistic overwhelm and shut down.

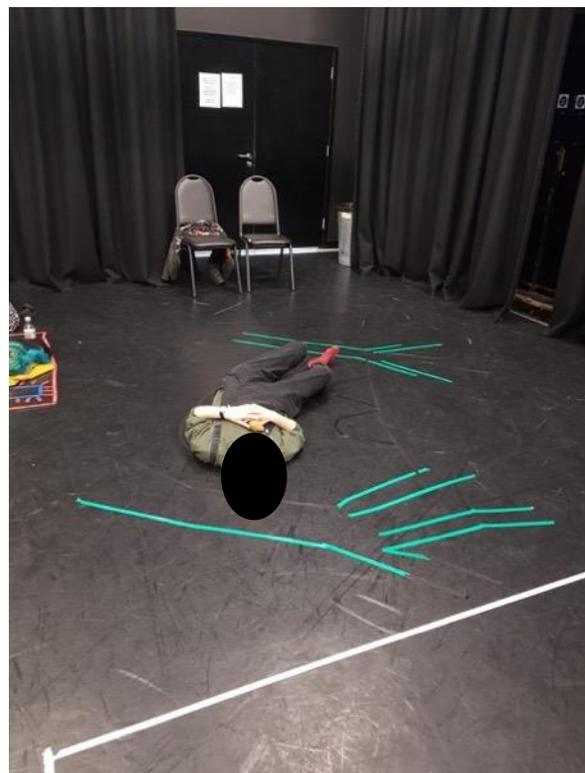


Figure 69: Participant inside of their Mobile Forest Fantasy safe space made with electrical tape, Fantasy Safe Space Workshop, 2018

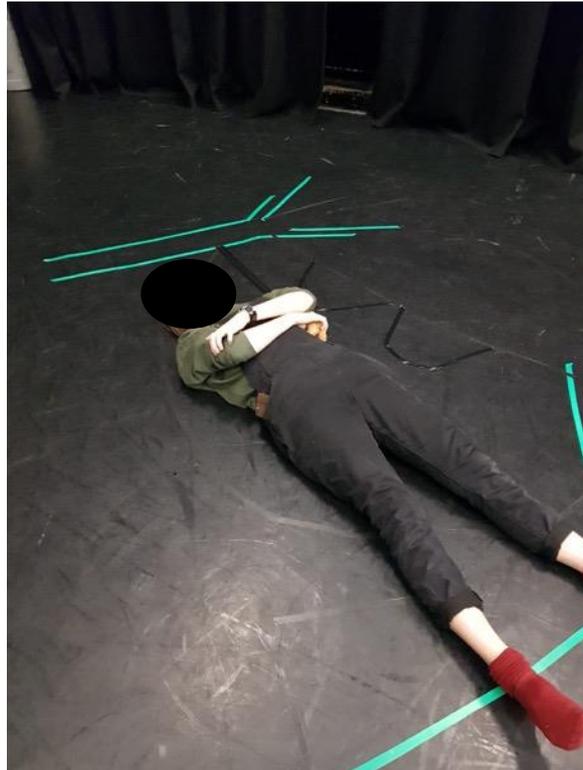


Figure 70: participant inside of their mobile forest Fantasy safe space made with electrical tape, Fantasy Safe Space Workshop, 2018

Another participant's (P15) fantasy safe space was mentioned in the interviews several times, by different participants. (P4) states. "...just in a forest. Like just completely surrounded by forest and it has some like [forest] noises. Yeah, that they really liked". P15's favourite place to be was the forest, they felt at home there and felt truly themselves in natural places. Their fantasy safe space was a forest inside of a camper van. The camper van was supposed to be a bit like the wardrobe in, *The Lion, the Witch and the Wardrobe*, so as soon as you open the doors to the camper van and walked inside you were emersed by a forest, this included all the senses, the smells, sounds and feel of a forest. P15 also wanted a hammock in the forest for them to relax and rest in. P15 wanted it in a camper van so that they could drive it anywhere they like and always had a forest to retreat to when they needed a safe space to rest and recover in (see Figures 70 and 71).

P4 also comments on their fantasy safe space and the need for it to be a haven from the sensory world including the room being 'soundproof,' having their 'own cats' a 'scenic view,' 'a really big bed' and their own reading material.

"I mean, I quite, I quite like the fantasy space one because I had like my own cats. And I had like that, overview. I can't remember, either the sea or a like forest [A view over the sea or the forest]. Either way, I really like that one. I quite like the creative ones....my space. Yeah, it was like soundproof. I had a really nice view to, I can't remember, it was like some sort of scenic view and it had a really big bed. And like, a stack of books by my bed. And my phone. Yes. I read on my phone. Yeah. And a cat" (P4)

P4 comments on the differences in the participants ideas of safe spaces,

"I have to said that I was in a great fan of (the forest fantasy safe space) like, don't get me wrong. I would love to go and walk in the forest, but I wouldn't want to live there. I've been on a few camping trips, and a few times I have been there. I've been stressed out about dirt. So maybe not the best situation for me... It was like, it's just really interesting to know what other people consider a safe space. And you know, how different they are and how they all work?" (P2)

[REDACTED]

Figure 71: Participant inside their Double Boundary safe space

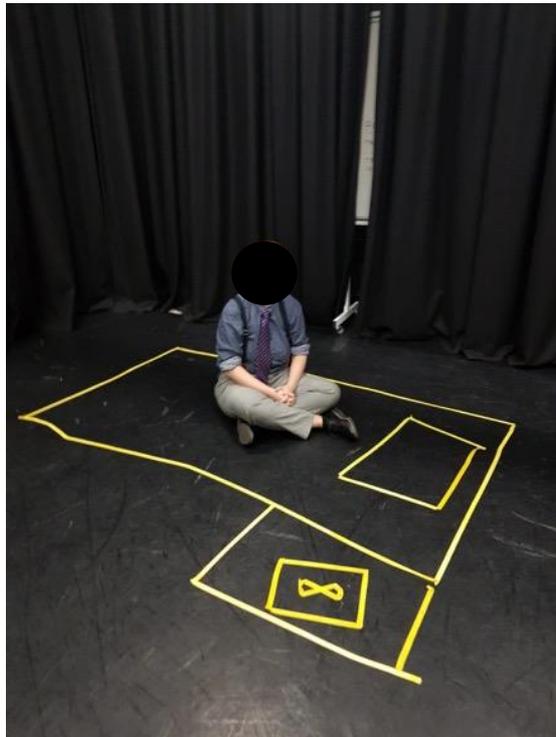


Figure 72: Participant in their Fantasy Safe Space

The other participants space that was commented on was P16's fantasy safe space.

P6 reports,

“Yeah, I really like the one with the two lines [P18’s fantasy safe space]. I don’t know who did that. But that design stayed in my, my mind more than my own... the safe space and the space around it still had like another line and one of them, people could still cross with permission, and the other one Absolutely not! [See Figure 72] Yeah. And I really liked the representation because I didn’t think about that. I was thinking like literally just like, like my bed. or something similar to my bed? [See Figure 73] But just this representation was really cool and that stayed in my mind more than my own”

(P6)

This double boundary system was created by a new member to the workshops who was just exploring the possibility of being autistic with my colleague and I during our pilot version of So You’re Autistic. I invited P18 to the workshop so they could speak to other AWCTN+ people and here their stories. P18 devised a double boundary system that P6 explains above, the outer boundary created in green tape as you see above represents a boundary that people can cross with permission, the inner line, created in yellow electrical tape represents a boundary that should ‘absolutely not’ be crossed. This suggests that some AWCTN+ people need a larger personal space area. Many autistic people speak about being more sensitive to touch as P1 states being sensitive to bed springs and their own clothes ‘messing me up’. I might suggest that these boundaries go beyond touch based on this fantasy safe space depiction of boundaries outside of an autistic person’s physical body and my own experience just sensing people that are too close to you can feel unbearably uncomfortable. I might be that AWCTN+ people need to be in control of their sensory

safe space as they feel that this might be the only place that they can be themselves and not mask their experience of the world.

The Fantasy Safe space workshop allowed participant to identify their personal safe space in relation to the sensorial world and stressed the importance of control of personal and physical boundaries for AWNBT+ people.

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Appendix 20: Notes of the Focus Group on SAG Performance

20.1: Focus Group

A focus group was carried out with the SAG co-performers on May 15, 2019 after the premiere performance of Super Autie Gang at the Autism Arts Festival, Canterbury April 28, 2019. I transcribed and coded this focus group and two follow up questions that I asked on Facebook messenger using the same methods as the interviews. I came up with several themes during the analysis that are closely linked to the workshops themes but gives a better understanding of the impact on the co-performers that took part in the rehearsals and performance of Adventures of Super Autie Gang.

Workshop co-performers were given space within the rehearsals and the performance for a live and online audience allowed co-performers as AWCTN+ people to articulate their experience as co-performers.

Acquiring tools

Co-performers felt that they acquired tools to change their world view to feel more autonomous and have pride in being autistic. These tools were:

- 1.) Validation of their lived experiences
- 2.) To give voicing to their experiences in a safe autistic space where they could be their authentic autistic selves.
- 3.) Connection and community with other autistic people
- 4.) A sense of pride in being autistic and autonomy and the ability to create the tools needed for self-acceptance with a group of other autistic people.

Validating their Experience: Accepting the Authentic Autistic Self

P17 felt the performance, especially the letter to Simon Baron Cohen, 'framed your experience' and helped to validate the co-performers experience. P17 stated, *"... [It] then allowed other people to say, that's exactly what happened to me. So, you gave the words and the space to people like the ideas and the concepts...where people might not have fully understood what happened to them. So especially the bit when you're reading the letter, and people [co-performers] are saying, 'and me and me and me'. It kind of makes as a, as a performer, or someone who was part of it, makes you feel as if you're not only given a space to express but, also giving us the words. Okay, because my experience of being autistic is, it's really hard to explain what's difficult... And it's much easier when, like you did, you said, it's not actually like, all of these people are saying, it feels like this...that's why it's so hard, because everyone else is telling me it's like this and it's not at all its like Annette said"* (P17).

Co-performers felt accepted for who they were and genuinely valued for their ideas and experiences during the rehearsal process. Which validated their experiences and allowed them to take part fully in the process. *"I like being part of something important. But like, it's not, it was not so like constructed in a way that you're going to like mess it up. Because there's no way to mess it up. Because it's just like, whatever you do is right... But normally when you're in, like, you know, in your class, and they're like, 'oh, no answers the wrong answer'. But you put your hand up, they are like, 'huh, yeah. Anyone else?' So, you know you had the wrong answer, but they don't [want to] be negative. Where as you like, project genuine [positivity], like, 'no, that is good'. And like you, you're not looking for like the next person to give like the right answer"* (P16).

Co-performers also felt validation from the audience of *Adventures of Super Autie Gang* (2019) and helped them be more accepting of their authentic autistic self. *“And also, what's more satisfying, like the performance, the fact that it's all like us being weird, and usually you can't [do that], and because it's so natural, and like people enjoyed it. It's better than them enjoying if we have like, deliberately try to make it good [neurotypical]. Yeah. I mean, obviously, we tried to make it good because I get. We just tried to, we made it us and it was so much more satisfying that people liked it, as us. Yeah, especially, when you usually have to suppress all of that”* (P16).

P16 comments on their decision to share the recording of the performance with their family and their reactions, *“So that was my part, because I felt so vulnerable being so weird, especially in front of an audience. Yeah, no, that's what the weirdest version of me [is]. I didn't know whether to tell people that it was there [online] or not. So, then I'd like just told my sister and she watched it and actually, in fact, she said it was very good. And then as I told my mum and my dad, and then they watched it and they really liked it. Oh, my mum's such a perfectionist. Like that's where I got it from as a kid. Like, we wouldn't do any. I wouldn't do anything for fear of it being wrong because my mum is such a perfectionist... But if you just let it go, and what that, all that performance is like, the ultimate, like, learn not to care, and it was still like perceived like really, ridiculously well, so it was really rewarding”* (P16).

P16 stopped caring about being ‘weird’ by the end of the rehearsals. *“I mean, the first rehearsal I kind of thought we were weird bad, not weird bad, but weird, I don't*

know what I mean. Like weird. Like uncomfortable. Then by the end it was [this is] weird, [but] I don't give a shit, it's fun” (P16).

P16 comments on the having the confidence to ‘*unleash their weird*’ after the rehearsals. *“Oh yes rehearsals and we have been hanging out. And then we get into this state where we're weird as in not weird, but we can fully be ourselves. And then you leave rehearsals, and you forget that our bubble has been broken and that you're going into the real world with people, and they are neurotypical, and then you like, unleash the weird on everyone and you have a good time being yourself” (P16).*

Autistic Space

Co-performers were given an autistic space to be able to voice their experiences and be their authentic autistic selves. Co-performer P17 explains this, *“It was like you'd already made, there was already that structure [of autistic space]... it was, this is how you [participants/co-performers] are allowed to behave [autistically]. Yeah, your understanding of each other [in SAG workshops, rehearsal and during the performance]... The fact that... your fundamental rules that run through that, in the fact that you're respectful of everyone [in SAG workshops, rehearsal and during the performance]. And I think that's what, what comes out. Obviously, your script is really helpful because you translate that into words but I think there is non-verbal [that these rules are communicated nonverbally]. There's a proper connection. We're a proper gang. We are proper group, great. And there's lots of people who were part of that group as well” (P17).*

The co-performers felt for the performance, *'to make sense in an Autistic way'* (P9) it needed to be Authentic *'that was all very genuine.'* and *'...actually everything that was in that (performance) was real'* (P9) and *'it's real'* (P16).

'But actually, that was all very genuine. Like I [genuinely] would be quite happy to just do a PowerPoint [speaking about PowerPoint performance] in the middle of anything. It doesn't matter if it's a performance or something like that... So actually, none of the show was a skit. And I think for some people who don't understand that neurodivergent aesthetic, then they're going to look at it and not see that that's actually how our brains work. That's actually how we imagined stuff. That's actually how we view the world' (P9).

P16 talks about the performance and how the co-performers were authentically autistic, *"Even like [P17] sitting knitting on the side, it seems like you were trying to be like, deliberately very autistic, like just sitting there maybe not caring, but you didn't really do that. Seems like, it seems like you're doing like an over-the-top projection of somebody that is autistic but like, no, that's literally just you..."* (P16 speaking about the Toe Walking monologue) *Yeah, yeah. I actually do check the corridor for people before I toe walk in the corridor and stuff. And I do treat myself to like, if there's no one around, you get a better toe walk than like if there's somebody else around. It's all real"* (P16).

Connection and Community with Other Autistic People

Co-performers felt connected to each other and the autistic audience, “we've got a voice. And we've ended up connecting in the people around us” (P9). P17 stated, “...you made a community...that's what you gave the space to? And even people who weren't part of the performance, like [person 1], could relate to it so closely. So that's like there is our little inner circle. Yeah, the gang that we made. Yeah. And we were proper gang. Yes. A proper gang, everyone in the audience could see that. And some of the people like [anonymous audience member], in the audience, or people that knew us, individually were able to come into that space...But then there were wider people [audience in person and online] that could come in as well. And then they were some people like right on the edge that were thinking? I don't really know. but I would like too” (P17).

Autistic Pride, Self-Acceptance and Autonomy

Co-performers developed a sense of pride in being autistic and autonomy and the ability to create the tools needed for self-acceptance with a group of other autistic people. P16 states, “But then seeing everyone's reactions was like a whole other different kind of enjoyment. That I didn't even know I wanted / needed, it was kind of like, oh, we have to perform it, because that's the reason we're doing it. But like, I enjoy being part of the gang and I was just doing that [performing on stage], because I have to [to be part of the rehearsals], but then like afterwards, especially like after it had been streamed, and you could see everyone's comments and stuff and then it's like, oh, it's really making a difference to people, and then it was like, pride in a different way” (P16).

Autonomy

When reflecting on the impact of the performance, co-performers felt they had the ability to create tools needed to be autonomous by reclaiming hashtags (#treatyourautism) and take back the treatment of autism –with autistic treatment wheel part of the performance and incorporating practical strategies they created in the rehearsal process. Co-performers comments on the reason for the treatment wheel analogy. *“But that is the point...”* (P17), *“We are taking it [treatment of autistic people] back, yeah”* (P9). P17 stated, *“Because it’s [the treat] something special... It’s really exciting. Instead of like, Oh, my God. Yeah. You’re doing the treatment. You’re deciding. You’re in charge. Not someone else coming along, going ‘that is a problem, that’s what we are going to do to it’ [treat you]... Yeah. So, this is you saying, ‘it’s not a problem. But it means well I am allowed to do this!’”* (P17).

Labels/ Role Reversal/ Empowerment

P16 comments on the role reversal of their experience performing in the Preshow of *Adventures of Super Autie Gang* (2019) inside the *Synaesthesia Diagnosis Machine* *“It was hilarious. It was fun. Because, like, they were looking to me for answers. So, like, it’s like, the opposite way around, isn’t it? Rather that they were like, they were looking to me for answers, because they wanted to know why they had the sheets and stuff. Like they were confused and not feeling fitting in. And I was like, I’m the one in charge here. And I’m telling you [that you] don’t fit in and I’m giving you this weird thing and I’m in control of the situation. So, screw you, whereas usually it’s like the other way around... Isn’t that funny, is that, is part of it being empowering, is that*

like, we, they're almost ashamed to be neurotypical. Which is like, I like the role reversal" (P16).

P9 explains the point of this Preshow in relationship to the experience of autistic diagnosis, *"but that's the point. It happens to us [being labelled negatively] all the time. Yeah. And we're trying to flip it on its head and things. And I just Yeah, I thought that was important and quite funny to do that. But I think it's more funny because we really don't explain anything, until hopefully, they're paying attention to the bit where it's actually with the you discussing synaesthesia on stage. And that's what I like about it. Because how many autistic children are given that label and they really don't really have, have any idea what it means, and they just have to accept it. And they have no idea what that means. They're not introduced to the community. They're not introduced to other decent autistic role models who can be like this is what it is. And this is what you can share with other people" (P9).*

20.2: Notes on advice from the co-performers for future practice: What made SAG successful in terms of practice and working with autistic people?

Accept and validate the co-performers ideas and experiences.

- Co-performers felt that whatever they did was right, they couldn't 'mess it up' they felt accepted for who they were and genuinely valued for their ideas and experiences. *"I like being part of something important. But like, it's not, it was not so like constructed in a way that you're going to like mess it up. Because there's no way to mess it up. Because it's just like, whatever you do is right..."*

But normally when you're in, like, you know, in your class, and they're [teacher] like, 'oh, no answers the wrong answer'. But you put your hand up, [and] they are like, "huh, yeah. Anyone else?" So, you know you had the wrong answer, but they don't be negative. Where's you like, project genuine, like, 'no, that is good'. And like you you're not looking for like the next person to give like the right answer" (P16).

Allow the workshops and rehearsals to, 'make sense in an autistic way' (P9) and adopting autistic values such as the big emotions or 'big feels' (P16) such as Justice, and Equality.

Co-performers felt that the workshops/ performance should *"make sense in an autistic way. It doesn't have to make sense in a neurotypical way" (P9).*

Co-performers spoke about autistic people having different experiences of emotions such as the concept of grand emotion. *"So, they, so the so-called easy emotions, like sadness and happiness and stuff we [autistic people] actually struggle with to some extent, but we have those grand emotions of justice, and equality, which co-performers felt are easier for them to express than sadness of happiness" (P9).*

Another co-performer explained autistic experience of emotion as *'to many feels', "But I like that thought, because it [Adventures of Super Autie Gang rehearsal and performance] was like-we experience everything as, like too many, too many feels.*

And so, like they had, like, this is too many feels, but like it's absolutely hilarious. And then like the next minute, it's like, really? [And then you] just cry” (P16).

Working Within a Structure

Co-performers felt that it was important to start with a well-defined structure so that they feel comfortable to take part. *“I think that's we kind of try to do with lots of things though isn't it is that you have to start with the structure, and we are happy. I know I am anyway, if I know that there's a structure if the structure change, changes, but we're doing that together, that's fine. But if it's imposed, if there's no structure at all, I'm really unhappy. Yeah, there's no structure, there's no way, we wouldn't know where to start” (P9).*

Willing to be Flexible

However, the co-performers felt that you also need to be willing to be flexible if your ground rules aren't working. *“In terms of giving us a space, you were like I am going to give you a space with my rules. And then you were like, I am going to pull my rules back, actually because with my rules it wouldn't be good” (P17).*

It was also important to give more 'making time' and rehearsals to help co-performers feel they have structure and time to get it right, to ease anxiety and allow for more involvement possibly. This was something I didn't always get right, and one co-performer missed one rehearsal and then felt 'lost'. *“I will be honest, I was obviously frustrated, because I missed that one session, and then the tent dance changed. So actually, for me, that was obviously quite frustrating. I understood why it*

happened. But because I couldn't have been, so you see what I mean. So, for me that was like, Oh, no, I'm lost now.” (P9).

Autistic Space is imperative for workshops/ performance to work including allowing for different levels of interaction with the workshop, rehearsals, and performance.

Co-performers commented on the importance of autistic space, inclusion, and different levels of interaction (or ‘autistic sociality’); *“Yes, I think that is where [P2]’s character comes in really? You didn’t have a big this is [P2]’s bit but it’s like [they] [P2] can still do it. Yeah. In terms of how people are different. Yeah. That’s the amount [of interaction in the performance] that [P2] could do because [they] didn’t come to all the rehearsals. And you [co-performer] might not have come at all and you [co-performer] might not [have] come to the performance. So, you might have actually gone alright, no thanks” (P17).*

Co-performers felt it was important to allow different levels of interaction, *“So like [P9] doing the PowerPoint” (P9 was not comfortable talking in front of the audience unless they has a PowerPoint) “but imagine like if your expectation was for everybody to do everything [in the performance not allowing for different levels of interaction]” (P16).*

P9: *“Oh, yeah, no, no, no.”*

P16: *“You would never [get us to do that]”*

P9: *“But then that, again, is showing that you're going to include people's voices regardless of how they want to voice them”.*

Appendix 21: Notes on the Awareness of Autistic Culture

When I began this PhD project, I was not even fully aware of what autistic culture was. To a certain extent, and due to my own experience and autistic culture research, I knew it existed and believe it is not fully described; it was there and important and it needed to be explored. Autistic culture is still being defined and grows every day. My understanding has become much more developed in this area. Through the workshops and, in many cases, in the pursuit of an autistic space the group uncover some elements of autistic culture. This includes a distinct language and customs that autistic people identify with and the idea of autistic identification or coming out as autistic. As Yergeau (2018) states in her book *Authoring Autism* “The autistic people have continued to write, publish, agitate and advocate...Catalogs

teem with autistic-authored books, many of which are oriented towards autistic audiences and together culminate to suggest the breath and heterogeneity of autistic publics” (Yergeau, 2018, p.23). The autistic movement and the creation of autistic culture started for the most part online with mailing lists, blogs and websites. Autistic.org now featuring a list of over 100 books written by autistic people for autistic people. There has been 30 years of autistic activism that started online through self-published blogs and online media communities such as *Neuroqueergroup blog* (<http://neuroqueer.blogspot.com/>) (Grace, 2013-present); *Autism and Race* (<https://autismandrace.com/>); and *Neuroclastic* (<https://neuroclastic.com>). Many books emerged as compilations of blogs and writing that originated online such as: *All the Weight of Our Dreams: On Living Racializing Autism* (Brown L. & Autism Womens Network, 2017), and *Type Words, Loud Voices* (Sequenzia & Grace, 2017), like *Loud Hands Autistics* (Bascom, 2012b), (Yergeau, 2018).

The autistic culture has been developing quickly since the beginning of the Autistic Rights Movement and Neurodiversity Movement in the early 1990's. We now have Autistic Acceptance Month (April), Autistic pride Day (June 18th) since 2005, Autistics Speaking day (Nov 1st), these movements and so many more are part of online and offline autistic culture where autistic people ‘multimodally’ tell their stories, develop their communities and cultures (Yergeau, 2018).

The autistic community has particular terms to describe their experience such as, the term happy and flap put together to create ‘flappy’ as a verb, or ‘flappause’ the autistic name for the deaf clap that is used in most autistic spaces. These are specific terms that refer to autistic culture such as stimming language and activities.

In the interviews, I was surprised by the number of times that participants talked in stims. Participants would communicate with a stim such as: 'here I am', or I am happy, sad, anxious, or angry. Also, when talking about stims, participants almost always chose to recreate their own stim or another person's stim instead of trying to describe it in words. I saw this as a form of autistic language or, as P1 described it, a 'supplementary language'. This was apparent when speaking about stimming, especially when talking about a group stimming together, but also referred to everyday interactions and communication. These were usually spontaneous expressions of emotions comparable to neurotypical hand gestures, which were recognised by participants as each other's happy, comforting, or anxious stims.

Other examples of autistic culture include the idea of an autistic space or autistic environment that are created for and by autistic people, such as Autreat, Autscope and the Autism Arts Festival. Also, the development of symbols such as the neurodiversity symbol and popular autistic memes and hashtags, such as Weird pride, #dollookAutistic yet, and #ActuallyAutistic are also examples of a distinct and rapidly developing autistic Culture online. Much of autistic culture is framed and defined by the neurodiversity paradigm, difference, and the social model of disability. Autistic people have shared similarities and differences in their experience of the world that are celebrated within the autistic community such as the awareness of each autistic person having a different specialisation, fascination, dedicated interests, or happy hobbies (the pathological paradigm term for this would be 'special interest' which is seen as a symptom of autism) or differences in sensory processing. Autistic people find acceptance and understanding for themselves and other autistic people within a shared community. As well as the call by the autistic community

for 'Nothing about us without us', we now have more research with, for and by autistic people to better understand ourselves and develop autistic culture and our relationship to neurotypical society.

Autistic culture is very connecting and accepting of difference. This is in contrast to the pathological paradigm's culture of autism that uses words to describe autistic people as diseased, disordered, in deficit, impaired, a person with an illness or person with autism (DSM 5, 2013). This paradigm labels autistic people as having problems, issues and as challenging to neurotypical people or uses terms that divide the community into neurotypical ideas of low or high functioning or having severe or mild autism, especially when it comes to communication. The culture of autism has promoted research on autism as a problem that needs to be fixed instead of research that would better the lives of autistic people.

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Appendix 22: Tips for Creating Autistic Space

I want to stress the importance of 'autistic space' to help autistic feel pride, develop better self-esteem, and well-being. This is also important to develop autistic culture and communication. My definition of 'autistic space' takes from this research, the growing group of autistic self-advocates that have worked tirelessly to cultivate in person autistic spaces such As Autreat, Autscope, the Autism Arts Festival, and the research of other participatory autism research projects. Owren (2013) wrote a masters thesis titled, *Autreat and Autscope: Informing and challenging the neurotypical will and ability to include* (2013).

Owren (2013) used Autreat (USA) and Autscope (UK) as examples for autistic space as these are autistic led conferences/retreats for autistic people. They set out several important elements that defines autistic space that I have paraphrased below:

1. The most important thing that defines autistic spaces is that they are a space created for and by autistic people (Owren, 2013).
2. It is significant that sensory issues are accommodated such as lighting, noise, smells, touch. It is also important to have facilities for people to self-regulate, as not all autistic people will need the same accommodations for their sensory needs. Rooms that are subdued in stimulus should be provided or as they are called now, 'Chill out spaces', and fill the need to decrease effects of sensory stimuli and give participants a place to regulate their sensory experience. They usually include a variety of sensory toys/tools for participants to do this, in other words, it is not an empty room, it's a room designed for autistic people in mind, thinking about lighting, noise reduction sensory seeking needs and a place to relax (Owren, 2013).

3. It is also important to enable autistic sociality, such as accommodating desires for regularity and routine and stability, providing a starter pack that gives all information about the events and provide things such, “providing opportunity, but not pressure for interaction...being more explicit [and] ...accepting of autistic behaviours” (Owren, 2013, p.4), such as, it is okay not to have eye contact, or not partake in small talk, and forms an agreed upon set of autistic social guidelines (Owren, 2013).
4. Finally, “Protecting the boundaries of the space” (Owren, 2013, p.5), which means autistic space must be predominantly filled with autistic people and autistic allies that will abide by the rules of the space (Owren, 2013).

With Owren’s (2013) and Fletcher-Watson et al. (2019) observations on autistic space and participatory autism research in mind, I have put a list together of things that I think could be included, or thought about, when trying to create autistic spaces.

What might be needed to create autistic space?

- For the ethos of the group to be grounded in the neurodiversity paradigm
- A dedication to dispel stereotypes about autistic people and the assumptions some people have about autistic people
- A respect for autistic people and culture
- To be run for and by autistic people
- Be authentic; a place where people can be their autistic selves
- There is support and empathy for autistic people
- It needs to promote autistic sociality and the encourage autistic to autistic communication in whatever form it takes.

- Value and encourage the celebration of autistic culture and 'autistic sociality'.
This includes the celebration and promotion of stimming as a form of communication.
- Value the importance of sensory perceptions in relation to the way autistic people experience the world and accommodate for sensory differences including self-regulation for sensory differences within autistic people.
- Acknowledge the diversity of the autistic community, celebrating the similarities and differences.
- Be a safe place where autistic people can be listened to, share their experiences, and feel safe enough to start to heal from a lifetime of invalidation, bullying and ableism.

What does an autistic physical space look like?

- You need to ensure that the room itself is manageable and suitable for a wide range of autistic people –
 - Some people like sitting on chairs not the floor
 - Or some might want to sit on the floor
 - Be mindful of the lighting- possibly use dimmer switches or floor lamps you provide to the space.
 - Offer as many self-stimulatory or self-regulatory opportunity as possible- does the floor offer a stim or does an office chair that spins or rocks offer a stim? Even small details can offer a stim.
 - Allow participants to take their shoes off, shoes can be constraining and uncomfortable.

- Have a box or suitcase with a variety of stim toys/tools that participants can try and share.
- Make sure to have a breakout spaces, even if this means you have to use a screen or a curtain- to delineate a small break out space in the same room.
- What does it mean to participate in an autistic space? Autistic sociality is still being discovered and periphery participation is still participation, in an autistic space. For example: allow lots of space so participants do not feel they need to sit all together, some people might want to sit away from the group and draw or read while listening.
- Inclusion is allowed for organic participation to take place autistic people step back to make space for autistic participation. Autistic sociality is much more straight forward than the neuromajority where people are expected to intuitively find the social space to engage. Autistic sociality would never single people out to include them (try not to put an autistic person on the spot by calling on them by name with an expectation to engage).

Notes on Autistic Cultures' Values and Recommendations for Good Practice

Valuing 'autistic sociality', including different forms of communication, different forms of interaction, including the acceptance of all forms of sociality, including the right to be in a space of autistic people to observe and listen, allow differences in showing interest in a conversation other than eye contact, encouraging and celebrating stimming as part of 'autistic sociality' and communication. Acceptance of difference in communication flow, allowing for different communication styles and dispelling neurotypical rules when communicating. Allow for different forms of communication

that may not be verbal. Such as alternative and augmentative communication (AAC), this is any means of communication that allows a person to use a language without being vocal or using conventional speech. This can involve using phones, tablets or computers that output speech, gestures, pictures or sign language.

To accommodate autistics sensory difference with chill out rooms that are mainly quiet rooms, with stim tools and other forms of stimulation to allow autistic people to self-regulate their sensory input, but also including a place to completely hide from any sensorial information if an autistic person is in autistic overwhelm, shutdown or meltdown, provide a dark chillout pod such as a small black tent or den/ screened off area. Also acknowledge that autistic people are social, just different from neurotypical sociality, and that they want to socialise with each other. A sensorial, comfortable social space is needed for autistic people to be social in, unlike a neurotypical space which can be overwhelming sensorially, autistic social spaces would be possibly several smaller groups of people in sensorially comfortable spaces.

Allow for autistic people to engage however they feel comfortable, this might mean allowing for very minimal engagement or peripheral engagement. This means making it okay for autistic people to share the same space as other people, listen and observe, but not necessarily feel the need to join in conversation or be approached by someone they don't know or, for that matter, anyone at all.

Respecting autistic personal space, this has been done with interaction badges such as:

Use some form of participation cards/badges – such as four different coloured cards, which read: green card: 'please include me today'; purple card: 'just listening

today'; orange card: 'one to one discussion only'; blue card: 'alternate means of participation please', that people can choose to wear or put in front of them to let people know how they want to participate (these cards were created by Chloe Farahar inspired by Autreat and Autscope interaction badges examples to allow different forms of participation).

The beauty of the interaction cards/badges is you can change them depending on how you are feeling on the day, which accommodates for the variety of autistic peoples experience due to other factors such as physical and mental health, lack of or levels of support, and other things that might affect how many spoons an autistic person has that day.

It needs to be a safe space where autistic people feel they can be their authentic selves without the threat of neurotypical commentary on autistic sociality. This needs to be protected and facilitators should be whenever possible autistic.

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Appendix 23: Notes on Stigma

This section contains notes about stigma that arose from some of the workshops. It may be of interest to the reader to have my preliminary thoughts on this rich area. Please note that this was not included in the themes as it appeared as reportage on the individual personal and medical history of some of the participants that wished to share this with the group. I think stigma experienced by AWCTN+ people would be another rich area that would benefit from future qualitative work.

Autistic Stereotypes, Delayed Diagnosis for AWCTN+ People

Autistic stereotypes delayed diagnosis for AWCTN+ people and, in some cases, participants felt invalidated when trying to seek an autistic diagnosis. Another theme that came out of the first three workshops was due to the prevalent stereotype that autistic children were predominately male until very recently (the majority of autism research reflecting the 4:1 male: female gender ratio), this impacted many of the participants experience: that clinicians, teachers and/or parents were resistant to diagnose, and therefore label them as autistic, because they didn't fit stereotypes. Due to the prevalence of the stereotype, participants in many cases didn't see it themselves. As one participant put it, *"I didn't [think I was autistic], it wasn't even spotted at first... the little three-year-old boy, who's like blond and, you know, playing with the little trains lined up... That image pops up a lot. So, it was kind of like it was hard to see beyond you know, the kind of stereotypes of autistic people and stuff at first"* (P8). Many participants' experiences with clinicians, teachers and parents was that there was a recognition that the participants did not fit the stereotypes so therefore they were not autistic. This meant the participants' diagnosis was delayed,

sometimes for years. About one participant's experience with a clinician, P6 states, "*I kind of had the feeling before [that I was autistic] and a psychologist I talked to years ago briefly mentioned, 'oh, yeah, you kind of have some autistic traits', but then didn't do anything about it and just said, 'Oh no, you're too empathetic, you can't be'"* (P6). Another's participant's experience with a general practitioner - P4 stated, "*I brought in a list of all the things from the NHS [autistic criteria], I said, 'Okay, this is the stuff I think I do'"* (P4). The participant also presented the GP with an online AQ test (The autism spectrum quotient (AQ-10) tool is recommended for clinicians to use with suspected autistic adults) they completed and, "*got a really high mark*" (P4). The GP dismissed this information and stated they felt that the participant was stressed due to A levels and spraining their ankle. The participant felt they were invalidated by this response and made them feel as if the GP was saying, "*you're being paranoid and your just stressed out,*" And the participant looked back in disbelief that the GP, "*didn't pick this up [that they were autistic]"* (P4).

Another participant, P7, found out after their mother suggested that they might be Autistic after they experienced mental health difficulties at their first year of university that their mother first suspected they were autistic, "*probably around like a year old,*" and P7's, "*mom always knew I was autistic and just never bothered diagnosing me basically"* (P4). Another participant's, P6, mother confessed after the participant was seeking a diagnosis at University that, "*she always thought I was autistic but the doctors when I was like a toddler just told her I'm 'just weird'. And some children are 'just weird'. And she was like, 'Okay, I guess' and then went on..."* (P6).

One participant felt that their teachers should have picked up that they were autistic and, due to stereotypes, this didn't happen. They referred to several school reports that point out autistic behaviors/experience such as having unique behaviors, and favorable that their friends, "understand [their] *habits*". (P4) states, "*in a different report it says, [P4] struggles maintaining conversations with people and starting conversations with others, often using facts to start her conversation.*' And I just thought, how you did you not realise this? I didn't talk about trains enough? I hated Maths?" (P4).

Stigma: Pathway to guilt and shame associated with being late diagnosed AWCTN+ people is multifaceted.

The participants reported that the stigma associated with being autistic can lead to late diagnosed AWCTN+ people experiencing guilt and shame about being and acting autistic (such as stimming) even before discovery or diagnosis. The path to this internal experience of stigma is manifold: the diversely cultured participants portrayed how culture overlapped with family attitudes and beliefs about autistic people but also about disability in general. Participants also felt guilt and shame about stimming in front of friends or work colleagues.

One participant noted that, "*so Chinese people... mental health equals stigma...*" (P2), in general the attitudes toward disability were highly stigmatised from a family point of view from parents, when P2 described their experience of being autistic in relation to their family they described it as, "*horrid as usual...*". From a parental perspective, their Dad, "*still doesn't trust me that I am Autistic*". Their mother, "*never*

talks about it” and from a sibling perspective, their brother, “doesn’t understand about autism...” (P2).

For example, P2 came home from university (this is at least 2 years after diagnosis) to visit with family in Hong Kong and the family all felt that the participant was ‘*exaggerating*’ their experience of sound instead of accepting that they have a different experience of sound, as an autistic person, “*my Dad turned on an engine and I was like whoa!!*” (They jump in their seat quite drastically) “*and my family are just like you are exaggerating, you have some exaggerated reactions!*” (P2).

This participant (P2) states their brother, “*doesn’t understand, and he sees Autism and disabilities as a get away from a difficult life.... So, extensions for one, he doesn’t see the point of extensions, that is just luxury. He doesn’t understand when people have limitations mentally. He understands physical disabilities, but mental disabilities are a different category to him*” (P2).

P4 came to the UK, when they were 11 years old to go to boarding school - their parents have always lived in Hong Kong. They think, “*that all this is a cultural stigma, to talk about [being autistic]. And there’s always that big stigma about it. And like, even my uncle who’s a GP, he says, you’re not autistic, you’re not autistic. Yeah, my dad when I got diagnosed, before, before I got diagnosed. No, sorry. When my parents had finished their assessment part. My mom, my dad said [The participant was repeatedly told] you’re not autistic. You’re just overly anxious. Or you’re not autistic. You’re just being stubborn*” (P4).

P4 also stated that their mother has expressed disgust with P4's autistic expression including stimming, *"I don't stim as much in front of my parents because I get told off for that... they used to tell me off a lot about that... I used to bounce my legs"* (a common autistic stim) *"and my mum would put her hand on my legs and say don't do that it's disgusting. She used a Cantonese phrase which basically translates to disgusting. So, because of that, I get really nervous stimming in front of them"* (P4).

P1 received a late diagnosis, and their family members were concerned about the label causing them to become more autistic, *"...I received such negative feedback on my diagnosis from family members... like, you are just going to learn to be helpless..."* (P1). P1's family member felt a label of Autistic meant it was an excuse for P1 to *'learn to be helpless'*.

Participant 3 was told by acquaintances, *"I was too pretty [to be autistic]"* and P3, *"had a sense of humour [so I couldn't be autistic], right?"*.

P7 felt that they needed to know someone a long time before sharing their stims with them and wouldn't dare share stimming with work mates for fear of stigma *"...[I] only [share my stims with] people I'm like, very, very close with, like to the point that like I've known you for like six years. Yeah, sort of thing. I wouldn't dare probably do it at work just because like, not everyone is open minded and stuff"* (P7).

Stigma: Distrust of research and medical profession and feeling like a test subject.

Another participant, P1, expressed distrust of the researchers and the medical profession, and feeling *'like a test subject'* when speaking about other research projects. In relation to the SAG workshops they stated, *"In other studies sometimes you feel like a test subject, and you get that even when you talk to doctors and stuff and they look at you, especially if you have a late diagnosis, they say umm that is curious can you tell me about it because it is new and I like data. I don't care that you are a human being"* (P1).

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