How can the discourses of autistics be articulated and legitimated to create spatial design criteria for indoor and outdoor space?

By

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‘But my personhood is intact. My selfhood is undamaged I find great value and meaning in my life, and I have no wish to be cured of being myself. If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms--recognize that we are equally alien to each other, that my ways of being are not merely damaged versions of yours Question your assumptions. Define your terms. Work with me to build more bridges between us.’ (Sinclair, 1992:9)

'...What is the use of my mind, which can think of the beyondness of blue, it had once seen in Emma's eyes and yet could not tell her anything about what it had seen? What use is my mind when I missed out my turn in the debate taking place? I could not give my point. What use my intelligence when I heard the rubbish from the experts on Autism and yet all I could do was flap my hands, which is believed to be one of my traits? And what use is my intelligence when I hear that I am one of those idiot-savants and cannot say my words? So I rename myself as an intelligent junk.’ (Rajarshi quoted in Biklen et al., 2005:131)

Abstract

Many people on the autistic spectrum have major sensory processing issues. In order to research this area for my PhD – specifically the issue of design in the built environment that takes account of the sensory difficulties experienced by autistic people – I needed, as a preliminary exercise in this MRes, to examine methods of accessing the views and requirements of autistic people.

I had intended for my later doctoral research to employ focus groups. Implicit in this method however is the danger of influence on the data by the researcher and more articulate members of the group. To attempt to overcome this I have looked into a range of alternative methods in this thesis, and in particular critical methodologies including the concept of ‘the hyphen’ and ethnodrama.

In this work, I have piloted the use of one of these methods, ethnodrama, taking the part of a middle-aged, autistic woman with visual, motor, and social impairments in a walk around a London suburb. My main finding concerned the difficulty of conducting simultaneous motor and verbal activity. I have found this a useful and productive pilot, resulting in my being more open to autistic perceptions and experience of space.

Dedication

To those who are told their lives are not worth living, do not expect to find a toilet they can use; who have to hide their difference for fear of losing their jobs; who have been ignored, patted on the head, talked about as if they weren’t there; stared at; manhandled; provoked; chased or otherwise abused because of their perceived difference from those who distinguish themselves as able-bodied and/or neurotypical.

Acknowledgements

With thanks to those referred to in my dedication, who for a variety of reasons cannot be named and to those who can, the late David Morris, Senior Policy Advisor on Disability and Deaf Equality to the Mayor of London, seconded to the London Organising Committee of the Olympic Games and Paralympic Games as External Access and Inclusion Coordinator; Dr Dorit Ben Shalom, Zlotowski Centre for Neuroscience, Ben Gurion University of the Negev; Dr Dinah Murray, AutreachIT; Lynn Plimley, Autism Cymru; my supervisor Gary Thomas, who told me it was not within the academic remit to be radical, forgetting I would read his books!!,members of London-ARM, Autscape and DANDA all of whom kept me focused. Also the library and IT helpdesk at University of Birmingham who tamed my computer and kept the information coming!!

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Chapter 1

Introduction

In this chapter, I set out the aims of my research for this thesis in the context of my future doctoral research. This thesis is, in essence, an overview of my methodology and philosophy, providing the context for my future doctoral research.

The aim of this MRes thesis is to explore how I can form a robust methodology for engaging in research with autistic[1] research participants as co-researchers to inform the context for my doctoral research. My intention is to establish an equal research partnership between autistic co-researchers and myself. To achieve this I look at autistic literature and online resources as well as diverse research methodologies. Wanting to resist the temptation to over identify with autistics and/or the risk of glossing over their experience in my doctoral research, in this thesis I examine and apply Michelle Fine's concept of the 'hyphen' through the use of ethnodrama. This results in the enactment of the possible experience of middle-aged autistic woman with visual, motor, and social impairments in a walk around a London suburb.

This enactment gave me a chance to enact my data so far to explore how some autistic people may experience space. This was undertaken as the focus of my full doctoral research ultimately is on the sensory and spatial requirements of autistic people in relation to the internal and external environment to create accessibility criteria for use by built environment professionals.

Autistics experience many environments as under or over-stimulating and/or difficult to process, effects ranging from uncomfortable to intolerable. Not all autistics are affected; the degree of impairment is variable within the individual and across the

[1] Note: I use 'autistics' as identity first language is widely used by user-led organisations of autistics, individual blogs and websites and is intended to be in line with the American Psychological Association, who argue for the use of the preferred term of the community (APA (2001) *Publication manual of the american psychological association*. 5th ed.Washington, DC; London: American Psychological Association. Robertson, S.M. and Ne'eman, A.D. (2008) Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly,* 28: (4), Tennant, S. (2008) *Person-first language and autism neurodiversity and the prejudice of politically correct terminology* [online]. http://autismaspergerssyndrome.suite101.com/article.cfm/personfirst_language_and_autism suite101.com [Accessed 18 December 2009] Robertson, S. M. and A. D. Ne'eman (2008). "Autistic Acceptance, the College Campus, and Technology: Growth of Neurodiversity in Society and Academia." Disability Studies Quarterly 28(4).

spectrum. There is a dearth of research on this topic, often because of the difficulties that arise when using traditional experimental methods to research the heterogeneous nature of autistic sensing.

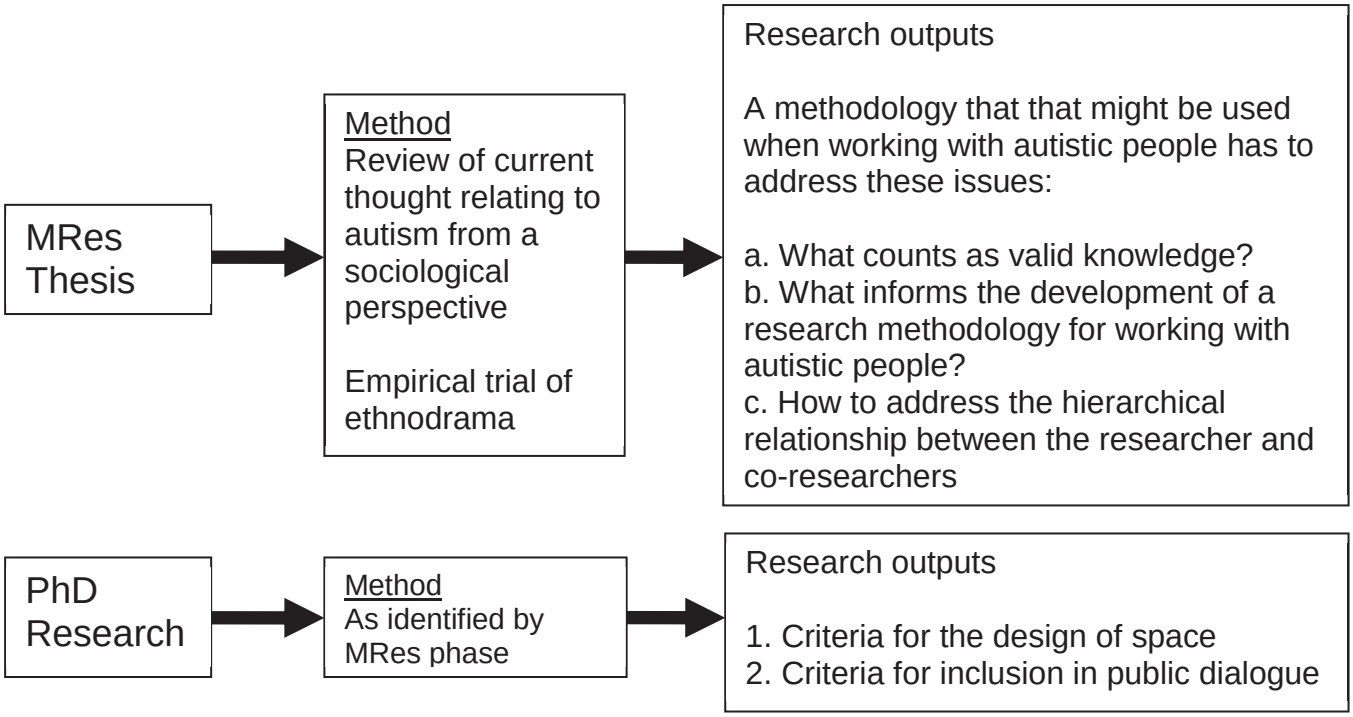

Figure 1 Distinction between my present research for my MRes thesis and my future doctoral research

Not meeting the sensory, social and communication requirements of people on the autistic spectrum leads to exclusion from employment, cultural and leisure activities. The aim of this research is to create a methodology for a fully inclusive research process where autistics create criteria for their participation in policymaking forums concerning these activities. This will provide the basis of my methodology for the doctoral element of this work, the aim of which is to develop criteria for the design of space. Figure 1 distinguishes between the research for this thesis and my future doctoral research.

The overall aim of my doctoral research (that is to say, subsequent to this MRes element) is therefore to discover the perceptions, aspirations and access requirements of autistics from their point of view. I highlight how this aligns with inclusive public consultation in relation to the environment in national and international government policies and legislation for all citizens as outlined in for instance the Compulsory Purchase Act 2004 (Great Britain, 2004), the Aarhus

Convention (Stec and Casey-Lefkowitz, 2000), and Disability Equality Duty (DRC, 2006).

For the current thesis, I intend to conduct a review of current thought in relation to autism from the perspectives of autistics, parents and professionals in order to inform my assessment of methods wherein I may be able to work alongside autistics most effectively. I shall do this by attending conferences run for and by autistic people, by examining autistics' websites, blogs, government legislation, and policy, academic and popular journals, and newspaper articles. I shall also use my own professional and personal friendships and networks with the autistic community and interested others including professionals.

My motivation for carrying out this research

I come to this work having been influenced by the philosophies of radical educationalist Paulo Freire, American humanist psychologist, Carl Rogers and Ubuntu, an African social and communal philosophy. These philosophies lead to the possibility of picturing autism as a culture in its own right. This, I thought, should surely have implications for how I analyse my data. It led to my exploring critical and indigenous methodologies that have been used to research with Native Americans (Cook-Lynn, 2008), San Bushmen (Tomaselli et al., 2008), Ghanaian activists (Madison, 2008) and Maori communities (Bishop, 2008). I combine all of this with critical pedagogy, to incorporate a methodology based on conscientisation to bring traditional conceptions of education, research, politics and democracy together to challenge inequalities of power regarding perceptions of what counts as legitimate knowledge and presentation (Denzin et al., 2008:28). The latter, I feel, has contributed to a marginalisation of autistic experience in academic literature.

In terms of my positionality here, much of my starting point derives from my experience of school where I felt my own ability was either ignored or undermined. This sense of injustice resonated during my first encounter with people with learning difficulties in a large hospital in the 1970s, giving a lasting memory of the room, bare except for the wooden chairs people sat on; the walls solid halfway up, with glass to

the ceiling. I remember a woman sitting head down on one of the chairs next to a radiator. The person showing us around said this constituted her life.

Subsequently I worked with children with learning difficulties and apparent autistic tendencies; my memory is of them being constantly shouted at despite it being clear they did not understand. Later I went on a disastrous holiday with a similar but slightly older group; they became very distressed and could not tell us what was wrong, reducing the holiday to keeping them safe and controlling their behaviour. More recently, I worked with an 11-year-old autistic boy, accompanying him with another worker on a walk. The boy was marched around as quickly as possible. When we returned to the unit, there was nothing for him to do, so we were both bored.

These experiences profoundly affect the way that I view people who are different – and particularly autistic people. They prompt my interest in the way that society treats autistic people and hence my future doctoral research.

My methodology is influenced by the lack of respect and culture of blame manifested by these experiences. Events such as visiting South African Townships as the apartheid regime came under increasing pressure exposed me to the philosophies of Paulo Freire, and later Carl Rogers and more recently Ubuntu. These philosophies influence my professional perspective as a landscape architect and social worker with a degree in applied sociology. They have led to an interest in urban design research which illustrates how certain groups – such as the young (Woolley and Johns, 2001), disabled people (Kitchin, 1998) and homeless people (Snow and Mulcahy, 2001) – are excluded from public space. These perspectives lead me to argue that physically and attitudinally accessible environments are basic human rights (McCaskill and Goulding, 2001). Adding these views to Rogers's and Freire's respect for human knowledge and agency led me to be of the opinion that successful design should be a consensual, collaborative process based on mutual respect (Day, 2003:viiii). Recently these have combined with influences from disability research, contact with the autistic community, and critical researchers leading me to perceive of autism and disability being on a continuum of social diversity (Baggs, 2008, Baron Cohen, 2000:489,497f).

I combined the influences outlined above with the need to find commonalities amongst competing autistic accessibility requirements, leading me to consider employing user-led focus groups both live and online for my future doctoral research. Focus groups are widely used in market research, consisting of a facilitator and up to 15 members who meet to discuss a common concern. In mental health research, the group rather than the facilitator determine the course of discussion, hence the term user-led. However, a main drawback of focus groups and research in general is the divide between researcher/facilitator and participants, resulting in possible undue influence by those leading the research. This could lead me to impose my worldview and cultural understandings on the research. To attempt to address this, in this study I use ethnodrama. Later I will explain how this allowed me to break me out of these constraints to create greater understanding of the cultural viewpoints of my autistic co-researchers. I felt this would enable me to develop a methodology whereby autistic people could participate in the research process on their own terms.

I also considered other methods that might help to improve access to the research process. For instance the use of ‘Go along walks’ for those who do not like working in groups. Using this method research participants describe their experiences as they walk.

Investigation into the use of participatory methods with autistics revealed that whilst there was some limited participatory research in the UK and the USA it was not necessarily aimed at influencing policy (Bagatell, 2007, Biklen et al., 2005, Broderick and Ne'eman, 2008, Hurlbutt and Chalmers, 2002). The research for this thesis and my future doctoral work has an indirect aim of influencing policy and design through my membership of British Standards Committees B/559/-/5 Neurodiversity Task Group and BSI task groups – Accessibility - External Environments with autistic colleagues.

Research context

Autism – sensory processing

While there are many theoretical positions on the causes and provenance of autism, I start this thesis and my doctoral research on the assumption that sensory

processing and integration issues affect many autistics' ability to function in indoor and outdoor environments. These cause varying degrees of distortion of the senses of hearing, smell, touch, sight and taste, motor processing and proxemics. This is further complicated for some by issues with the integration of memory and emotion. The theoretical position on which I am basing my research is founded on the work of several researchers, notably (Ben Shalom, 2009:1, Kern et al., 2006:480, Spencer et al., 2000:2765).

Effects are noted by autistics as ranging from uncomfortable to acutely painful, making many environments intolerable. Activities that are automatic for non-autistic people are not necessarily so for autistics, Sinclair describes plugging in his eyes in order to make sense of what he is seeing and Williams describes rooms as a vague blur until someone points out the audience (Sinclair, 1992:4, Williams, October 2009). Sinclair describes having to find his legs before he can walk; Gerland describes not knowing where her body is in space (Gerland, 1997:130, Sinclair, 1992:4). Ben Shalom describes in her study how autistics with perception issues see the detail before the whole, for instance white, round and one circle within another before realising it is a plate (Ben Shalom, 2005:643). Caldwell argues that the 'world is a swirling kaleidoscope' that never settles for many. Sinclair describes attempting to monitor and process changing sensory inputs fast enough to produce the outputs required (Caldwell and ebrary Inc, 2005:42, Sinclair, 1992:4).

Some people describe themselves as mono processing so cannot or have not been able to process information from more than one sense at once (Bogdashina, 2003 Chapter 3, Gerland, 1997:122,123). Added to this, autistic people can be hyper or hyposensitive or a combination (Williams, October 2009). Some are diagnosed to have synesthesia where for instance taste is sensed as shape, smell as colour and so on (Caldwell and Horwood, 2008:55f). This heterogeneous collection of issues confounds existing approaches to research and sets autistic people’s voice at the margins when it comes to inquiry into these issues (Grandin quoted in Beil and Peske, 2005:xi, Iarocci and McDonald, 2006). For some, serious difficulty can result in repetitive behaviours that can look bizarre or challenging and/or the person can appear obstinate, awkward, or fractious.

Autism as 'other': spatial and social exclusion

Autistics are 'othered' by the marginalisation of accounts of their daily experience and lack of access to economic and political activity leading to stigma and social restriction (Biklen et al., 2005:81,168, Hurlbutt and Chalmers, 2002:104f, Waltz, 2005:433). From the mid-1990s there has been a concerted effort via new technology by a significant proportion of the autistic community to combat what they take to be the negative connotations given to autism by organisations such as Autism Speaks (Autism Speaks, 2009) and campaigns such as the Ransom Notes Campaign (Solomon, 2008). There is still a sometimes, hostile dialogue between those who want to ‘cure’ autism and those who argue autism is a culture.

Exclusion from disability discourse

An argument can be advanced that even within disability discourse, the focus of the social model away from impairment to the structural causes of disability marginalises autistic experience (Debbault quoted in Beardon, 2008:17, Plimley and Bowen, 2006:72ff, Smith, November 1st, 2006). I would argue that this historical marginalisation is one of the reasons that we have criteria for physical accessibility as laid out in Part M of the Building Regulations (ODPM, 2004) which do not despite the Disability Discrimination Act 2005 (DRC, 2005) contain criteria for sensory accessibility, apart from visual and hearing impairment. This could be compounded by most autism research focusing on the medical causes of and cures for autism rather than focusing on lived experience.

Autism and policy

The aim to create an inclusive methodology in this thesis corresponds with the ethos of current government policy. For instance **Supporting People With Autism through Adulthood** (Auditor General, 2009), and the **Adult Autism Strategy** consultation, show that the government's aim is to create a situation where:

> All adults with an ASC are treated as equal citizens and are fully and appropriately supported to fulfil their potential. They can access a range of appropriate and timely support, reflecting the complexity of ASCs, that promotes inclusion. Their social needs are met through support to develop

and maintain their family life and relationships. They can also access meaningful activities during the day and evening, which could include employment or voluntary work, but also non-work related activities that are important to the individual and established through an ongoing person-centred approach (Department Of Health, 2009)

Policy and legislation for environmental design

In developing national policy in this country, concern about sensory requirements appears to be restricted to those who have hearing or visual impairment. Considerations relating to autism appear to be absent from statutory policies governing built and outdoor environments (London 2012, 2008:24,25,38,46, ODPM, 2004:43,70). Building Bulletin 77 Designing for Pupils with Special Educational Needs and Disabilities in Schools is the only government document relating to spatial design that mentions autism by name, briefly referring to sensory issues (Revised 2005:30f). I suggest this omission acts as a barrier to employment and leisure activities for autistics, being a factor in accounting for only 6% of autistics being employed, far lower than the overall figure for disabled people of 49% in 2003 (Knapp, 2007).

Research

Research with autistics

The quantitative, medicalised philosophy of autism research focuses on developing childhood therapeutic intervention, understanding autism as pathology or in relation to typical development (Jordan, 2001:vii). This leads to autistics mainly being subjects rather than participants in research. Disability research argues that research using the medical model is not able to provide an understanding of the lived experience of disabled people or address the social and political barriers they face (Oliver, 2002:2). Disability theorists argue for qualitative research controlled and carried out by disabled people, which addresses their lived experience, using theories that create change, are open-ended and nondogmatic (Lather, 1987 quoted in Oliver, 1992:107).

Statement of the problem

- The lack of involvement in research by adult autistics as participants or co-researchers manifests itself in the lack of consideration of inclusive research designs and methodologies to meet the requirements of adult autistics.

- Within mainstream society, the social and communication requirements of autistics are not included in accessibility criteria which means they cannot participate in many policymaking forums to address their concerns.

This illustrates the need for research that addresses autistics' economic, social, and political marginalisation, challenging the centrality of research informed by the medical model. This requires a change in the relations of research production so that autistics become instigators and stakeholders in research activity. The aim of this would be to address the gap in knowledge regarding their sensory, social and communication requirements for accessing employment, public environments and civic discourse (Oliver, 1992:102). One way of doing this is to employ emancipatory research. However, there is no precedent for doing this with people whose dialogue and behaviour does not conform to socially expected norms, such as the ability to read body language, voice intonation, use speech pragmatically, sequence speech, process it fast enough and so on (Bogdashina, 2005:189-196, Booth and Booth, 1996:55).

Purpose of the study/aims and objectives

By taking account of the issues I have raised I aim to develop methods wherein autistics determine policy rather than merely reciting their experience to argue for their acceptance (Mitchell, 2009, Walters and Hewitt, 2009). I will also explore the dilemmas in creating a methodology that is balanced between the requirements of autistics and the academy. This will include identifying barriers to effective data gathering to establish the authority of the autistic community's diverse knowledges and ways of communicating, to create an 'autismcentric' methodology (Biklen et al., 2005:17, Fine, 1998). As part of this process, I intend to use ethnodrama to increase my understanding of autistic spatial experiencing by enacting data from autistic

literature and online resources, to demonstrate experientially how easily behaviour outside the norm can create spatial discomfort and exclusion.

From the above I have identified these key objectives:

- To understand the cultural context of autism – autistic spatial and social – and how this leads to marginalisation

- To develop a reflexive, critical research methodology using the concept of the 'hyphen' and ethnodrama to inform my understanding of autistic spatial experiencing and my role in future user-led focus groups as part of my doctoral research.

Research question

How can the discourses of autistics be articulated and legitimated to help develop spatial design criteria for indoor and outdoor space?

The importance of the study

I should conclude with a note on why I feel this study is important. To be included rather than merely tolerated is a matter of social justice. The methodology governing this study coincides with government aims regarding the social inclusion of autistics by focusing on the creation of an inclusive and accountable research methodology. In doing this, autistics will create accessibility criteria for participation in civic dialogue to enable their political and economic participation in my future doctoral research (Knapp, 2007, NAS, 2009).

Chapter 2

Review of current thought in relation to autism

The aim of this chapter is to look at current autism-related dialogue, existing autistic participation in research and specific methodologies used for research with specific groups of disabled people. I also outline my review of current thought relating to autism, carried out by:

- attending meetings and conferences run for and by autistic people;
- examining autistic accounts in academic and popular literature;
- inspecting websites and blogs;
- reviewing academic and popular search engines;
- reviewing government legislation and policy;
- examining academic journals, popular journals and newspaper articles.

I also include data from professional and personal networking within the autistic community and interested others including professionals. This data is important, as the methodological development for my research extends beyond the physical or procedural surroundings for dialogue to scrutinise the relationship between the autistic co-researchers and myself. The aim of this is to understand autistics' interaction with society and space. A central part of this is understanding how distorted assumptions regarding their culture, aspirations, and requirements leads to spatial exclusion.

Positionality

I have already briefly outlined my positionality in Chapter 1, but given its centrality to my inquiries I feel it is necessary to go into it in some additional depth here. Central to my positionality is a focus on social justice in both my professional disciplines of social work and landscape architecture, extending to all other areas of my life. I believe in equality based on inclusion (not just tolerance), and such equality includes equal access to all aspects of civic participation including dialogue and the ability to access indoor and outdoor space. This is the context for my research.

This context is influenced by my own exposure at school to arbitrariness and pettiness that had nothing to do with learning, but where paradoxically Christian humanism was instilled. This led later to my contact with the Society of St Francis, an Anglican religious community that emerged from the Anglo-Catholicism of the Oxford Movement in the 1830s. This, combined with liberation theology, particularly as presented by Kenneth Leech and Archbishop Desmond Tutu, combined with the influences of Paulo Freire and Carl Rogers instilled in me respect for the uniqueness of every individual and their agency, providing it does not impinge upon the rights of others (Leech, 2006, Pusey House, 2009, Society of St Francis, n.d., Street Spirit, 2005, Tutu, 1999). Involvement with the Franciscans led to contact with homeless people, the gay rights movement, and the beginnings of the impact of HIV and AIDS, and the anti-apartheid movement. It created in me the desire to understand social issues by direct involvement. These experiences shifted me from being a 'helper' who saw people as victims to viewing people as human agents with strengths and skills to address their own issues.

I discovered that 'helping' in the form of blankets or food helps the individual in the moment, but does nothing to address structural inequality. This shifted my conception of agency using Rogers's example from the 'Doctor' to the client and in Freire's as grassroots activism in the form of conscientisation, leading me to view individuals and communities as experts and active agents in their lives (Freire, 2008, Rogers, 2004). I discovered when I was working in child protection, whilst maintaining focus on my statutory role and the legal requirements on parents not to harm their children, we could resolve many issues by exploring the family's positive skills and coping strategies to apply them to the present. I found working on an 'equal' footing, learning and exploring in a non-hierarchical way is respectful and effective (McLaren and Leonard, 1993:9, Rogers, 2004). Ubuntu, an African consensual, social and communal philosophy that I encountered more recently also emphasises non-hierarchical relationships and respect for the individual on the basis that we are all part of one another and therefore equal: one person *'…is diminished when others are humiliated or diminished…'* (Tutu, 1999:35). Rogers and Freire led me to see autistics as agents and experts in their own lives. This was in the context of working within the communal philosophy of Ubuntu. Therefore, I see autism as part of a diverse culture which we should respect and make an effort to understand.

Disability research also influences my positionality, particularly the distinction between the social and medical models of disability. The social model argues that disability is constructed by and needs to be dealt with by society rather than being seen as an individual medical issue (Barnes and Mercer, 1997:1). The medical model applied to autism significantly determines both the understanding of autism and the focus of research. That focus is mainly on children, controlling or curing autistic behaviour – not addressing issues surrounding autistic adults' inclusion.

Informed by this context and my positionality the aim of my doctoral study is to research autism from an autistic perspective, how autistics experience society, and how autistics organise themselves culturally and politically to respond to the focus on curing or control. This research also involves investigating the attitudinal and physical barriers autistics experience to getting across their views, aspirations, and requirements.

Autism and learning difficulty

One of the main stereotypes of autism created by the promotion of the medical model in relation to autism is the failure by many to distinguish between autism and a learning difficulty, thereby assuming that all autistics have a learning difficulty. Goldberg states that cognitive ability has never been part of the diagnostic criteria for autism in any of the versions of the DSM in which autism has appeared (Cowen, 2009:22, Dawson et al., 2007:657, American Psychiatric Association quoted in Goldberg Edelson, 2006:66). The DSM is the Diagnostics and Statistics Manual of Mental Disorders (DSM), published by the American Psychiatric Association and has worldwide influence.

Goldberg Edelson states that the majority of children with autism continue to be described as having a learning difficulty despite recent epidemiological surveys showing the prevalence of learning difficulty is between 40 and 55% (Goldberg Edelson, 2006:74). Autobiographical accounts of autistic adults, for instance those involved in the research of Biklen (2005) and Hurlbutt and Chalmers (2002), state that their intellectual abilities were unimpaired. However because their behaviour and

social presentation were perceived as characterising a learning difficulty, some having limited or no speech, it was assumed they had a cognitive impairment.

The arguments for autism to be viewed as a culture

Understanding the development of autistic culture is important to my research as it illustrates that autistics can develop an autism-friendly environment for discourse. This suggests that it could be attitudinal factors that excludes autistics from mainstream dialogue. This is why I focus not on employing a fixed set of research techniques for working with autistics. Instead, I focus on developing an emergent methodology that dialogically explores difference throughout the research process, and thereby creates an inclusive environment.

A major setting for autistic dialogue and a main reason for its expansion is online communication. Autistics argue this is a powerful communication tool, some claiming it is equivalent to sign language for the deaf (CBC Canada, 2008, Dekker, 2005). They argue that preference for the Internet over other forms of communication is due to telephone and face-to-face contact requiring auditory processing, a 'kind of paralanguage' (CBC Canada, 2008). This includes tone of voice, a predetermined pace of speech and other 'non-verbal language aspects' (CBC Canada, 2008). Face-to-face communication also requires the reading of facial expression and body language (CBC Canada, 2008). Gerland, describing this difficulty, argues that smiles are enough to confuse and make an autistic person uncertain (quoted in Davidson, 2008:795). Internet communication such as online groups, chat lists and blogs slow down the fast pace and rhythm of typical discourse (Davidson, 2008:796). This allows for a delay in response which almost never happens in live conversation, with the consequence that you are either quick enough to keep up or perceived as socially inept (Davidson, 2008:796). Online communication obscures difficulties in comprehension that cause difficulties in keeping pace with the flow of conversation. It also hides unusual movements or behaviours that accompany some autistic speech which if visible, would cause people to dismiss the speaker’s views (Murray and Aspinall, 2006:7).

Davidson suggests that there are persuasive arguments from autistic authors: *'…that autism is emotionally spatially – in every sense – otherwise…'* due to autistics'

differences in perception and processing that *'…involve Other ways of being- in- the-world'* (O'Neil quoted in 2008:793). Some autistics suggest there are parallels between the development of the deaf community and the psychiatric survivors[2] movement, arguing autistic culture now is where deaf culture was a century ago (Prince-Hughes quoted in Davidson, 2008:793, Dekker, 2005).

In her investigation of the autistic community, Davidson argues, as I do, that we should:

> '…make space for conceptualising difference constructively, to enable recognition of complex Other [author's capitalisation] ways of understanding and expressing experience.' (Davidson, 2008:794)

The information from this data also helps me to understand why sensory processing issues which have such significant impact on the lives of many autistics are not a prominent focus of autism-related research and why criteria to meet sensory processing and integration requirements (apart from those for deaf and visually impaired people) are absent from the research literature. This understanding informs the development of my research methodology.

Existing participatory methods for people who have impairments in communication and social interaction

There is no direct research on autistics' participation in focus groups in the research literature or via academic and popular search engines, using the search terms 'focus groups autism', 'user-led focus groups autism'. These terms take the viewer to focus groups for parents not adult autistics.

There is a rather limited body of research using a participatory approach. A study by Biklen coincides with the philosophy of my work in its assumption of the competence of autistic people. (Biklen et al., 2005:1). Biklen carried out a two year qualitative study of autobiographical accounts of autism gained through interviews,

[2] This term is used is both online and in academic literature to describe those who have survived the mental health system e.g. Cresswell, M. (2009) Psychiatric survivors and experiential rights. *Social Policy and Society,* 8: (2): 231-243. Beresford, P. and Wallcraft, J. (1997) "Psychiatric system survivors and emancipatory research: Issues, overlaps and differences". In Barnes, C. & Mercer, G. (Eds.) *Doing disability research.* Leeds, Disability press

conversations, e-mail correspondence and participant observation (Biklen et al., 2005:1). Hurlbutt and Chalmers carried out research using interviews and visits, covering a wide range of topics. Their conclusion was that people on the autistic spectrum want to be considered experts on autism (Hurlbutt and Chalmers, 2002). Bagatell carried out an ethnographic study on the process of identity construction in a twenty-one year-old autistic man. This was part of a larger study of 'high functioning' adults (Bagatell, 2007:414). Her participants' conclusion was that attention should be shifted from deficits to autistics' social participation (Bagatell, 2007:425).

In relation to this omission, Waltz argues that participatory and emancipatory research methods have passed autism by, being most developed in the form of user-led research, involving psychiatric survivors (Faulkner and Layzell, 2000, Waltz, 2006). As an example, she cites the Autism Research Co-ordination Group that asserts that 'user participation' in research design is of key importance. However they only provide one instance of inclusion involving the Medical Research Council, who when taking statements from people with autism and carers during their review of autism research included only one person with autism (author, Donna Williams) in their lay group, as opposed to 12 parents and charity representatives (Waltz, 2007:355).

Waltz argues that communication requirements, special interests, and a lack of history of community organisation could hinder the research process. My experience of community groups is that they are effective, using strategies that work for the group, rather than externally imposed structures and that success breeds success (Waltz, 2006). Waltz states that the only researchers who regularly use participatory and emancipatory research with autistics are those based at the Autism Centre at Sheffield Hallam University (2006). Beardon and Edmonds have carried out research with autistics with Asperger Syndrome. The ASPECT team (Asperger Syndrome People Each Contributing for Themselves) were a group of seven people, four of whom were Aspergers, a parent and two professionals using questionnaires to identify issues of concern relating daily experience of the 237 respondents (Beardon and Edmonds, 2007). However, I still feel there are limitations due to there only being four people who have Aspergers in the research team. A larger group and maybe

several groups opened out to include those defining themselves as autistic may have created a different set of questions. The comment of one participant relates directly to these observations:

> I feel this questionnaire like so many is setting an agenda and constraining the answers. … We need to be at the centre of our own solutions, but only by causing society to realise that there is no rigid division between needy and undeserving, NT and AC, able and disabled that we are all in a society of differing levels of dependency and need, and that to be interconnected by such a process of supporting as well as being supported we can have a whole society. (Research participant, Beardon and Edmonds, 2007:334)

The argument here is that the range and quality of the questions is determined by the research team rather than the participants' concerns (Faulkner and Thomas, 2002:2). Beresford's respondents argue that:

> If the questions have been set by someone who has been in the situation, they are totally different from questions that have been put forward by any other group because we have had the experience. (Mental health service user/survivor quoted in Beresford, 2007: 336).

Beardon has also carried out research with people with Aspergers Syndrome who had been arrested, which looked at whether the person's behaviour could be explained according to the way AS was affecting them at the time. (Beardon, 2008:2). Here Beardon discusses issues relating to the interviewing of people on the spectrum from within the medical model, referring to theory of mind, central coherence, and executive functioning. Whilst I agree these can be useful 'shorthand' to facilitate communication with some people on spectrum, they are contested by some autistics and professionals in terms of the tests carried out to arrive at these conclusions (Biklen et al., 2005: ch 1, López and Leekam, 2003:285, Mottron et al., 1999:203).

Due to the constraints on the length of this thesis, I do not have space to discuss these arguments and their possible implications during the research process.

Beardon does advocate respect for the heterogeneity of the community by the use of a flexible and responsive approach, arguing that the 'richness and singularity' of responses was what made the research process enjoyable as well as giving credence to the results (Beardon, 2008, p. 5). Beyond this participatory research relating to any kind of neuro impairment appears to be limited to psychiatric survivors and those with learning difficulties (Beresford and Turner, 2005, Gilbert, 2004). Participatory rather than emancipatory methods have been used with people with learning difficulties as they often have little access to the written word and may struggle with verbal articulation (Chappell, 2000:41). Focus groups are advocated by Nind, in a review of qualitative research with people with learning difficulties. She states they are successful in providing peer support and validation in the same way that Autscape, Autreat and London-Arm do for autistics (Cambridge & McCarthy quoted in Nind, 2008:11). However, Nind argues success can be problematic due to the mix of behaviours, backgrounds, communication, and social issues. The composition of the user-led groups such as Autscape etc. is by self-selection mostly through online communication and word of mouth, dependent on location and transport costs, although more recently conference calls have been used successfully.

User-led Research

One benefit of user-led research is that it attempts to remove the division between disabled and non-disabled to attempt to create a non-hierarchical research methodology. Another argument is that it examines issues and creates outcomes that are relevant and meaningful to the co-researchers, identifying issues about which the originators of the research may not be aware (Faulkner and Thomas, 2002:2, McLaughlin, 2009:8). Beresford quotes one service user who argues that *'It has identified new theories, new paradigms and new ideas which give explanation for our lives'* [user's word] *experiences'* (Beresford, 2007:335). User-led research also enables the dialogues of marginalised and mainstream communities to be heard alongside each other with equal weight (Faulkner and Thomas, 2002:2). However, user-led research is not without its limitations: McLaughlin argues that if the participants are not well trained this will reflect in the quality of the research (McLaughlin, 2009:9). Drawing on the work of others, he suggests that co-

researchers may require support to undertake the research, for example supporting the completion of practical tasks and mentoring. Chappell takes a different perspective of outside support. She questions how the integrity of disabled people's accounts can be maintained if this is linked to an imperative by the research community to have non-disabled allies convey their experiences in a way which is acceptable to them (Chappell quoted in McLaughlin, 2009:41). Other disadvantages are the dominance of medicalised research, for instance its focus on neutrality and objectivity and the assumption of bias due to the closeness of the research participants to the topic being researched (Turner and Beresford, 2005:65,69). Many interviewees believed user-led research was at a significant disadvantage compared to other forms of research, arguing that there needed to be structural and attitudinal changes for this situation to change (Turner and Beresford, 2005, pp 130-40).

From this information, I will now go on to discuss the development of my methodology in Chapter3.

Chapter 3

Methodology

> Too often, as Zarb (2003) has recently observed, research which has called itself emancipatory has ignored the meaning-making and ownership by disabled people of the research process, and failed to deliver an understandable and clear vision of the research agenda. (Goodley and Lawthom, 2005:146ff)

As I noted in my introduction, this MRes thesis is undertaken in part as a research preparation for my full doctoral thesis. My central points of issue in undertaking it have concerned the ability of existing forms of methodology to address the wishes and requirements of autistic people in a range of matters. My focus is on autistics' access to and use of space in the built and natural environment. Given my focus on these methods, I have given particular attention to issues of data gathering and analysis, taking into account what might be called the 'epistemology of participation'. Because of my focus on method in this MRes thesis, this chapter is rather longer than is usual in a work of this kind, bringing together issues of participation with issues of method.

Bias

Before I discuss my methodology per se, I will address the apparent bias in my data. This arises due to the need to get accurate data, which requires me to be as close as possible to its source with its associated issues of social justice. This goes against the traditional neutrality of the researcher in relation to the data. Thomas and Glenny support close involvement arguing it is mistaken to believe that you can *'...unproblematically separate the disinterested from the interested, the apolitical from the ideological...'* (2005:11). Said also states *'it is impossible to be neutral as the researcher when researching the process of othering'* (quoted in 1978 in Khawaja and Mørck, 2009:40). Blair argues that *'Making one's politics explicit is no more likely to introduce bias into one's analysis than declaring that one does not have a value position.'* Arguing that neutrality is untenable and would create an exclusive hegemonic research community (2004:244), Blair states that the aims of social

justice require not neutrality but absolute integrity, a rigorous attitude and approach to research (Blair, 2004:245).

Moving on to my methodological development, this is derived from my review of the current context of autism and existing participatory methods used with autistics and other specific groups of disabled people. I will identify the research paradigms, which guided the creation of my methodology for the research for this thesis. The first aim of my methodology is to gain information from within the autistic community and their frame of reference rather than medical or parental perceptions. This involves creating an environment for an equal meeting of minds, rather than following a global tick list for communicating with autistics, with the automatic assumption of difficulty and difference where there may be none. My experience has shown me that using active listening, being open and able to face where I got it wrong and do something about it are more important. This includes being aware of conscious and unconscious prejudices as I go about the second task of my research to understand autistics' values and worldviews to identify with their experiences as far as I am able. I have to be aware that this is influenced by my positionality also taking into account the diversity of the autistic spectrum and their diverse social affiliations. As their experience also includes marginalisation due to social and communication impairments, my research frame and methodology overlap to reflect this. This requires a research paradigm that is not limited to the seeking of new knowledge but which is also an ethical and emancipatory endeavour (Denzin and Giardina, 2009:29). Chapter 2 highlighted the complexity of this process due to the unequal and conflictual relationships between autistics and wider society. This raised questions as to how I was going to avoid repeating this during the research process.

In addition, user-led focus groups, as I wish to employ them in my doctoral research, fall outside the standard focus group format. In the context of my future research, I wish to be more of a participant observer rather than distanced moderator. The expertise and running of the group will be shared but possibly with me taking on a large part of turning the process into effective research (Lloyd et al., 1996:309). This ambiguous position has led me to consider what my role would be. I felt that having a commitment to an equal relationship would not be enough to create real dialogue and partnership (Lloyd et al., 1996:312). One of the reasons for my concern was that

many of the autistic co-researchers might still consciously or unconsciously automatically assume that as I had instigated the research I was the leader and would defer to me. Additionally there could still be a divide between my 'non-disabled' status, my socially internalised, negative connotations regarding disability and perceived infringements of culturally internalised norms by some of those on the spectrum. At the other extreme, I was concerned that overly identifying with the community could result in my falsely romanticising or assuming similarities with autistic community. This would come at the expense of the attempt to truly understand the community hindering the process of formulating useful design criteria. Therefore, I needed a research framework to address the research relationship.

This chapter explores the research philosophies and methods that I think will assist me in this process. I will start by looking at focus group and user-led research design and its applicability to my doctoral research to set the scene for my concerns regarding my role as researcher in the context of this thesis. Then I will look at critical theory, especially critical pedagogy as overarching paradigms to address my concerns and performative research to address the practical application of my methodology.

Focus Groups

Initially I identified user-led focus groups for my doctoral research, as they have parallels with Rogers's Encounter Groups. They have been used with other groups of disabled people and meet many of the criteria for emancipatory disability research by challenging the relations of research production (Oliver, 1992:101, Rogers, 1970). Encounter groups have similarities with user-led focus groups in that they are leaderless with a focus on facilitating communicating and empathy (Rogers, 1970:12). In this case, my focus would be on my role in communicating and identifying with the group, whilst being aware of and negotiating difference.

Textbook descriptions of focus groups such that of Bloor discuss the role of the facilitator in some detail, Kitzinger argues that the interaction between the research participants and the facilitator is pivotal (quoted in Lehoux et al., 2006:2092). Bloor

argues the facilitator should not be marginal to the group. Rather, they should be a background figure more like a stage manager (Bloor, 2000:52). This is partly how I envisage my role. The disadvantage of this, Bloor suggests is in the potential for the facilitator to have undue influence on the dialogue based on their own experience rather than the group's experience (Bender and Ewbank, 1994:68, Bloor, 2000:49). This is something I am very concerned about and a significant focus of this chapter. The advantage of focus group discussion is that the interaction between the group members can bring to light issues they may not have thought of in isolation, as well as creating a forum to attempt to reach a consensus on criteria for the design of space for my doctoral research (Bender and Ewbank, 1994:65). In my case although the user-led focus groups for my doctoral research, will depend heavily on the facilitation skills of the group members, rather than an individual facilitator, people may still look to me for guidance. This is complicated by the fact that, while acknowledging that we are all on the spectrum of autism and disability, any disability I may have affects my life to a very much lesser degree than most of the co-researchers. Therefore, I am in a different position to many researchers who work with user-led groups.

This is the central issue in my doctoral research. User-led focus groups are a good way of discovering from the inside out what the requirements of autistics are. Beresford refers to an important point made by a researcher working with wheelchair users:

> Every single one of them said that there were bits of their lives that they could do if they had the right wheelchair but nobody ever asked them what they wanted to do, so they never had the right wheelchair (quoted in Beresford, 2007:336).

This clearly illustrates the assumptions made about the lives of wheelchair users by previous researchers, with implications for disabled people's social and economic participation. Direct contact would have highlighted these issues and promoted wheelchair users' rights. The prevention of situations like this informs my research design and methodological development. Beresford, who has carried out research into the effectiveness of user-led focus groups used with psychiatric survivors, states that participants highlighted *'…its ethical, practical, philosophical and methodological*

advantages over other research approaches.' (Vernon, 1997; Lindow, 1999; OpenMind, 2002; Beresford, 2003; Faulkner, 2004 quoted in Beresford, 2007:338) Methodological benefits were not limited to relevance, including the identification of new issues, the filling in of gaps left by other research. Beresford's participants also argued that it is inclusive allowing for collective advocacy and empowerment, with a commitment to change (Beresford, 2007:335,336,337). User-led focus groups are an ideal setting for this; the application of 'the hyphen' (which I describe in the following section) keeps the research relationship under constant revision. This allows me to monitor my attitudes, interaction and position in the group, to avoid becoming dominant or directing the agenda, whilst producing usable research.

My doctoral research will focus on autistics' daily existence, which is coloured for most by experience of discrimination. This focus will challenge socially held assumptions about their lifestyle and aspirations as well as their access requirements. Critical theory addresses this focusing on how reality is shaped by forces outside the individual such as political, economic and gender relations that become fixed over time. In this case it includes assumptions about the lifestyles and aspirations of disabled people, compounded by inaccurate conceptions of autism which create unequal social relations (Guba and Lincoln, 1994:109). Critical theory takes a subjective view of this reality using dialogue between the researcher and participants to uncover it. This addresses methodological design issues which traditional and user-led focus group design do not (Guba and Lincoln, 1994:109). The addition of critical pedagogy, Fine's concept of 'the hyphen', fully described below provides a framework for negotiating difference. Performative ethnography used in my enactment aids my accessing and understanding autistic perceptions concepts that are beyond my present range of experiencing. This will be the focus of my ethnodrama which will inform the creation of a methodology enabling me to work alongside autistics acknowledging our differences without pathologising, romanticising them or arguing we are the same (Jones and Jenkins, 2008:474). The hyphen examined through ethnodrama provides a good starting point for understanding and articulating these issues.

The hyphen

The need to address these issues led me to look in detail at Fine's concept of the 'hyphen'. The hyphen in grammar is used to link words or phrases that are linked but different. This is also true in Fine's use, relating to any aspect of human diversity having commonalities and differences. Fine argues that recognition of these is vital to the research process. This concept opens up discussion of the issues surrounding the relationship between the researcher and those who are marginal. Fine uses the hyphen to articulate the epistemological and ontological distance between

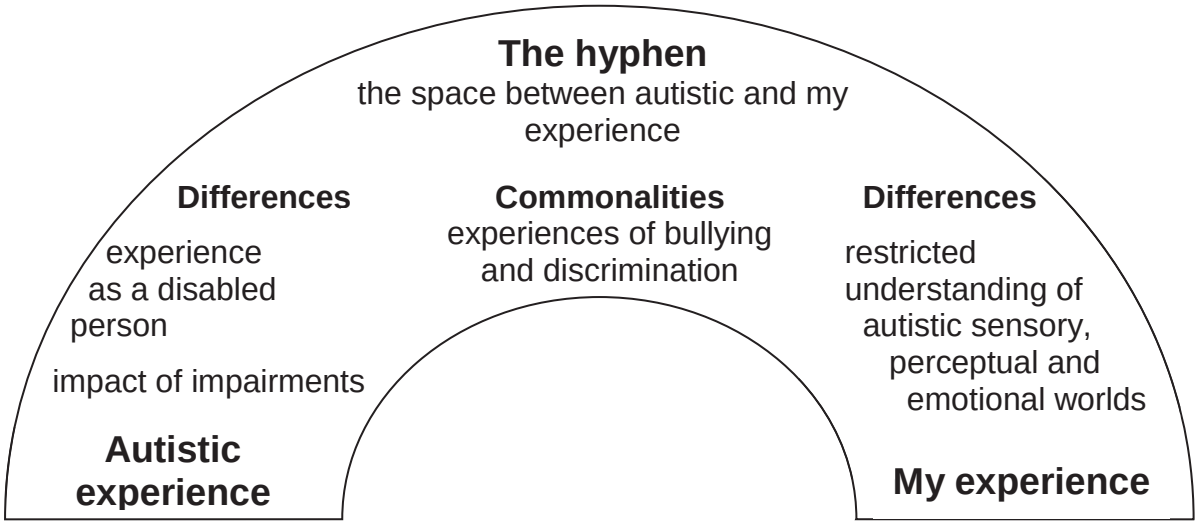

Figure 2 diagramatic explaination of the hyphen

researcher and 'Other'. She argues that 'unearthing' the blurred, 'knottily entangled' boundaries between self and Other is critical. In my case this involved noticing internal contradictions, for example my endorsement of autistic existence, whilst resisting autistic self-identity (Fine, 1998:134). Fine argues that collaborative examination of the research relationship resists Othering whilst disregarding the hyphen perpetuates it. This omission, by obscuring dilemmas, protects privilege, secures distance, and laminates contradictions. Fine states that researchers are always caught up where the 'Self-Other' joins in the politics of everyday life. She argues the hyphen separates and merges personal identities with our inventions of Others (Fine, 1998:131,139).

Jones and Jenkins suggest this creates a complex, uneasy, unsettled relationship, based on learning (about difference) from the Other, rather than learning about the

Other suggesting this '...straddles a space of intense interest.' (Jones and Jenkins, 2008:473,471). The hyphen creates open sites of learning on both sides of the collaboration, learning from difference rather than solely focusing on the Other (Jones and Jenkins, 2008:480). I believe the key is to attempt to ameliorate or eradicate the hierarchy between the researcher and participants to create a consensual relationship based on mutual understanding and respect, rather than one based on ability and disability.

This highlights the messy intersection of power and cultural domination lying between the temporarily-abled and those perceived as neurologically different (Jones and Jenkins, 2008:473). The 'politics of the hyphen' in this case are where my and autistic identity overlap; complicated by my socially derived, internalised ableism, and autistic experience. Other issues are understanding concepts such as context blindness and alexithymia, for instance difficulties in emotional regulation which do not always fall within mainstream discussions of autism (Berthoz and Hill, 2005, Williams, 2009, n.d.). Also present is the conscious and unconscious wish to erase, soften, deny, consume, expand, homogenise, or romanticise this division wishing to handle pain at injustice and confusion (Jones and Jenkins, 2008). This arises when I need to confront culturally determined, internalised norms, rather than struggle to understand autistic's sometimes very different conceptualisation of social norms (Jones and Jenkins, 2008). The hyphen assists me to avoid over identifying or taking a static view of my ever evolving relationship with the co-researchers .

I decided to explore ethnodrama as it allows me to look at the hyphen as the gap between autistic and my experience of space. Ethnodrama is also used by critical theorists to challenge existing structures to create change by allowing people, in my case the researcher, to experience the research data in real time. My method is also influenced by autoethnography, the idea of using the self, in the creation of my character to learn about the 'other', in this case autistic people (Jackson and Mazzei, 2008:300ff). Ethnodrama allows me to do this by living out, as far as I am able, given my 'allied' status, the descriptions that I have encountered of autistic interaction with space (Alexander, 2005:411). A similar process was followed by students doing research with migrant street vendors which illustrated the precariousness of the street vendors' lives (Alexander, 2005:413). My initial aim is to explore the possibility

of creating an emotionally charged encounter, beyond my experience of sensory and motor issues, but which includes the effect of my behaviour on those around me.

My ethnodrama consists of my simulating some autistic characteristics and then walking around a North London suburb, which I will explain in more detail in Chapter 4. To create my character I used principles from method acting, to develop a thorough understanding of Anne, a characterisation of a middle-aged woman with autism, by exaggerating my own idiosyncrasies and inner emotional state.

I chose method acting to inform my performance because of its action in stimulating and strengthening the unsaid and ability to present the acting out of moral dilemmas in similar way to ethnodrama (Verducci, 2000: 88). Verducci argues that method acting nurtures empathic capacities both in the audience and the character, demanding an internal shift to into others' perspectives and their affective life (Verducci, 2000). Verducci quotes Nodding who argues that '…when the other's reality becomes a real possibility for me, I care' (Verducci, 2000:89). Verducci states that 'An ounce of behaviour in the actor's world is worth a pound of words' (Verducci, 2000: 90). She goes on to state that when an actor substitutes something from their own life into a play it arouses an emotional response similar to that of the characters (Verducci, 2000: 93). This allows the actor to experience moments of the performance as if they were happening to them. This is important, giving me a sense of how it might be for autistics. However, Verducci points out that we can never fully comprehend the world of another. Despite this, Alexander argues we can experience and understand the culture under study in a new way (Alexander, 2005:413, Verducci, 2000: 93). Verducci argues that drama provides a forum for addressing the complexities and ambiguities of moral dilemmas, which is something Denzin also argues (Denzin, 2009:159-162, Verducci, 2000: 96). The moral dilemma in this case being the right of ease of movement in public and private space and the competing access requirements of other users.

Ethics

One of my main concerns in creating, the ethnodrama was that the characterisation may be universally applied to all autistics, people who have learning difficulties or

psychiatric survivors. I could see no way of completely avoiding this possibility especially as I would not be able to explain to everybody what I am doing. Therefore, I gave very careful thought to the quality of my performance and the development of a credible character that had integrity. In addition, I wanted to play out behaviour I have witnessed as a support worker, which results in condescending and unhelpful responses. I questioned whether this would restrict it to being a cathartic and expressive exercise. I worried that it may not meet the requirements of my research or further understanding regarding autistics with sensory issues, experience of space, and their right of access. I concluded that the benefits outweighed the disadvantages and worked with a professional drama coach to get feedback on the integrity of the project and my characterisation.

Ethics of using ethnodrama to deceive

The other ethical consideration was deceiving the audience. Would a method other than ethnodrama be more effective? Would the end justify the means (Thomas, 2009:129)? The message of Milgram's controversial research which involved asking participants to give an electric shock of increasing severity to another person, shows us how easily we obey rules even when we believe they hurt another. However, for some of the participants administering the shock caused great distress. Was this justified by the outcome of the research? Milgram hoped it would be a paradigm for the study of obedience, however it was cited, more than replicated and the controversy it raised deflected attention from the issues of obedience to authority. In my case whilst feeling very uncomfortable about the possibility of making life difficult for others and deluding them – I am normally a very honest and compliant person – my main concern rather is that my character is an honest and convincing character, who while different also has integrity. However being somewhat unpredictable and 'strange' could leave some people feeling threatened. Nevertheless, in a controlled way this is how I want people to experience my character, replicating how uncomfortable we feel if someone exhibits behaviour that is perceived as culturally inappropriate. I felt that this end justified the means. Conquergood argues that when ethnographers get close to their data *'life is not always pretty'* as are the consequences of being perceived as 'not OK' (Conquergood, 2003: 399). The other issue was safety; having obscured vision meant I could not see cars or people

without turning my entire head, which then meant I could not see where I was going. However, my support worker, Alison, was pointing out obstacles; she only had to steer me around a few things. Alison had past experience of working as a support worker and was ready to stop me if I was doing something that would cause risk to others or me.

Validity

I measure the integrity and validity of my ethnodrama performance against an evaluation of experimental ethnographic texts of a number of North American and indigenous scholars by Denzin (Denzin, 2003). Denzin creates a set of criteria around which my performance is based. He argues that the performance must assert the authority of the culture under scrutiny, encouraging respect and a wish to be educated on behalf of the viewer regarding the reality of the participants' existence beyond social stereotypes (Denzin, 2003: 254). To do this I carefully constructed my character, considering how I could portray her in a way, which illustrates the issues, simultaneously demonstrating her integrity and worth and stimulating interest. Richardson argues the performance must also contribute towards understanding (Richardson quoted in Denzin, 2003: 255). My performance quickly brought me in touch with the reality of motor processing and visual issues. However, I have to be aware that my perception is limited to my experience that in all probability is not the same as other autistics, autism being a spectrum condition. However, it represents reality for me as a researcher as I experience in real time the effect of space on my behaviour and other people's reaction to me (Richardson, 2000: 254). Another criterion is that the performance must reveal the vulnerability of the author (Richardson quoted in Denzin, 2003: 255). In my case, my vulnerability is evident in the exaggeration of my idiosyncrasies and vulnerabilities, things I do anyway, but stripped of social conventions.

Other criteria are that the work must generate new questions (Richardson quoted in Denzin, 2003: 255). In this case, a question for me was does limited vision mean autistics are less emotionally responsive because they cannot see to copy or react to the emotions of others? Is it because of this some do not fully learn social conventions or respond emotionally, rather than it being an inherent impairment.

Another criterion asks whether the research encourages new research practices and a move to action. The presentation of my work, as an ethnodrama and discussion at the future 6th International Conference of Qualitative Inquiry, will hopefully lead attendees in their roles as educators and researchers to consider their interaction with students and research participants they perceive as different (Richardson quoted in Denzin, 2003: 255, Richardson, 2000:255). This research has also given me valuable insights into my practice as a support worker.

To sum up, Denzin argues that ethnography should unsettle, criticise and challenge taken for granted, repressed meanings, inviting moral and ethical dialogue, with the researcher reflexively clarifying their own moral position (Denzin, 2003: 257). He values performance that engenders resistance and offers utopian thoughts about how things can be changed (Denzin, 2003: 257).

Positionality directly related to this method

As a starting point, I needed to understand my attitudes to autism, having a legacy of culturally derived, discriminatory attitudes to and limiting perceptions of how autistics function, through being part of a society that does not ascribe equal value to disabled people.

Martin and Talpade Mohanty suggest the destabilisation of identity is related to the notion of *'…home as a site for constituting self and expelling Others.'* suggesting that *'...the giving up of home will necessarily mean the giving up of self and vice versa.'* (quoted in Fine, 1998:134) I use 'home,' as a metaphor for my identity to explain my feelings of insecurity, facing what I have fought most of my adult life not be, except on my terms, what Murray terms an 'oddity' now not only do I have to recognise, it I have to embrace it (Murray, 2009). I have a similar reaction to Cowen who recognised his autistic cognitive style, but when faced with the suggestion that he was part of a 'beleaguered minority' was surprised and not ready for it (Cowen, 2009:2).

Using critical methodology and the hyphen to achieve an equal relationship and understand the world from a diverse community such as that of autistics needs

flexibility and ingenuity. What Kincheloe terms 'theoretical dexterity' which Cannella and Perez argue *'requires an intellectual agility and flexibility that facilitates revision of research conceptualisations and purposes as data is collected and analysed...*' (2009:171). This leads to the development of 'critical bricolage' which they argue requires a deep understanding of theories and conceptual lenses from a wide range of life, geographic and power locations (Cannella and Perez, 2009:171).

The need for this broad focus led me to look in depth at critical pedagogy which has its roots in the work of Freire. Here the focus is on research participants as agents in a process that scrutinises the structures that uphold marginalisation and challenges existing hegemonies of knowledge. Critical theory also looks at the relations of research production through for instance, as I have discussed, Fine's conception of 'the hyphen' and critical indigenous research methodologies. This is also a central focus of disability research, the argument being that whilst non-disabled people commission and control research the relevant questions do not get asked due to non-disabled people's assumptions about disabled peoples' lives (Oliver, 1992).

Performative methodology addresses issues as a continuum from challenging existing structures in texts to enacting them as ethnodrama. It allows people experientially to engage with data both through the playing out of moral issues and engaging emotionally with them (Denzin, 2009:159ff). In my case performance is to allow my 'audience' and myself to live the data (Alexander, 2005:415). This data concerns the experience of being in a space with someone who not only behaves differently but also makes demands on those they share the space with. We are supposed to accept people with disabilities but do we really? The purpose of this is to illustrate the dilemmas involved in this. How accepting are we really? Who do we want to share space with? Do we tolerate people who think differently, are somewhat out of step? Do we try to exclude them? Would we rather they were not there, and what can we do about it? What is it like to not be able to see well or not feel well, or to find it hard to marshal all one's body parts to co-ordinate movement whilst dealing with noise and visual clutter and the expectation of the following of social norms?

These are issues I go on to explore through my performance described in the next chapter.

Chapter 4

Ethnodrama Film Study

Purpose

The purpose of my ethnodrama is for me to experience some of the issues faced by people on the autistic spectrum as they move around in public space. My intention is to create a simulation of these experiences. This is to gain some understanding of what is happening physically that makes it so difficult for those on the spectrum with sensory processing and integration issues to access both indoor and outdoor space. Another issue is how their behavioural responses to the sensory and social demands of the space affect their acceptance in that space. This recognises that autistics' behaviour can unsettle others' perception of what is normal/abnormal, acceptable/not acceptable. I shall undertake the ethnodrama by setting up a scenario that consists of a walk around the streets of a London street including a visit to a park and a shop.

My character 'Anne'.

The character I have built around Anne is based on the assumption that she as with most of her generation were left undiagnosed, autism being seen as a manifestation of childhood schizophrenia in the sixties (Autism-PDD.NET, n.d.). This means that she has never been diagnosed with anything apart from hazy references to mental health issues and learning difficulty. Anne's mother is still alive (72) and buys clothes for her; she is not close to her family, having been sent to boarding school/residential establishments from age 4. She sometimes refers to this period as an unhappy and abusive time but does not say why. Anne lives in her own flat, which she owns and has support workers who come twice a week to help with, housework, shopping, and bills. Anne's flat is controlled by the workers who constantly change and often have very little training, finding her 'rude', 'challenging' and unappreciative. Anne works in a university, where she obtained employment when she went there as part of a research, project. Anne has her own little room, no windows, and unheated, which she likes, because she cannot tolerate heat and there is less sensory stimulation. Anne publishes papers in journals, usually co-authored because she has brilliant

ideas but cannot make them into 'academic speak'. Anne also appears as the token autistic at conferences to tell interested others about ‘how she copes’, but never to have a say in structural changes that would make her less marginal. Anne would rather use the internet than talk. This means she does not talk very often, but when she does, she is very direct, her voice is loud, and monotone, her conversation is often out of sync with those around her. Therefore, she is reluctant to engage in conversation. Anne is also deterred by the unintended consequences of her directness, her wishes not being acted on, and her lack of awareness of social conventions, which irritate her. Assumptions are made that Anne has no feelings and therefore does not care, which frustrate and upset her. Anne is quite prominent in the autistic and research world, where she communicates by internet, because it does not require an understanding of facial expressions or vocal intonation. This goes unappreciated by her support workers.

During my preparation for the walk I spent many hours imagining every aspect of Anne’s character, how she would move, how she would respond to particular situations, setting up various scenarios in my head (Johnstone, 1994:1152). Allowing myself to be possessed by the mask of Anne’s character (Johnstone, 1994:144), I ‘thought’ myself into my character and developed a mixture of defiance, wariness and compliance that I had witnessed many times within those I worked with, one or a combination of attitudes, which could emerge at any time. I could have well have misread these emotions or they were perhaps masking fear in the person I was working with.

Method/Process

Characterisation of Anne

The mere process of researching with the intention of acting out what I had read in the literature gave me key words to further my research. I was surprised that even preparation was giving me new data, allowing me to make new connections with the literature and my experiences as a support worker.

A key element of method acting is imagining the background of the character. I developed this with Alison Goldie, a drama facilitator (Goldie, 2009). I felt it was

essential to have input from a qualified person to ensure that my character was believable and had integrity. Although creating a stereotype is unavoidable, I wanted to make sure this was considered, not excessive or inaccurate and limited to what is needed for my research. This is to experience what it is like to be in spaces where my character is viewed as ‘other’ and attempt to take control of that environment on my character’s own terms as a disabled person. My character is a collage of personalities including my own and to be believable I created someone who has some similarities to me. Anne, in a sense, had to become my alter ego.

Once I had given her a story I then had to create an internal world to give me ideas about how environments might affect her behaviour (Verducci, 2000:89). Method acting provided a framework for this together with my experience gathered from working on and off with various groups of neurodiverse people for 25 years. Verducci argues that method acting nurtures empathic capacities and an internal shift to the perspective of those being enacted to understand their affective life. Underneath her at times controlling and overbearing appearance, my character is watchful, her sensory world is unpredictable and she is confused by the stimuli around her, which is compounded by confusion about people’s intentions and expectations, caused to some degree by her distorted vision and difficulty in recognising people (Bogdashina, 2003:127, Gerland, 1997:88ff).

Anne's appearance is disjointed, to create ambiguity, reflecting her multiple support workers, her mother, and Anne’s taste in clothing. Anne wears a baseball cap, quite a good quality one pulled down over her face with dark glasses to keep out the light and reduce other sensory stimulation. I have created a lining for the glasses that is not visible from the front with a half centimetre diameter hole in the middle to obscure my vision. This makes Anne move and hold her head in a strange position as well as limiting her vision. She wears a shoulder bag in an unconventional way around her neck and as the straps are too short this looks strange. For this research, she wears quite a modern suit and polo neck jumper but with a very worn t-shirt with a strange message across the front and dangly, large pink earrings.

In addition to sensory issues, my character also has issues with proprioception – that is, understanding where her body is in space – appears floppy and clumsy, and

rocks when not occupied. Rocking gives Anne an awareness of her body, blocking out and providing comfort when her sensory system becomes too overloaded (Bogdashina, 2003:60). Researching and then practising enacting these issues provided me with important information regarding the understanding of their effect even before I carried out the walk.

Method

The ethnodrama consisted of a walk around Crouch End, a typical Victorian North London suburb. It was beginning to get dark at the time. I was in the clothing outlined above. The glasses had an inner paper lining in each lens that had half a centimetre hole in it that I looked through, which severely restricted my vision. The glasses were sunglasses with reflective lenses that hid the hole in the paper. The route was a circular one, taking us through several residential streets, a park and a shop. Alison took on the role of support worker, to give her a reason for being with me and to keep me safe. The walk took place at half past three when children were coming out of school, despite the time; the gloomy weather meant that dusk was drawing in fast, restricting visibility.

To create the posture and movement for this walk I used method acting and techniques regarding posture and body awareness from the Alexander Technique. This gave me a method of thinking myself into my character, going into my body to imagine it as a jumbled mass of parts haphazardly or unconnected with each other depending on what was happening (Johnstone, 1994:152, Williams, 1998:49ff). I combined this with internally creating a visualisation of my character becoming like a puppet with no strings, a body with no muscle tone, that I have to propel haphazardly in the direction I want to go (Freitag et al., 2007:948, Vernazza-Martin et al., 2005:91, Xue et al., 2007:565). This gave at least a partial stimulation of the difficulties of motor planning experienced by many autistics (Xue et al., 2007:565). The results were a distinctive very fast floppy walk, which even half way through the session I found exhausting. I did not get much pleasure from it.

The gait and body language I used is a mixture of what I have witnessed as a support worker and read about in the literature (Bogdashina, 2003). In this state, toe

walking and lack of body tone and motor co-ordination means that I am forced to lean forward which propels my body forward giving it a haphazard momentum making stopping and changing direction haphazard and hard to control (Xue et al., 2007:566). This means that I move forward very fast and then appear to stop suddenly often looking like I am just about to bump into someone or something due to my limited sight. Limited sight means I do not see things until the last minute my poor muscle tone and co-ordination make it hard to slow down. My fast walk at first was also partially due to feeling self-conscious, but I soon entered a state where I became unaware of what others thought, partially due to my limited sight and the difficulty keeping on my feet. As I entered into the ethnodrama, my lack of sight left me with a feeling of being cushioned from the people around me making me less self-conscious. With obscured dark glasses and dusk starting to draw in at the end of the walk, combined with my poor muscle control and motor planning meant during the ethnodrama I was somewhat of a liability. I could have been perceived as having no road sense but my restricted vision made it hard to see the curbs unless they were several feet away. Unless I looked down, I could not see them and if I did that then I could not see where I was going because the glasses give me tunnel vision (see figure 3).

Figure 3 This photograph shows the position of the holes in the plastic insert placed behind the lenses to obscure my vision

The effect of the glasses was that at one stage I nearly walked straight into a lamppost due to the offset of the holes in the glasses. With tunnel vision all of a sudden there is much more information to take in, in a very small space of vision and time and it is hard to get an overview of what is happening. With no restriction of my vision, I would have been able to take in whatever I was seeing without even thinking

about it. Here a lot of the time I was just guessing and hoping I did not get run over or fall over! I had to turn my entire head to see cars. A possible explanation for some autistics concentrating on detail at the expense of the whole could be that this prevents them falling over or hurting themselves?

Findings

The street

The pavements were also uneven; even a slightly raised area caused by a tree planted in the pavement was enough to throw me off balance. Also wearing court shoes instead of trainers was uncomfortable for my feet and added to my instability. The thin soles of the shoes meant I could feel every crack in the pavement; the unevenness and my unstable gait meant that despite very moderate heels I was often painfully turning my ankle. The momentum of my body meant I did not stop, or prevent it, just carried on, the imbalance resulting in the sole of my foot hitting the ground hard, painfully and feeling very strange. Like what it was, a thin piece of leather hitting the ground that may or may not find a flat surface, with consequences for my balance and ability to navigate round people and the pavement. I could not rely on my feet to balance me – that created constant uncertainty. The discomfort of the impact of my feet on the pavement was a major distraction. Lack of vision I think focused me much more on how I was feeling than normal. Any kind of unevenness in the pavement came to awareness as a sudden jolt needing me to realign my body quickly. My unstable gait meant I was always in danger of bumping into Alison, making it hard to walk beside her and focus on where I was going. This meant I could not look at her to gauge her facial expressions and neither could she see my expression. Part of the difficulty was due to the narrowness of the pavement. I had to react far faster due to my restricted vision because modifying my movements meant I had to take concentration away from where people were in space, which meant I bumped into them. In addition, I was aware of the children and did not want to frighten them or hurt them. Sharing the pavement with them and their associated buggies gave a good feel of difficulties of navigation; complicated because the very young ones were below my line of vision. As I walked, I was acutely aware of multiple stimuli, and tasks, cars, people, children, buggies, the cracks, and unevenness in the pavement, the need to be aware of curbs and lampposts. Walking

along the street unless I looked directly at the ground I could not see where my feet were in relation to the edge of the pavement. This led me to fall off the edge a couple of times, which jarred my whole body. In addition, I could not see traffic coming from behind me without turning my head, which meant I could not see in front of me, to see where I was walking. So when looking I could only focus properly on one thing at once, I could not focus on cars, people and where my feet were at the same time. Alison was directing me, but a lot of it I did not hear because I was concentrating on keeping on my feet. That was my prime target. Keeping on my feet and trying not to bump into people. Then all of a sudden despite Alison's warnings a hedge would hit me like a lighter version of a punch bag that I would bounce off, having to regain my balance. The sudden movement would hurt my feet as the court shoes wondered round my feet and the soles of my feet hit the pavement with the middle of the sole, more often than not on a crack. The shoes were quite loose although they were my size; ill-fitting shoes are common in my experience as a support worker, we forget to check they still fit and if the person does not or cannot complain nothing happens. Alison was keeping up a continual conversation similar to the ones I often have with the people I work with, although perhaps she was jollier and less confident. However, Alison did not know this character that was moving fast, talked in a loud monotone, saying whatever came into her head which was very direct and often critical. E.g. when Alison pointed out the hedges overhanging the pavement so I could avoid them:

> 'They should cut their hedges, can't have hedges taking over the pavement, I bump into them, I don't like it, make them cut their hedges they ought to have by laws against it. The council should do something about it. The council should prosecute them...'

And off into great tirade, delivered in what could be concluded to be a loud, demanding, aggressive monotone.

For a lot of the time it was hard to talk and walk, never mind navigate my way, stay on the pavement, not walk into people or be run over. This could have been because I was thinking of the answers to Alison's questions, which I may not have been doing if I was autistic. However, most of the time I was just responding to what was around

me, using improvisation techniques and experience of some autistics' dialogue with an awareness that this may also reveal my inner world out of character as once dialogue starts, it is as if the story is being told by an outside force (Johnstone, 1994:75ff,131). For many autistics' social inhibitions are to some degree impaired therefore some are very direct or spontaneous in their conversation and their interaction with their environment, often saying whatever comes to mind to which works very well with improvisation (Johnstone, 1994:131).

Crossing the Road

Walking across the road, I took my life in my hands, although Alison was ready to intervene to keep me safe. Limited vision meant I heard traffic but could not see where it was to avoid it. I could not automatically see the curb and had to coordinate my body to turn without falling down the curb. Then to cross the road I had to navigate the camber. Going up and down over it was intensified, then I had to try and see the opposite curb edge so I did not trip, trying to control my body so I could move through the people on the other side, consisting of adults and children some of whom because of their size I could not see. All of this in a very short time with no co-ordination. This meant that I hesitated going down the curb and going up the curb the other side. This affected my ability to judge the time I would need to cross the road. This is a common experience I have working with service users in my role as a support worker.

The Park

I began walking through the park, as it was getting slightly darker which meant that through my glasses the things I saw were indistinct. Alison was pointing things out, but the curved path and its narrow width meant that my attention was focused on staying on it. I constantly found myself with half my foot on the path and half usually, the heel pressed in the soft grass on the side of the path, slightly twisting my ankle each time. This created uncertainty similar to being on the pavement about where my feet were and what my feet would feel, a hard, or half hard surface with my heel stuck in the grass, although this was less uncomfortable there being no height differential between the grass surface and the path. This affected my balance and ability to move. This made it very hard to listen and respond to Alison, who was making social chitchat, which I remember very little of despite having a very detailed

recollection of what my body was doing. I do remember Alison pointing out a play area and flowers, but I could not see them clearly as moving, talking and looking, beyond seeing where I was going was too difficult. Looking required me to turn my head, which meant I could not see where I was going. If I looked at my feet to keep them on the path then I could not see what was in front of me. If I took my eyes off the path, which was only about a metre wide I would bump into Alison or find my heel yet again stuck into the grass. Many autistics do not like what would have been intermittent, sudden unpredictable light touch, finding it painful (Grandin and Scariano, 2005:36). My focus was remaining on my feet, not on my surroundings beyond the pavement I was trying to walk on.

The Shop

After the park we went into a shop, again I needed to locate the step, but once inside the floor was smooth and predictable, although the light and the visual clutter of the shop's stock came as a shock despite the dark glasses. To find what I wanted I had to turn my head. I spoke in a very loud voice choosing and getting Alison to buy me a drink. I could not see how people were responding, with my restricted vision, although the shopkeeper did not seem at all perturbed. On reflection, it would have been better if I had brought the drink myself, as that would have created direct contact.

Limitations

A major limitation was that the glasses and remaining in character meant I was not aware of people's reactions. Alison reported very little reaction to my performance apart from one woman who looked at me suspiciously. She explained this was why even documentaries had scenes set up to illustrate the point being made rather than relying on spontaneously occurring demonstrations of the issues being reported. My awareness of peoples' reactions was very restricted due to my limited vision because of my glasses being obscured. This was a major drawback, as was not incorporating more verbal interaction with the public or perhaps going for a meal. In my role as a support worker, overt issues are people either openly or surreptitiously staring in restaurants and shops. Other issues are the waiter or sales assistant talking to the support worker rather than the disabled person.

Reflection on the performance

Anne's presence during the enactment was a complex one. Anne's voice and speech was overbearing and overconfident, yet my voice and the fixed views I was verbalising gave a flavour of some kind of difference and vulnerability. Whereas Anne's behaviour was a mixture of wariness, ready to fight or flee due to the fear of sensory overload, fear can often be felt as aggression by the observer complicating any interaction due to sensory overload (Grandin quoted in Calvi, 2005). This unpredictable 'behaviour' draws attention to many autistics as it is seen as a threat, people not knowing how to read them (Johnstone, 1994:83). Johnston refers to this type of activity and presentation as 'status' stating that it is something that is constantly being read and negotiated both consciously and unconsciously in society. Many autistics have no conception of these subtleties so my character, Anne, manifests mixed messages regarding her status and her understanding of other people's status adding to the confusion (Johnstone, 1994:33ff). Anne's unmodulated voice could also be seen as aggressive or unnerving as I imposed my views in a diatribe without waiting for an answer. Anne's floppy body language and moving quickly did not match her tone of voice also adding to the confusion. Therefore, my speech and body language were giving several contradictory messages at once to the people in the street. Despite this, Alison did not report much overt staring probably due to 'British reserve'. Another factor could have been that in the street people could move out of the way or move on, my presence was imposed on them less than say in a restaurant or shop where space is more limited. Here my presence would have been more immediate and for longer and people having to spend more time exposed to my 'behaviour'. I did get the sense that people were moving out of my way but I did not want to test this too far as the pavement was pretty crowded at times with a lot of small children. Despite being unable to judge the public's response, I got far greater feedback than I had imagined about the difficulties of moving around in space with limited sight and poor motor co-ordination. The enactment placed me at the centre of the data as it was emerging, allowing me to develop my own understandings which resulted in changes in my perceptions and attitudes (Alexander, 2005:413, Jackson and Mazzei, 2008:300ff).

The effects of these changes I will explore in my conclusion.

Chapter 5

Conclusion

This research started by looking at focus groups to legitimate the voice of autistic people in preparation for my doctoral research. However as my research got underway, my role as a researcher with a predominantly nondisabled identity came to the fore. This highlighted dilemmas regarding whether the research would be truly user-led or would resort to traditional hierarchies and ways of seeing the world, which assume majority functioning is automatically superior to autistic perceptions. Overcoming this possibility and increasing my understanding of autistic people's spatial experiencing became my priority. From my literature review and my contact with autistic people, I found that there is a distinct autistic culture that for most involves a distinctive way seeing, understanding and therefore operating in the world (Davidson, 2008:794).

This led me to explore in this work a range of methods for working with others, which will form the platform for much of the work that I shall do in the doctoral element of my research. This focus led me to critical methodologies such as critical pedagogy whose objectives I found best matched with my positionality, the issues, and aims of my research. Critical pedagogy aims to expose and critique the structures that support inequality through a dialogic process. The dialogic process meets with the objectives of my research aiming to involve both the researcher and co-researchers as agents, within a non-hierarchical relationship. I also looked at indigenous methodologies, where the goal is to create a relationship with the research participants based on mutual respect, and equal value of the research participant's worldview and ways of knowing. Thereby indigenous research aims to study from within the cultural lenses of those under study, which is one of the aims of my PhD.

I have also explored 'the hyphen', which provides the opportunity for examining in a carefully framed and structured way my encounters with those with whom I intend to work. By doing this it offers the possibility of framing these interactions dispassionately and in such a way that the possibility of over-identification or romanticisation is minimised. The hyphen by acknowledging difference and exposing

them to scrutiny provides additional understandings of the data and the research relationship. Exploration of the hyphen also allows for an ongoing renegotiation of the research relationship to address any tendency to resort to taken-for-granted assumptions or hierarchies that may distort subsequent data.

I have also empirically explored ethnodrama by analysing and dramatizing and temporarily living out issues that I have observed, read about and discussed with autistic people (Anderson and Jones, 2009:299ff, Schipper et al., 2010:2). This work is therefore an extension of my original methodology to give me a clearer understanding of something approaching an experience of autism and an autistic's experience of space. The application of the hyphen to ethnodrama gave me significant understanding of how it might be for a person with autism.

Despite limitations arising from my not having a fully autistic identity, ethnodrama gave me a deeper understanding of autistic spatial experiencing than my previous contact with the autistic community had done. This includes experience as a support worker, reading, and seminars. One crucial insight was that if one or more senses are impaired it means having to be more efficient at processing sensory information to compensate. I feel this cannot be merely accepted in terms of the person accommodating in other areas. Therefore, the assumption that a person has poor sight, for instance, equals less ability to see may not be correct. It could be that this reduction means that the individual could be using whatever sight they have more efficiently. This shift in perception has implications for changing other understandings. For instance, I felt that focusing on my ability to stay on my feet restricted my interaction with other people and the environment. Could this be why some autistics appear very aloof, as they have to ration their sensory processing ability to for instance stay on their feet? Therefore, some people's distance is not due to not wanting to interact, but rather a strategy to stay upright or cope with some other contingency. This was so in my case, I focused on immediate experiencing, details that would prevent me falling over or bumping into people, rather than talking or taking an interest in the global, such as the view of the flowers or play area in the park. Also, my feet hurt and my gait meant that I felt tired. Although I realise that some autistic people find it hard to be aware of other's presence and do bump into people, I wonder if this due to lack of sight or the ability to process others' presence

or something else? Staying on my feet was what I prioritised as important. This meant my attention focused on things in the environment that were immediate to prevent falling, rather than immediately taking in the entire environment, for instance in the park and commenting on it. Conversation mostly had to be dragged out of me, as my priority was to stay on my feet, rather than being interested in what with reduced sight are extraneous issues, such as talking, looking at flowers, play equipment, or people. In addition, the ethnodrama led me to reframe ideas about 'poor' motor processing and visual impairment. Could we see this as different or even enhanced, as it appeared to me that I had to be more competent to overcome impairments of co-ordination and vision? I had to act faster on limited information to prevent falling etc. Therefore, I suggest that autistic people may have to be better at using their senses than others; could this cause an over compensation that results in them becoming more sensitised in both positive and negative ways.

My experience during the ethnography illustrates how autistic experience is and can only be partially represented even in autistics' own accounts. More important is a gradual realisation over several years confirmed by enacting Anne's character about the limitation of my ability to grasp these perceptions, which require intellectual, emotional, and experiential comprehension. Literature and contact only provides a limited intellectual and emotional understanding. This has brought to awareness that understanding has to go beyond intellect and emotional processing, requiring a shift in my own existential understanding of the world (Alexander, 2005:415). This involved the recognition that this is often circumscribed by my socially and culturally prescribed worldview, with norms, ways of knowing and experience that marginalise the experience of those who perceive the world differently. This is compounded by my having less severe sensory reactions, mostly affecting one sense at a time rather than multiply, which is the case in the ethnodrama with my character, Anne. Also my social presentation most of the time does not get negative feedback in the same way as many autistic people.

The implication of this for my future doctoral research is that I can take nothing for granted and that negotiation of the hyphen through dialogue and multiple research methods is going to be needed. For instance, the assumption that someone has poor social and communication skills or is aggressive when I am trying to make 'empathic'

conversation while we are walking. The assumption being made due to their response being terse or out of step focused on their concerns rather than engaging in a mutual conversation. My research showed that this may not be the case, but more that the person has to prioritise focusing on balance, mobility, and wayfinding to stay on their feet and not bump into people. What is superfluous conversation to them in this instance is treated rightly, once you understand, with some degree of contempt. This links to other issues where we often have partial understanding, such as in my case, that whilst all autistics have feelings, some cannot name them, whilst others can do this, but have issues in expressing emotions, especially nuanced ones.

This research has demonstrated to me that I need an experiential understanding of these ideas by exposure to the community on an equal basis. This needs to be based on exploration of the commonalities and difference as manifested in the hyphen. This includes performative research involving experiential enactment to fully understand autistic experience that cannot be comprehended solely by reading – I have to live it. This leads me to wondering what other mainstream ideas about autism and autistic experience I will continue to be reframing. Understanding of these issues is vital as they affect autistics' presentation and interaction with space and other people. How the space and people react directly affects their wellbeing and inclusion.

Tackling these issues means that in my doctoral work I will be much nearer having a foundation for being open to the various ways of knowing and being of the group. This will be combined with a readiness to step outside my own experiencing to be able to discuss in depth the nuances of autistic experience I will find within the focus groups during my doctoral research. I feel have made an experiential shift – albeit a limited one – in understanding space from autistic people's perspective and will be able to apply this to thinking more flexibly beyond my cultural and social understandings of how things might be in my doctoral research.

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