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Faculty of Social and Human Sciences.

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Living without a diagnosis – formations of pre-diagnostic identity in the lives of AS
people diagnosed in adulthood.

by

Michael James Bracher

Thesis for the degree of Doctor of Philosophy

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UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL AND HUMAN SCIENCES

DIVISION OF SOCIOLOGY AND SOCIAL POLICY

Doctor of Philosophy

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By Michael James Bracher

Abstract - Asperger Syndrome (AS) is currently understood as a neurodevelopmental condition associated with difficulties in social communication, social interaction, and social imagination. Many AS people also experience differences in sensory sensitivities and perceptions of the surrounding world. Most diagnoses are now made in childhood; however, there remain a number of people who are diagnosed in adulthood. Within this group, there are also a number who, born before 1980, grew up in an era before the condition had been identified and diagnosed, and therefore spent a substantial part of their lives living either without a diagnosis or with an incorrect diagnosis. This is an under-researched group, whose pre-diagnostic experiences have thus far not been subject to detailed investigation,

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and as such are often poorly or inconsistently understood both academically and by service providers. The primary aim of the thesis is to explore their experiences by addressing the following three questions:

- 1. How do AS people understand their dispositional selves in the pre-diagnostic phase of life?**
- 2. How do self-other relations affect pre-diagnostic understandings of self?**
- 3. How does management of everyday insecurities relate to formations of the pre-diagnostic self?**

These questions will be explored through comparative analysis of seven autobiographies, authored by AS people who were diagnosed in adulthood. The analysis is informed by a neo-Bourdieuian approach to identity through which I develop an account of relations between *authenticity* (one's ability to experience dispositionally appropriate ways of being), *accountability* (referring to the social and cultural conditions of exchange with others) and *legitimacy* (the experience of one's ways of being as valid) as a way of framing some of the issues faced by AS adults in pre-diagnostic life in relation to the themes above. I suggest that this framework can offer a useful perspective on pre-diagnostic issues by drawing attention to the interrelation of dispositional and social circumstances in shaping individual life experiences.

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Academic Thesis: Declaration of Authorship

I, Michael James Bracher, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Living without a diagnosis – formations of pre-diagnostic identity in the lives of AS people diagnosed in adulthood.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references below]:

Signed:

Date:

List of Acronyms

ADRC – Autism Diagnostic Research Centre (*Southampton, UK*)

APA – American Psychiatric Association

APPGA – All Party Parliamentary Group on Autism (*UK*)

AS / AD - Asperger's syndrome / Asperger's disorder

ASD / ASC – Autism Spectrum Disorder / Autism Spectrum condition

DSM – Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association)

GP – General Practitioner

HFA – High Functioning Autism

ICD – International Classifications of Disease (World Health Organisation)

MUS – Medically Unexplained Symptoms

NAS – National Autistic Society (*UK*)

NT - Neurotypical

TD – Typically Developing

WHO – World Health Organisation

Note on language:

In this thesis, I use the term 'AS people' to refer to those who have a diagnosis of Asperger syndrome, in preference over 'person first' forms such as 'person with Asperger syndrome'. My use of this terminology is not in conflict with many of the ideas and ethical aims that underpin 'person first' language, but rather it reflects some of the wider debates around the relationship of autism to disability. These issues are discussed in more detail in 1.3.3.

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Introduction.

In this thesis I explore pre-diagnostic identity formation among people diagnosed with Asperger Syndrome (AS) in adulthood. AS is a condition that is associated with difficulties in social communication, social interaction, and social imagination (Baron-Cohen, 2008a, 1; NAS, 2011a). Social communication difficulties can include problems with facial expressions and body language, or implicit meaning in written or spoken language (Baron-Cohen, 2008a, 58). Many AS people also experience the world differently in terms of their sensory and perceptual experiences in relation to, for example, light levels or patterns, sounds, particular smells, colours, textures or tastes (Bogdashina, 2003, 44-83). This can affect the quality and/or intensity of what is experienced, resulting in hyper/hyposensitivities (i.e. a more or less intense experience of stimuli than the typical range in non-AS people) that tend to be multimodal (i.e. taking different experiential forms and occurring in different sense domains) and pervasive (Kern et al., 2006; Leekam et al., 2007; Tomchek and Dunn, 2007; Klintwall et al., 2011; Samson et al., 2011).

AS-related differences can vary significantly between individuals, and can also be affected by changes in the environment and social context, or emotional state of the person (Attwood, 2007, 279-291). For example, a person may be able to

function comfortably in a setting where an annoying sound is present, if the social environment is suitable and/or their awareness is directed significantly away from the noise (Bogdashina, 2001, 4-7). However, if the social context and/or environment presents other issues, perhaps sensory (for example, too many sounds or lights) or social (for example, anxiety in the presence of unfamiliar company) then this can affect a person's threshold of tolerance (Bogdashina, 2001, 4-7). While problems with social and environmental aspects of everyday life are common features of life for AS people, one should not assume that 'being AS' is necessarily a negative or harmful phenomenon (Clarke and van Amerom, 2007; Baron-Cohen et al., 2009). For many in this group, AS-specific experiences are central to their wellbeing and sense of self and, as we shall see, whether or not one can freely experience these ways of being is constrained by social and cultural constraints (Gernsbacher et al., 2006; Milton, 2012; Milton and Moon, 2012). This is not to state that AS-related differences are reducible to either social or cultural factors, but rather that individual experiences of 'being AS' are inextricably linked to the conditions in which lives are lived (Molloy and Vasil, 2004).

AS is currently classified as part of the Autism spectrum of neurodevelopmental conditions (ASCs); the word 'spectrum' is used because, while these areas of difficulty are common to all people with an ASC, individual experiences can vary

significantly (Baron-Cohen, 2008a, 1; NAS, 2011a). While those diagnosed with 'classic autism' will also have difficulties in learning and cognition, as well as partial or complete absence of speech, people diagnosed with AS will not (Baron-Cohen, 2008a, 29-34). People in the 'classic autism' range often require lifetime care and support, while many AS people have average or above average abilities in a range of areas but may benefit from support in dealing with problematic interactions and environments (Rosenblatt, 2008, 30). Most AS diagnoses are now made in childhood, and awareness of AS has increased substantially since the condition was first introduced into the DSM and ICD in the early 1990s (Baron-Cohen et al., 2007). However, some will not be diagnosed until adulthood, and for them the pre-diagnostic phase of life may be especially challenging, as they meet with difficulties in everyday life that often have no obvious causes (Attwood, 2007; Newport, 2001). Existing research indicates that having a diagnosis often has significant implications for how one understands and presents oneself to others, although the quality of this experience can vary significantly both within and between individual biographies (Molloy and Vasil, 2004; Bagatell, 2007; Huws and Jones, 2008; Singh, 2011). AS people often understand and engage with the social and environmental aspects of the world in ways that are different from many non-AS others (Milton, 2012; Ryan and Räisänen, 2008), and diagnosis can help a person to understand these differences and their implications for everyday life (Baron-Cohen, 2009; Moloney, 2010; Singh, 2011). Conversely, not having a diagnosis can involve

confusion over the reasons for these difficulties, with implications for how one understands and presents themselves to others (Huws and Jones, 2008; Molloy and Vasil, 2004; Rosqvist, 2012; Singh, 2011). Furthermore, those born before 1980 may be at particular risk of having grown up without a diagnosis, due to the lack of awareness of the diagnosis prior to its entrance into the aforementioned diagnostic manuals, and it is to this group that the present investigation is directed (Baron-Cohen et al., 2007).

The main body of the thesis is divided into two sections. In *part one* (chapters 1-5) I will frame the intellectual and ethical context of the project, introduce key themes and research questions, and establish my theoretical and methodological approaches to them. The first step (in chapter one) will be to explore the historical development of AS both as a diagnostic category and an aspect of personal and collective identity. Here, I will draw attention to the fact that AS remains a condition that is only partially understood, with no specific biomarkers or aetiological explanations. As such AS can usefully be understood through Hacking's (1999) concept of the 'interactive kind' involving interplay between biology, culture and social processes and cannot be reduced to any one domain. This is significant because it points to the value of social scientific investigations for exploring how experiences of AS-related differences may be shaped by the conditions of the 'live'

social world. In chapter two I will set out the research case for the general focus and specific research questions that frame my investigation, firstly by justifying the focus on the pre-diagnostic experiences of AS adults born before 1980, and secondly by identifying three specific areas for investigation:

- 1. How do AS people understand their dispositional selves in the pre-diagnostic phase of life?**
- 2. How might living without a diagnosis affect self-other relations?**
- 3. How are everyday insecurities understood and managed in the pre-diagnostic phase of life?**

In chapter three I set out my conceptual approach to framing and exploring these questions. Firstly, I will argue that Bourdieu's interrelated concepts of practice, habitus, field and capital can provide a useful and appropriate framework for framing and exploring the relationship between perceptual differences, dispositionality and social agency. However, this will require a return to the phenomenological underpinnings of his work in order to re-frame some of the perceptual assumptions which underpin his normative concepts, as well as attention to Bottero's developmental critiques. This provides the basis for my approach to identity, drawn from the work of Bottero, who utilises a Bourdieusian approach to frame identity in terms of links between dispositional, reflexive and

collective aspects of self, as a way of overcoming some of the limitations associated with purely reflexive or social constructionist approaches (which comprise the majority of those used to explore AS people's identities) (Bagatell, 2007; Brownlow et al., 2006; Molloy and Vasil, 2004; Sterponi, 2004). Finally, I will introduce the interrelated concepts of authenticity, accountability and legitimacy as 'thinking tools' (Bourdieu, 1990b) for exploring formations of pre-diagnostic self.

Chapter four sets out my methodological approach involving a life story approach, drawing on autobiographies written by AS authors. Here, I discuss the ethical and epistemological advantages and limitations of this approach, and how interpretive and positional issues were managed in reflexive practice during the research. The process of selection and analytical approach will be set out and discussed in relation to the structure of the analysis in part two. Finally, I will give an introductory summary of each autobiography, and indicate its position within the analysis in part two.

Chapter five marks the beginning of part two, where I discuss how four of the autobiographers (Gunilla Gerland, Wendy Lawson, Lianne Holliday Willey and Will Hadcroft) came to understand their dispositional selves in the pre-diagnostic phase of life. I will highlight several themes emerging from the autobiographies: the

development of dispositional self in relation to strengths and limitations, configuration of these understandings as differences, importance of variations in intersubjective and wider cultural conditions for shaping the dispositional self, and the implications of this for a person's ability to experience authentic ways of being. In chapter six, I explore how dispositionality relates to reflexive and collective aspects of identity in negotiation of self-other relations, in the lives of the three other autobiographers (Jeanette Purkis, Jen Birch and John Elder Robison). This discussion here will also demonstrate how, in addition to dispositional aspects of self mediating opportunities for connecting with different social groups, understandings of dispositions may themselves be configured by social participation within the 'cultural horizon' of different fields, and also how pre-diagnostic understandings of the self in relation to others can be shaped by reflexive understandings of dispositional differences. The discussion here will also show how dispositional aspects of self may combine with reflexive and collective elements in formations of pre-diagnostic identities.

Chapter seven explores how management of everyday insecurities is implicated in pre-diagnostic formations of self. The structure of discussion in this chapter will differ from the two previous chapters, as I will explore five of the autobiographies in relation to two themes (i.e. parenthood and the workplace). In 7.1.1, I will explore insecurities relating to parenthood, firstly by comparing how Will Hadcroft and John Elder Robison's dispositional identities shaped their orientations to fatherhood, and

secondly by exploring Wendy Lawson's experience of being a new mother labelled as schizophrenic. In 7.1.2 I will discuss management of social and sensory insecurities in the workplace, and their relationship to pre-diagnostic identities. Here, the importance of social resources in the form of supportive collegial relationships will be explored through Jen Birch's writing, before I turn to Gunilla Gerland's account of dealing with sensorily challenging environments as a day nursery worker. Gerland's narrative will serve as an illustration of how the stress of dealing with everyday insecurities, as well as not understanding the reasons for them, can leave AS people particularly vulnerable to destabilisation by unforeseen events (in this case, her mother's mental health crisis). In conclusion (chapter eight), I will summarise the discussion in the individual chapters, as well as the more general points raised by the investigation, in relation to how they help us to understand pre-diagnostic formations of self. Implications for further research will also be discussed, as well as potential future research directions.

**Part One - Towards an investigation of pre-diagnostic identities
- rationale and approach.**

1 – Framing AS as an object of study.

As indicated in the introduction, the main aim of this thesis is to explore the pre-diagnostic experiences of people born before 1980 who were diagnosed with AS in adulthood. However, the status of AS as a diagnostic category, as well as an aspect of individual and collective identity, continues to be debated in both clinical and social sciences, and therefore it is necessary to begin by exploring these debates. In this chapter, I explore the development of AS as a way of understanding and categorising particular people, their differences and experiences. I will discuss the history of the concept, both as a diagnostic category and as a locus of identity for new communities (in particular, those online), and investigate how these have shaped contemporary understandings of AS. From here, I examine different ways of framing AS in terms of disability and/or difference, especially given current gaps in knowledge. I will discuss my use of language, and the decision to frame AS in categorical terms through Hacking's concept of the 'interactive kind', as something that is subject to variation in terms of application and definition, involving different combinations of social, environmental and biological factors that are only partially understood. The purpose of this chapter will be to situate and justify the ways of understanding and discussing AS that I have adopted in this thesis, in preparation for the next chapter, where I establish the focus and specific questions of this

project, and situate them within the existing body of literature on the experiences of AS people.

1.1 – AS as a diagnostic category.

AS is a diagnostic category that has undergone considerable change throughout its history and into the present day, resulting from a variety of debates within clinical, self-advocacy, practitioner and wider public arenas (Silverman, 2008). For example, current diagnostic criteria for AS have focused hitherto on social and communicative differences, with sensory and perceptual factors classified ‘associated’ rather than ‘core’ features of a diagnosis (i.e. they are not currently classed as necessary conditions for diagnostic recognition) (NAS, 2010, 2). However, in the upcoming Diagnostic and Statistical Manual of Mental Disorders (DSM) fifth edition of the American Psychiatric Association (APA), they will likely be included as core features of the diagnosis (Baron-Cohen et al., 2009, 1380-1382; NAS, 2010, 1-2). This also reflects an increase in research attention, as well arguments made by practitioners and self-advocates, around the importance of sensory and perceptual issues (Kern et al., 2006; Tomchek and Dunn, 2007; Baron-Cohen, 2008b; Baron-Cohen et al., 2009; Schroeder et al., 2010; Elwin et al., 2012).

The status of the category has also been questioned in recent clinical debates; the current edition of the World Health Organisation (WHO) International Classifications of Disease (ICD-10) lists AS as a diagnosis of 'uncertain nosological validity', a statement indicative of the indeterminacy around the category (WHO, 2010). Despite this, current research suggests strongly that AS-related differences in social, communicative and sensory experiences develop as a result of differences in neurological development; however, no specific biomarkers or clear aetiological explanations have yet been provided (Baron-Cohen, 2008a, 85; Tantam, 2012). Thus while no complete neurobiological account of AS exists, differences in neurodevelopment are implicated strongly in AS, albeit with the reservation that there may not be a singular or unitary 'cause' (Happé et al., 2006a; Baron-Cohen, 2008a, 85; Schroeder et al., 2010). Diagnostic criteria are also undergoing change, for example, it is highly likely that AS will be subsumed into the category of 'Autism Spectrum Disorder' in the upcoming DSM-V, while at the time of writing there are no such plans for the next revision (11th edition) of the ICD (NAS, 2010; Singh, 2011; NAS, 2012b). Therefore, it is important to acknowledge that we are dealing with a category that continues to change, and has been shaped by particular socio-historical conditions.

1.1.1 - Historical context

The emergence of AS as a diagnostic category is bound up with developments in the scientific framing of behaviours and traits associated with the condition, embedded within wider processes of cultural and technological change. As Nadesan argues, AS emerged:

...out of a constellation of institutions and practices specific to the early twentieth century that include (1) the emergence of the child as a research focus (2) the emergence of personality [as opposed to exclusive focus on intellectual capability] as a research focus and clinical locus, and (3) the emergence of interpersonal dynamics as a research focus and clinical locus as a source point for individual pathologies (Nadesan, 2005, 26).

The 'discovery' of AS is thus tied to the framing of children as legitimate objects of psychiatric enquiry, and to their availability for clinical inspection. Grinker notes that, prior to the twentieth century, children were not usually admitted to asylums, and most did not attend school until the mid-nineteenth century (2008, 63). In addition, 'eccentric children' were often accepted and even indulged in Europe and America, particularly if they filled a social or economic position within their community (Grinker, 2008, 63). The emergence of AS therefore required a shift in the boundaries of clinical interest and changes in perceptions of childhood and normality (Grinker, 2008; Nadesan, 2009; Feinstein, 2010).

AS as a diagnostic category is rooted in Hans Asperger's descriptions of six children who displayed what he described as 'Autistic Psychopathy', involving above average abilities with language, but problems with intuitive aspects of social interaction (Baron-Cohen and Klin, 2006). Asperger was aware of the historical backdrop to his work, and in particular how the limitations of psychiatric practice at the time shaped his interpretation of the children's behaviour. Reflecting on this 'discovery', he situates his work within a wider paradigm shift (Kuhn, 1962) in child psychiatry:

Let us remember the early thirties. At that time psychological problems in children had become fashionable...Tests were coming into use for getting to understand anomalies of intelligence. But none of this helped with the children I am about to describe. The disturbance was elsewhere and made one think of personality traits which the then current psychiatric circles did not describe or clarify. The disturbance was not so much intellectual, but lay more in the child's relationship with other human beings; in his lack of *contact*. But at that time this lack of contact was not recognised and it had no name. So how was a doctor trained to observe and categorise, to describe the peculiarities of these children? (Asperger, 1979, 46).

As Nadesan notes, Asperger's work was part of a wider shift in psychiatric practice from measuring 'intellectual' deficits to describing 'abnormalities' in the child's

personality (Nadesan, 2005). It is perhaps unsurprising, given his description of medical training, that when presented with children that defied existing categorisation, he felt compelled to invent one. Asperger's observations were brought to the attention of English-speaking audiences through the works of Lorna Wing and Uta Frith, leading to the establishment of AS as a formal diagnosis in the early 1990s (1992 in the ICD, and 1994 in the DSM) (Baron-Cohen and Klin, 2006, 1). In the intervening period, the technological and institutional focus on ASCs had shifted from psychoanalysis to the neurodevelopmental paradigm (Feinstein, 2010). The explanatory focus was no longer on disturbances of early childhood relations with the mother, but how factors in the development of the brain and nervous system might account for behavioural and experiential differences (Feinstein, 2010). This neurodevelopmental perspective remains the dominant scientific paradigm (Kuhn, 1962) in contemporary research on ASCs (Attwood, 2007; Baron-Cohen, 2008a; Feinstein, 2010); however, contemporary understandings of AS, as well as aspects of diagnostic criteria, continue to be debated. So what does this mean for understanding AS as a diagnostic category?

1.1.2 – AS as a diagnostic category

Hacking (1999) has described Autism Spectrum Conditions as examples of an interface between biology and culture, where factors relating to each domain are necessary but not sufficient to explain or even define observed differences. Furthermore, Hacking argues that in ASCs, biological factors appear to *interact with* classifications through social processes, giving rise to what he terms an 'interactive kind' of phenomenon (Hacking, 1999). Classifying something as a brick or a table does not change anything about its material properties (Hacking refers to this as a 'flat effect' that is unchanging); however, classifying human beings can alter both the conceptual and material conditions of what is observed, and this can then affect classifications (what he terms a 'looping effect') (Hacking, 1999). In autism more generally, Hacking observes that variations in institutional and interactive responses to those classified as 'autistic' can change the context in which features identified with autism may arise (Hacking, 1999). Setting up AS as a generalised deficit in sociality, for example, may frame social encounters with people categorised in this way such that breaches in interactions become more visible or more likely (for example, in programs of therapy, support services, or changes to educational, study and workplace environments).

This 'looping' effect is indicated in the work of Clark and van Amerom (2007), who compared institutional understandings of AS with those diagnosed through analysis

of internet blogs (Clarke and van Amerom, 2007, 763-764). Contributors identifying as AS pointed to the negative effects of framing the condition exclusively in terms of social deficit, such as leading others to encourage them to mimic 'normal' behaviours (Clarke and van Amerom, 2007, 771-773). This created what the AS bloggers referred to as 'surplus suffering', both by directing attention away from accommodating their differences, and by compelling them to act in situations that were difficult or confusing (Clarke and van Amerom, 2007, 771-773). Furthermore, problems encountered as a result of these impositions were then interpreted as confirmation of globalised deficits, thus producing the 'looping effect' (Clarke and van Amerom, 2007, 771-773). This is not to state that participants did not encounter difficulties in everyday life, but rather, that in the view of many contributors, a great deal of additional stress and suffering emerged from overly general understandings of the social capabilities of AS people.

Hacking's definition of an 'interactive kind' is useful in understanding the social implications of AS as a form of diagnostic categorisation. It is important to emphasise that this is *not* a rejection of biological factors, but rather an attempt to understand their interplay with cultural, environmental and historical factors, and serves to inject a note of caution as to how far we should draw inferences about the capabilities of specific people from diagnostic criteria. Understandings of AS are not

confined to these 'official' criteria, but have also developed in relation to the collective identities of people who associate themselves with the category. For some, while the diagnosis may provide a starting point for understanding difference, it may not be reified as a complete account of the self (in many cases it is criticised), but rather provides a basis for further exploration of one's identity. This is particularly significant given the emergence of AS-majority communities and their significance for personal and collective identities, as well as the notion that AS may involve different dispositions towards social interaction, rather than simply deficit.

1.2 – AS communities, identity and sociality.

From the time of its entry into the ICD and DSM, the idea that AS only involves impairment has been challenged, notably through the concept of 'neurodiversity' (Sinclair, 1993; Sinclair, 2007). Neurodiversity originated with the sociologist Judy Singer, who argued that AS did not simply involve a 'deficit' in social interaction, but pointed to different ways of seeing the world, which should be celebrated alongside other forms of human diversity:

For me, the significance of the Autistic Spectrum lies in its call for and anticipation of a Politics of Neurodiversity. The Neurologically Different represent a new addition to the familiar political categories of class/ gender/ race and will augment the insights of the Social Model of Disability. The rise of Neurodiversity takes postmodern fragmentation one step further. Just as the postmodern era sees every once too solid belief melt into air, even our most taken-for granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information, in more or less the same way, (unless visibly disabled) are being dissolved (1999, 12-13).

Neurodiversity has been a key concept for those (both AS and non-AS) who have sought to challenge purely negative or pathological understandings of the condition, and these developments are linked to the practical possibilities for social connection afforded by the internet (Davidson, 2008; Brownlow, 2010a; Bagatell, 2010; Jaarsma and Welin, 2012). Online communications offer opportunities for social exchange that can help mediate difficulties associated with co-present interactions; for example, as Davidson (2008) and Brownlow (2006, 2010) note, textual communication in particular is well-suited for this purpose, providing a measure of control over the quality and rhythm of exchanges as well as the physical environment in which interactions occur (Brownlow et al., 2006, 315; Davidson,

2008, 791, 796). AS-majority communities have emerged through internet discussion groups, chat rooms, and autism-specific virtual places such as the island of *Brigadoon* in the online avatar-based world of *Second Life* (Brownlow et al., 2006, 315-316; Brownlow, 2010a, 16). Internet spaces have also offered arenas within which to develop practical strategies for addressing common types of difficulty (Davidson, 2008, 802), and to contest deficit-focused narratives of AS people's experiences (Brownlow, 2010a, 17-20). These discussions are often attended by social and political claims around the individual and collective legitimacy of AS-related experiences, culture and practices (Clarke and van Amerom, 2007).

It is difficult to overstate the impact of internet communications on the lives of AS participants. In 1997, Harvey Blume observed:

It is not only that for many autistics the World Wide Web provides a rich store of metaphors for their mental processes -- or that, in reverse, the mental processes of autistics can stand in as symbols of the associative hyper-linking graphic chaos of the World Wide Web. There is a much more practical side to it. Simply put, for many autistics the Internet is Braille.

One autistic wrote: "It was through the Internet that I discovered AS and the whole concept of neurological differences. Without the Internet, I'd still be seeing myself as the cause of my own 'failure' (failure to be NT)... . it wasn't until I met other Aspies on the internet that I was able to gain a deeper understanding of what being Aspie means." (Blume, 1997).

Since this article first appeared, the size and number of autistic communities online has grown substantially (Davidson, 2008). At the 2011 *Computers and Autism* conference organised by the NAS research division *Research Autism*, autistic spaces online were framed as one of the first sets of communities of which the emergence was dependent upon the internet as a medium (NAS, 2011b). This relates not only to online communities, but also face-to-face meetings organised by and involving a majority of AS-participants. Discussions between long-standing professionals and researchers at *Computers and Autism* also offered a historical perspective on the impact of the internet. The overriding theme of these discussions was that very few, if any non-AS practitioners working in the field expected those categorised as AS to be capable of establishing their own communities prior to the emergence of the internet. For example, in her opening speech, Lorna Wing voiced her 'surprise' at the existence of a conference linking autism and internet technologies due to her assumption that online communication would be incompatible with autistic

people's dispositions. However, in her closing address Wing noted that the event had changed her perception of what was possible for people on the spectrum in relation to the internet (NAS, 2011b).

If some had believed that internet communications might be unsuitable for people on the autism spectrum, much less was it expected that research and education conferences organised and attended by a majority of autistic people would or could succeed. However, as examples such as the *Autscape* and *Autistic Intelligence* conferences indicate, majority-AS communities have not only emerged in both online and co-present forms, but have done so in ways that mediate many of the practical issues associated with interactions in majority non-AS fields (Autscape, 2011). The emergence of AS communities online, and subsequent co-present meetings, are thus one of the major reasons why notions of AS consisting of a uniform absence of sociality have been discredited.

This has also been noted in research literature, for example, Jones and Meldal (2001) analysed 'single-authored accounts of first person experience' from the personal websites of five people who self-identified as having an AS diagnosis (Jones and Meldal, 2001, 37). The authors highlighted awareness of communication difficulties, attempts to fit in with non-AS people using role play, the importance of

the internet and autism-specific social networks, and a desire for relationships as key themes in discussions. They argued that in light of these discussions 'the view of people with Asperger as having little or no interest in social relationships is simply not sustainable' (Jones and Meldal, 2001, 39). This claim was supported by later research undertaken by Howard et al. (2006), who focused on understanding and negotiation of friendships. The authors conducted a single case-study of a male AS adolescent using a multi-methods approach involving participant photography, semi-structured interviews with both the participant and his parents, and assessments using the Youth Quality of Life and Friendship Qualities scales (Howard et al., 2006, 621). They reported that the participants' understanding of friendship involved shared interests, provision of help and support, mutual caring and responsiveness, forgiveness and reciprocity, casting further doubt upon a universal lack of interest in social relationships in AS people (Howard et al., 2006, 622-625).

Elsewhere, Whitehouse et al. (2009) explored relationships between friendship, loneliness and depression in AS adolescents. 35 AS participants and 35 non-AS controls, matched on chronological age, gender and school year were asked to complete a number of questionnaires for comparative analysis including the De Jong-Gierveld Loneliness Scale, the Centre for Epidemiological Studies Depression Scale (CES-DC), the Friendship Quality Questionnaire (FQQ) and Friendship Motivation Questionnaire (FMQ) (Whitehouse et al., 2009, 313-314). Scores from

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instruments measuring depression and loneliness were compared with those exploring friendship quality and motivation indicators (Whitehouse et al., 2009, 310-311). AS participants reported poorer quality best friendships compared with controls, while loneliness was also higher among this group (although these scores were not in themselves deemed to be 'high') (Whitehouse et al., 2009, 316-317). Interestingly, while loneliness scores were predicted by overall friendship quality (FQQ) values in the control group, this was not the case for those in the AS category (Whitehouse et al., 2009, 318). The 'conflict/betrayal' subscale of the FQQ was however found to be a predictor of both depression and loneliness in AS participants (Whitehouse et al., 2009, 318). AS participants had lower scores for intrinsic motivations towards friendship on the FMQ than the control group, suggesting that understandings of and dispositions toward friendship may have differed between the groups (Whitehouse et al., 2009, 317). While observing that some of their findings 'may be consistent [with the assumption that]...AS individuals have less desire to develop friendships than typically developing peers and may even favour social isolation', there was also evidence that friendship remains important for AS people during adolescence (Whitehouse et al., 2009, 317-319). This suggests that for AS people, dispositional orientations towards social relations may differ qualitatively from those of non-AS people; however, these understandings are not mutually exclusive and may be part of a wider continuum of relationality. While everyday social encounters often present challenges for AS

people, underpinned by differences in the way information about the social world is processed and understood, this does not imply a uniform absence of sociality.

The emergence of majority-AS communities has been significant in challenging accounts of the condition as involving only deficit and provides another example of the category AS operating as an 'interactive kind', where those diagnosed have challenged aspects of their classification, and thereby changed not only understandings of AS but the language in which it is discussed (e.g. through terms such as 'neurodiversity'). This underlines the relevance of framing AS as an 'interactive kind', not only in terms of challenging overly general claims about sociality, but by re-framing it from something inherently pathological, to a condition involving a variable range of strengths and limitations. As a diagnostic category and an aspect of personal and contemporary identity, AS is a category that has undergone significant change, and may well do so again in the future. Given this contingency, we need to consider how to frame and discuss AS as an object of study.

1.3 – Framing and discussing AS

1.3.1 – Disability or difference?

Given the discussion thus far, one aspect of framing and discussing AS area to consider is the extent to which AS can or should be considered a disability, in light

of different and at times competing accounts of AS. For example, in Madriaga et al.'s report on transitions to higher education for AS students, the authors argue that:

There are two competing views of AS, firstly, an 'official' view of the condition based on a medical model of disability; and secondly, an alternative, 'vernacular' view of the condition based on the social model of disability... The medical model view of AS considers the condition within the autistic spectrum. It is believed to be a 'devastating developmental disorder' (Williams, 2004, p. 704), or a 'neurological abnormality' (Frith, 2003, p. 1), 'due to a physical dysfunction of the brain' (National Autistic Society, 1998, p. 26)...This perspective is considered an 'official' view because individuals with AS will not be able to access specialist funding without an 'official' medical diagnosis. (2008, 12)...Instead of viewing disability as an indicator of individual failing and stigmatisation, the social model of disability comprehends disability as purely social phenomena [sic]. This means that disabled people are not disabled due to their impairments. They are disabled due to dominant societal attitudes that are perpetuated by taken-for-granted notions of non-disabled people as 'normal' (Madriaga et al., 2008, 11-12).

The authors draw on the work of Molloy and Vasil, who present what they refer to as a 'vernacular' view of AS as a discursive construct, used to typify and communicate understandings about a diverse range of people with different needs, dispositions and biographical circumstances (2002, 666). This creates a language that allows different service providers and agencies to develop common understandings of a fixed category, as a target for interventions, affordances and assistance. The authors argue that 'AS is never simply located within the individual: no gene or discovery of different neurological "wiring" arrangements will wholly explain AS' (Molloy and Vasil, 2002, 662). While not denying the existence of physical impairments, these are seen as separate from experiences of disability that stem from understandings of normalcy and the pathologisation of difference (Molloy and Vasil, 2002, 659)

The 'vernacular' view indicates how understandings of AS emerge in the context of a need for fixed categories that can then be the basis for intervention, 'treatment' and assistance (Madriaga et al., 2008, 12). This can be beneficial, for example, a child may obtain specialist funding or assistance as a result of receiving an official diagnosis; however, their categorisation may also mark them out for 'specialist' provision that segregates them from other children (Madriaga et al., 2008, 12). Thus one function of the 'official view' can be to emphasise particular aspects of AS people's experiences (often specific people recruited for clinical research), to the

neglect of others. In contrast, the 'vernacular' view draws attention to the importance of social positioning and institutional priorities in how AS people are understood by particular actors, and how operations of clinical and institutional power may exclude experiences that do not fit with categorical understandings. Deficit-focused categorical understandings may also lead people to treat deviance from a perceived 'normal' range of social and environmental experiences and behaviours as pathological (a process that Madriaga has referred to elsewhere as 'ableism') (Madriaga, 2010, 24). This recalls Clarke and van Amerom's (2007) discussion of 'surplus suffering', and is also supported by Milton's suggestion that such practices may have broader consequences for experiencing one's differences as legitimate:

The imposition of one's views upon another and the subsequent internalisation of this view can be seen to be a form of internalised oppression, where the negative connotations of the normative model of pathological difference become a self-fulfilling prophecy (Becker 1963), leading to a self-imposed psycho-emotional disablement (Reeve, 2011). For those who resist, such self-identifications and attempts to normalise – however 'well intentioned' – are experienced as an 'invasion' of the 'autistic' 'lifeworld' by people wanting to modify one's behaviour to suit their purposes and not one's own (Milton, 2012, 3).

The concept of 'psycho-emotional disablement' is here used to indicate how 'surplus suffering' caused by problematic demands for adaptation, may lead to the 'invasion' and reconfiguration of experience at the phenomenological level (i.e. through internalisation of ideas of one's ways of being as inherently harmful or defective). Research indicates that many of the challenges encountered by AS people in everyday life have social and environmental elements which, to varying degrees, can be improved, mediated or even removed by appropriate adaptations (Clarke and van Amerom, 2007; Madriaga et al., 2008; Ryan and Räisänen, 2008; Davidson, 2010; Madriaga, 2010).

The distinction between the 'official' and 'vernacular' views (and by extension the medical/social models which underpin them) is useful heuristically, in order to understand how different actors have emphasised different aspects of AS-related experiences. However, as Shakespeare notes, it is advisable to note the limits of the medical/social model dichotomy with caution, as many perspectives on disability will incorporate aspects of both 'models' (2006, 15). In the case of AS, this is important because the positions of some of the clinicians (Baron-Cohen et al., 2009; Baron-Cohen, 2008a; Attwood, 2007; Tantam, 2012) and practitioners within the literature which can cut across both domains. It is also useful to note that what is

termed the 'social model' may itself involve varying perspectives, with differing degrees of emphasis on the relationship between physical differences and/or impairments, and experiences of disability. For example, as indicated in a cartoon from the disability blog 'Square 8' (see Image 1). The cartoonist ('Bev' – a blogger who identifies as AS) here contrasts a caricatured view of the social model with her own understanding, based around recognition of needs, decision making rights and power relations. Interestingly, the cartoonist here distances herself from an ontological separation between impairment and disability. Thus, not only may different perspectives not sit easily within either domain of the medical/social model set out by Madriaga et al. (2008), but also understandings of these models may vary.

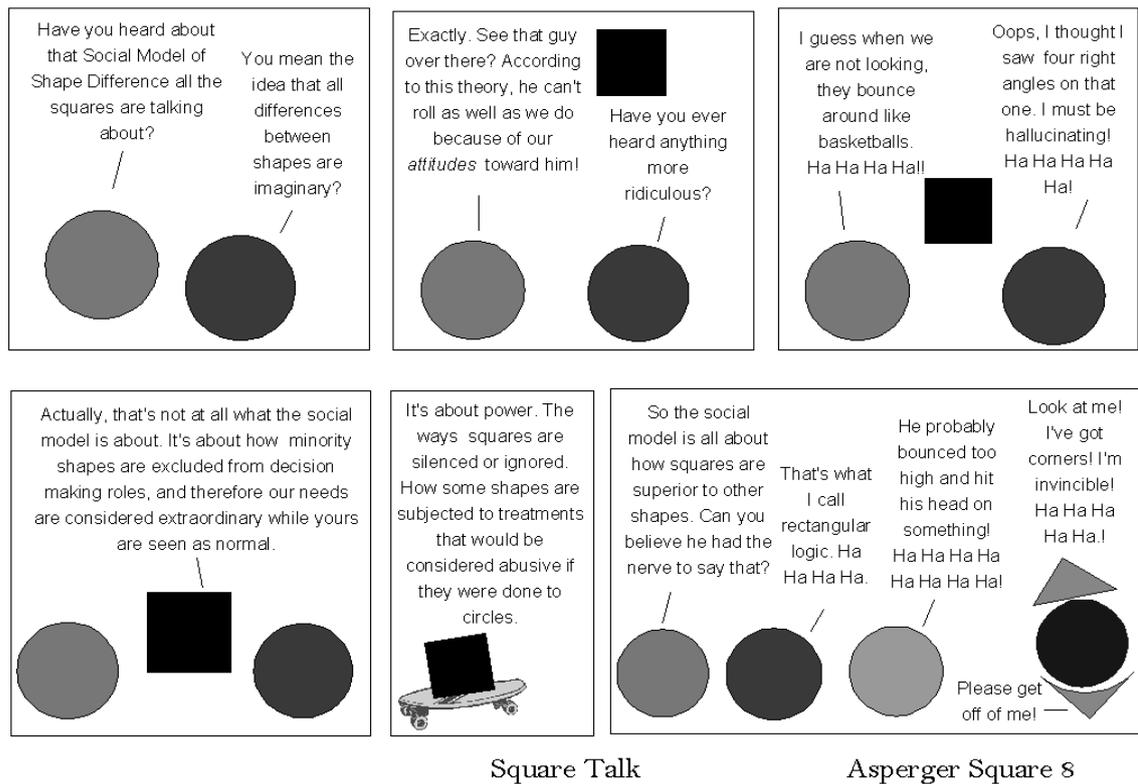


Image 1 – An episode of the webcomic series 'Square Talk' -

<http://aspergersquare8.blogspot.co.uk/2009/10/square-talk-social-model.html>

The ontological separation of impairment from disability is also problematic for other reasons, such as the exclusion of those who do appear to connect impairment and disability in their descriptions of experience. For example, AS author Donna Williams writes of her 'body as other', in which her ability to connect with the world around her (which she terms 'resonance') was continually interrupted by sensory sensitivities:

I spent much of my very early childhood slapping, biting and trying to run away from my body to get rid of it following me with these annoyances and interruptions to resonance. It was like these sensations were 'blinding' me, cutting me off from the sense I used most to get a feeling of cohesion and understanding of the pattern, feel and nature of objects, people, situations and happenings...My later experiences in mid to late childhood and into adulthood of self-in-relation-to-other involved attacking myself out of frustration and sense of invasion and overload...I saw my body as external and theirs [other people's], not mine. Only as a tool, a sensory tool, did I feel glad to have it (Williams, 2003, 89).

Here, the author identifies disturbances in her experience of body as a source of discomfort and distress, similar examples of which are reflected in autobiographical writing by other AS authors (Bogdashina, 2003, 56; Davidson, 2007, 666-667). This is not necessarily in conflict with the points made by Madriaga et al. regarding the importance of social and environmental factors in everyday experiences of disability. Rather, (following Shakespeare's caution) it serves to illustrate that not *all* experiences of disability in relation to AS can be reduced entirely to social or environmental factors, and points to the diversity of both individual experiences and ways of framing and talking about AS.

In his work on autistic autobiography, Hacking argues that these texts 'are not just stories or histories, describing a given reality [but are] creating the language in which to describe the experience of autism, and hence helping to forge the concepts in which to think autism' (Hacking, 2009, 1467). He also urges caution with regard to their reception, using the example of promotional materials claiming to offer insights into '*the* autistic mind', as opposed to a perspective that is constituent of a wider 'interactive kind' (Hacking, 2009). Analyses of writing by AS authors indicate diversity of biological, social, cultural and environmental circumstances, and corresponding ways of discussing and framing AS. One area of variation relates to how different AS people frame and communicate their experiences. For example, Clarke and van Amerom's (2007) analysis of blogs by AS authors indicated widespread support for the 'notion that there was nothing inherent in their [AS] differences to merit a pathologizing designation' (2007, 769). Elsewhere however, autobiographers such as Gunilla Gerland (1997, 248) and John Elder Robison (2008, 194), have described AS as a 'handicap'. This is not to state that either of the authors frames their conditions entirely in negative terms; Gerland places great value on her 'sharp vision' (1997, 249) as a positive AS-related trait, while Robison sees his 'Aspergerian traits' towards 'logic and reason' as dispositional strengths (Robison, 2008, 190); but rather, that experiences of AS and the language used to represent those experiences can vary. This diversity also

extends to framing AS people's need for the support of non-AS people, an example of which comes from a BBC interview with AS author and researcher Wendy Lawson, in which she states:

We need to walk along beside each other, we need your support, and I would suggest to you that we can have quite a lot to give back to you, in all sorts of ways; we have lots of talents (Hill, 2000).

However, in Brownlow's exploration of AS forums online, comments by one AS contributor ('Ronald') we find a contrasting sentiment that indicates potential limits on how far some AS people wish to enter the non-AS world:

If you are Adult with Autism Diagnosis you have to have experience with medicine. Applied Behaviour Analysis is a way to bring you completely into the social world and I do not want to go. I want to stay in my world and just visit the social world (Brownlow, 2010b, 247).

This diversity has direct implications for practice, with respect to how support for AS people is framed, as orientations to social interaction may vary (this is supported elsewhere by the findings of Whitehouse et al., 2009). The appropriateness of what is termed 'social inclusion' may therefore depend on what is meant by inclusion as

well as the dispositions and preferences of the individual (Madriaga et al., 2008; Madriaga, 2010). This is indicative of a wider point regarding variation in experiences of AS, which can involve both positive and disabling features of differing combinations and qualities that reflect different configurations of biological, social and environmental circumstances. In addition, while people in the AS category typically experience difficulties in relation to the social and environmental aspects of everyday life, this does not mean that the condition should be thought of entirely in terms of deficit, for there are also examples of positive associations with AS. To attempt to arrive at an overarching idea as to the status of AS in relation to disability is thus perhaps unwise. Given the ambiguities and contingencies discussed thus far, we might even question the degree to which AS is useful for understanding its associated experiences, differences and difficulties.

1.3.2 - Do we need AS at all?

Happe et al. have argued that 'heterogeneity within the autism spectrum is perhaps the biggest single obstacle to research at all levels', with research increasingly suggesting that a single 'explanation' for autism spectrum conditions is unlikely (2006b, 1220). Elsewhere, Moloney has voiced concern over the ambiguity and range of application of the AS diagnosis, and speculates that 'many' of the problems

associated with the condition may stem from differences in socio-economic conditions:

As a worryingly elastic diagnostic label, Aspergers [sic] syndrome seems to be capable of extension to a wide range of individuals who might otherwise have little in common save their isolation, their apparent interpersonal awkwardness, their dislike of change and, in a socially and vocationally competitive age, the understandable concern of their families...Given the doubts about the coherence and validity of the diagnosis, there is the nagging thought that in many, and perhaps most, instances what we are talking about is not so much a clearly demarcated 'developmental disorder' as a spectrum of character traits or dispositions that fit poorly with the ethos of our current business and consumer culture. More frequently than is recognised, the 'problems' presented by Aspergers syndrome may lie in a world that increasingly struggles to accept any form of difference from the notional norm...(Moloney, 2010, 146).

Given the degree of variability both in language used by AS people to describe their experiences, social conditions and variable application of the category in different settings, might it not be better just to do away with AS altogether? This is the

proposal of Timimi et al. (2010), who argue that the changing history of the autism spectrum and failure to provide clear aetiological explanations indicates that it is of no scientific, clinical or social value, and should therefore be abolished (this claim relates to the entire spectrum). As the discussion thus far has indicated, elements of social construction, historical contingency and variability in terms of understandings and applications of the term AS are evident; however, this does not mean that Timimi et al.'s proposals should be accepted. Highlighting existing gaps in knowledge does not necessarily equal falsification of current understandings, and Timimi et al.'s work provides no convincing refutations of findings suggesting patterns of neurological difference between those categorised as AS and non-AS people. In addition, their suggestion of wholesale rejection of the autism spectrum without any adequate replacement is at this point in time ethically dubious (Bracher and Thackray, 2012), as Baron-Cohen writes in relation to the possible removal of AS from the new edition of the DSM:

We...need to be aware of the consequences of removing it. First, what happens to those people and their families who waited so long for a diagnostic label that does a good job of describing their profile? Will they have to go back to the clinics to get their diagnoses changed? The likelihood of causing them confusion and upset seems high (Baron-Cohen, 2009).

Elsewhere, despite his reservations Moloney also acknowledges this as an ethical issue in the development of knowledge and provision in relation to AS:

Of course, it has to be acknowledged that for many the diagnosis has its uses. For those who are able to negotiate the current health and social care systems acquisition of this label may open up pathways towards financial and material assistance and also towards improved personal assistance at school, college or work, all of which may be badly needed and, when made available, may make the person's world an altogether more benign place. There may also be some advantage to being diagnosed with Aspergers syndrome, where the alternatives might include the more pejorative labels of 'psychosis' or 'schizophrenia'... (Moloney, 2010, 146)

Clearly, there are complex ethical issues at play that require careful consideration, and these may not involve a universal answer. In the absence of more concrete suggestions as to what might take its place (Timimi et al. make no such proposals), the status of AS as a category of ethical significance is perhaps one of its clearer features. Whatever the degree of certainty regarding its ontological status, or the potential problematic effects of labelling, in the current context getting an AS

diagnosis often has very real ethical consequences for those diagnosed and their families (this will be discussed in 2.1.2). Acknowledging the contingency and uncertainty associated with the term does not imply wholesale rejection of its value or operation in the lives of people associated with it.

It may be that, given changes in the institutional organisation of support and assistance for people currently categorised as AS, we may see moves to a more 'person-centred' model focused on individual needs rather than categorical understandings (this is something that Timimi has argued for elsewhere) (Timimi, 2011). However, the type of institutional change that this would require goes beyond AS as a diagnostic category towards questions regarding the treatment of impairment and disability in more general terms. Wholesale rejection of AS at this point in time would not, in my view, be ethically supportable without a clear idea of how the existing needs of AS people and their families could be met. AS may not be the same, or even exist, as a diagnostic category in ten or twenty years time; however, at this point it does, and its existence has ethical weight irrespective of how its ontological status is understood.

1.3.3 – Talking about AS – notes on language

There is also the question as to how far AS-related traits are in any sense separable from the ‘rest’ of the person; Asperger syndrome (AS) is sometimes referred to as ‘Asperger Disorder’ (AD), particularly in the clinical literature (it is also sometimes rendered in the possessive form ‘Asperger’s’) (White et al., 2009; Mazefsky et al., 2010; Singh, 2011; Lawrence et al., 2010). ‘Disorder’ implies disruption to a normative state (an ‘order’) by some process or event. This does not appear to fit AS very well, as it would imply that there is a ‘normal’ person obscured or corrupted by AS ‘symptoms’, and that this is may in some sense be reversible or ‘curable’. For some, such as Jim Sinclair, the idea of Autism Spectrum conditions being separable from the person is not sustainable:

Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person - and if it were possible, the person you'd have left would not be the same person you started with (Sinclair, 1993).

However, literature from elsewhere indicates that this view is not be universally accepted by all AS people. In their exploration of the relationship between AS, identity and adolescence, Molloy and Vasil observed that participants faced a common challenge of separating out 'which aspects of their personalities, interests and behaviours display AS traits and which have nothing to do with AS' (Molloy and Vasil, 2004, 121). They also observed that participant experiences of 'AS symptoms' changed as they grew older, with implications for their experiences of self:

During late adolescence, when the teen is grappling with additional and more complex elements of identity, such as vocational identity, a political identity, a religious identity, and so on, it is likely that his or her sense of identity will be less heavily based on earlier, simpler, perhaps conferred aspects of identity. For adolescents...who have experienced a marked decrease in their AS 'symptoms' as they have grown, their present sense of identity is less clearly dominated by their diagnosis of AS. AS simply holds less significance in defining who they now are (Molloy and Vasil, 2004, 123).

It is possible that these statements could be reconciled. Sinclair's statement could be read as a phenomenological argument regarding the possibility of separating

constituent experiences from the totality of the person; while Molloy and Vasil's observations could reflect a labelling/framing effect, in the sense that only the difficult aspects of difference were attributed to AS (neither position would directly contradict the other). What the discussion here illustrates is that different people categorised as AS may frame their experiences in various ways. Given the ambiguities surrounding the diagnosis, does this variation place the category AS itself in question?

Among those who accept (to whatever degree) the diagnosis as a concept for understanding a particular set of people, there is variation in how AS is framed and discussed. The UK National Autistic Society has published a guide for journalists and the wider public entitled *How to talk about autism*, in which they offer a table of contrasting terms labelled 'do say' and 'don't say'; for example, autism (including Asperger syndrome); *do say*: he/she has autism; *don't say*: an autistic/autist/autie/aspie [Some individuals may refer to themselves in this way, however]' (NAS, 2012a - emphasis in the original). As the authors acknowledge, this contrasts with how other AS people choose to talk about themselves, while arguments from elsewhere have problematised the type of 'person-first' language suggested by the NAS. Sinclair gives three reasons as to why 'person first' language may be inappropriate for talking about AS people: firstly, because 'person-first

language' is intended to make us see the person rather than their impairment, which implies that AS-related differences are exclusively impairments (Sinclair, 2007). Secondly, that AS is a marginal or peripheral part of the person, rather than fundamental to their identity and ways of being (Sinclair, 2007). Finally, that AS-related traits can be separated from the person, or that their lives are lived 'in spite of' rather than through their differences (Sinclair, 2007). The positions of both NAS and Sinclair have merit, and it is difficult (perhaps impossible) to favour one over the other, given the discussion thus far regarding the ontological status of AS. Therefore, it is perhaps better to see them as reflecting of the heterogeneity of experiences and perspectives on AS, and the corresponding range of terms used to describe and discuss them.

Finally, I must say a little about a term originating within AS-related self-advocacy literature, that has also been readily accepted by some social scientists (Davidson, 2008; Davidson and Smith, 2009; Brownlow, 2010b; Jaarsma and Welin, 2011) to describe non-AS people, *neurotypical* (NT). Neurotypicality relates to the autism spectrum in the sense that it refers to a 'normative' range of social, communicative and perceptual experiences that exclude those associated with the autism spectrum (Brownlow, 2010b). In majority AS communities, particularly those online, it is often used to separate non-autistic people ('neurotypicals' or 'NTs') from those on the autism spectrum (the 'neurologically diverse') (Brownlow, 2010b). This is a

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term which originates with Jim Sinclair, the use of which has expanded beyond its original boundaries of AS communities online, and entered popular usage by non-AS others. At the time of writing, NAS includes the term in its online guidance for 'talking about autism', citing it as a desirable term preferable to 'normal' when referring to non-AS people (2012a). However, this term has not been without criticism, for example, AS autobiographer Stephen Shore explicitly avoids using 'neurotypical' for what he views as its 'slightly derogatory connotations' in favour of the term 'non-spectrum' (Shore, 2001, 163). While there is evidence that NT has been used in a derogatory context to refer to non-AS people (for example, in online discussion forums) this does not characterise the entirety of its usage (Brownlow et al., 2006). However, there are also other reasons for avoiding this term.

The neurodiversity movement has brought to the attention of wider publics important questions relating to biosociality and the nature of embodied difference in contemporary societies. In my view, the term NT risks limiting these questions by reproducing the type of overly general concepts that were originally subject to criticism. NT as a concept is used to distinguish autistic people from those not on the spectrum; however, it also homogenises those positioned within both categories. Neurodiversity, if one takes this to mean a plurality of embodied dispositions shaped by variations in neurodevelopment, likely involves far greater variation, and in this sense the validity of the term is therefore questionable. For 56

my purposes here I therefore prefer the term 'non-AS', in part because, while serving a distinctive function, it also respects the ambiguities and unknowns in current knowledge on AS/non-AS differences. Ultimately, however, it may be that no such clear separation can be found, and so this distinction again reflects a categorical, rather than an ontological understanding.

1.4 - Summary

In this chapter, I have set out to frame and justify my approach to AS as an object of study, and to position this within the context of historical and contemporary debates. I have explored the history of AS both as a diagnostic category, and as a way of understanding experiences of difference and disability. I have attempted to show how, while AS lacks a definite aetiological explanation, neither the category nor the set of phenomena to which it relates can be understood entirely in terms of social, environmental or biological processes; rather, it appears to involve relations of mutual affect between the three domains, all of which are themselves partially understood and subject to variation. Through Hacking's concept of the 'interactive kind', I have set out my position on the ontological status of AS, and supported this with evidence from existing literature with respect to the diversity of experiences and perspectives arising from people in this category. I have indicated that while

experiences of disability are common for AS people, these may not be the inevitable result of a 'flat effect' in terms of social, environmental or biological factors, but may involve varying combinations of them. This is reflected, I argue, in the diversity of language used to describe AS-related experiences, which has led me to adopt this perspective.

In the next chapter, I will set out the specific focus of the investigation that follows, and position this within the context of existing social scientific research on AS. I will argue that the pre-diagnostic experiences of adults who live for long periods of life without a formal diagnosis represents a significant gap in existing literature, that is of demonstrable intellectual and ethical significance. The discussion will explore important themes within existing social scientific literature, including the impact of the diagnosis, as well as research from elsewhere on the impact of living with an undiagnosed condition.

2 – Focus on pre-diagnostic identities (rationale and research questions).

Having set out my understanding of AS as an object of study, and discussed the implications of this for the term in which it is framed and discussed, I now turn to the specific focus of thesis. Which is to explore the pre-diagnostic experiences of AS people born before 1980 who were diagnosed in adulthood; I will also identify the specific research questions to be pursued, and indicate the ethical and intellectual significance of my investigation.

2.1 – Why focus on pre-diagnostic identities?

In order to frame the focus on formations of pre-diagnostic identity for AS people diagnosed in adulthood within the context of existing literature, it will be necessary to first explore research relating to AS people in general. This is because (as I will indicate) pre-diagnostic experiences of those who receive their diagnosis in adulthood have yet to be explored in any significant detail in research literature. My approach in this section will therefore be: firstly, to explore literature relating to the wellbeing of AS adults, in order to highlight some live intellectual ethical issues relating to the experiences of people in this category; secondly, to indicate the

significance of the relationship between identity and diagnosis; thirdly, to justify the specific focus on pre-diagnostic identities in light of the preceding discussion.

2.1.1 - AS adults and wellbeing.

The majority of research on AS has focused on children, with comparatively little attention given to the lived experiences of adults (Baron-Cohen et al., 2007; Lawrence et al., 2010, 229). However, in recent years there has been increasing concern with the challenges faced by those in the latter group, in particular with respect to outcomes associated with wellbeing. For example, Jennes-Coussens et al. explored quality of life of AS young people in Alberta, Canada using the World Health Organisation (WHO) Quality of Life measure, the Peer Support Network Inventory and semi-structured interviews (2006, 403). The responses of 12 AS young men aged 18-21 were compared with those of a non-autistic control group (n=13) in order to explore factors affecting quality of life (Jennes-Coussens et al., 2006, 403). The authors reported similarities in the types of issues identified as significant by respondents, such as living arrangements, education, social support, number of close friends, and overall quality of life; however, there were significant

qualitative differences between the groups in terms of wellbeing (Jennes-Coussens et al., 2006, 410). AS participants reported less satisfaction with their physical health, particularly in areas relating to pain and discomfort, dependence on medical treatment, activities of daily living, work capacity, energy and fatigue, mobility, sleep and rest. The authors argued that this may be linked to the issues with sensory sensitivity and motor function, citing participant reports of difficulties in manual labour-type jobs and learning to drive (Jennes-Coussens et al., 2006, 410). They also observed high levels of self-perception of 'social skills deficits', which participants saw as having a major impact on quality of life, while half also reported being unemployed despite all but three respondents having completed high school education (2006, 411).

These findings have been reflected elsewhere in a UK report exploring the lives of autistic adults and their parents/carers¹, as well services provided by Local Authorities (LA's)², and NHS Primary Care Trusts³ in England (2008, 44). Here, Rosenblatt (2008) also observed that the social lives of adults on the spectrum (including AS people) were often highly restricted (2008, 44), with 75% of

¹ Two stage questionnaire – 1,412 respondents to the first stage which asked for details regarding the person with autism. Of these, 1,179 respondents also completed the second stage which concerned experiences of adults on the spectrum. Within this group, 42% completed the section by themselves, 18% did so with support, while the remaining 40% of responses were completed by parents/carers (Rosenblatt, 2008, 46)

² 53 out of 150 Local Authorities responded (36% response rate) (Rosenblatt, 2008, 46).

³ 24 of 148 Primary Care Trusts responded (16% response rate) (Rosenblatt, 2008, 46).

respondents reporting that they 'did not have any friends or found it hard or very hard to make friends', and 72% stating that they would like to 'spend more time in the company of other people' (Rosenblatt, 2008, 44). Only 15% of respondents were in full time employment while 66% held no form of employment (including voluntary work), and over 60% reported being economically dependent on their families (Rosenblatt, 2008, 44). Lack of control and choice in social life was widespread among those surveyed, with only 15% living in their own homes 'with support', despite 37% reporting that they would like to live in their own flat or house with support (Rosenblatt, 2008, 44). Of those living in their own accommodation, over 70% of those living on their own reported being harassed or bullied (Rosenblatt, 2008, 44). In addition 33% experienced a 'serious mental health problem' linked to a lack of social support (2008, 2). This is reflected elsewhere in research suggesting that mental health morbidity may be particularly high among AS people compared with the general population, and that social isolation is a significant factor in this (Ghaziuddin, 2005; Baron-Cohen, 2008a, 98).

The final report of the UK All Party Parliamentary Group on Autism (APPGA) echoed Rosenblatt's findings in relation to the types of issues faced by adults on the autism spectrum (including AS) in the transition to adulthood (Allard, 2009, 5-12). Transitions to adulthood typically involve profound changes in the social and environmental organisation of daily life, for example in transitions from school to

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work/training/further study (Allard, 2009, 2-5). Inadequate planning by service providers, as well as a lack of appropriate inter-agency coordination were seen to increase the risk of poor transitions (Allard, 2009, 2-5). These findings were again supported by Lawrence et al., who conducted a review of literature relating to the transition to adulthood for AS people in order to establish what the authors describe as a 'comprehensive, evidence-based transition assessment guide' for healthcare professionals framed through Maslow's hierarchy of needs (2010, 227). Areas of concern included management of diet and exercise, management of sensory overload, transportation and mobility, housing, community integration, love and belonging, self-esteem and self-actualisation (Lawrence et al., 2010, 230-236). Reflecting the findings of both Rosenblatt (2008) and Allard (2009), the authors conclude that professionals supporting AS young people and their families need to identify needs early and allow adequate time for adaptation to new living arrangements (Lawrence et al., 2010, 236). Taken together, these studies indicate that AS people may face a range of challenges as they move through the life course, as a result of changes in the social and environmental organisation of everyday life.

Portway and Johnson argue that 'longer term' risks such as unemployment and mental ill health need to be understood in the context of exposure to 'everyday' risks, such as being misunderstood, bullying, isolation and loneliness (Portway and Johnson, 2005, 76-78) The authors explored risks encountered by AS people in

everyday life through semi-structured interviews with 25 (4 female, 21 male) participants aged 18-35 and their families (2005, 74-75). Problems with sensory aspects of environments, misunderstanding social norms, and coercive or abusive behaviour on the part of other children or young people were common; while social integration was often framed as 'at best superficial' (Portway and Johnson, 2005, 81). The findings also reflected issues with housing and independent living: only one of the respondents lived independently, while over half (16) lived in the parental home, with the remainder residing in supported housing or with daily support from parents (Portway and Johnson, 2005, 79). Many parents were also engaged in what were described as '24 hour mental commitments' involving psychological guardianship, social support, and putting into place 'unseen safeguards' against mental distress for their children (Portway and Johnson, 2005, 79). This dependency was itself framed as risk, with the benefits of support weighed against the risk of dependency for stifling personal development and opportunity (here framed as a dilemma for both AS participants and parents), pointing to the wider role of social relationships in mediating both everyday and long-term risks.

Research indicates that the needs of AS adults are often poorly understood by service providers (Allard, 2009; Rosenblatt, 2008), and in particular Portway and Johnson emphasise the need to understand more general profiles of everyday risk

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exposure. However, this also implies a need for careful attention to the narratives of everyday experience provided by AS adults, and this has been a limitation of some of the existing literature on wellbeing and risk. Jennes-Coussens et al.'s (2006) quality of life measures are based upon pre-determined indicators, with little discussion of how these might play out within the lives of specific participants. For example, the authors claim at one point that 'results [relating to satisfaction with physical health] may relate to clumsiness of movements or to sensory hypersensitivity' (Jennes-Coussens et al., 2006, 410); however they do not appear to have followed up on this point with participants in their semi-structured interviews, limiting the specificity and scope of the claim. Similarly Lawrence et al.'s (2010) use of Maslow's hierarchy of needs to frame important areas in the transition to adulthood is limited by a lack of engagement with first person narratives in their review of literature. While they emphasise 'self-actualisation' as important for maintaining quality of life, they give no examples of how this may be achieved by specific people, or any accounts of variation.

Portway and Johnson's unqualified description of the behaviours of their participants as 'odd' or 'bizarre' also betrays a failure to explore the potential meaning or significance of these activities as legitimate and valued experiences, or as important strategies for coping with social and/or sensory issues (2005, 80). This is significant because wellbeing does not simply imply the absence of difficulty, but

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also the ability for individuals to be involved in their communities, and to pursue happiness. For example, the World Health Organisation (WHO) uses the term 'wellbeing' in their definition of 'mental health':

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community (WHO, 2011).

Literature discussed in this section indicates the relevance of this definition to AS people, who are often at risk of mental ill health as a result of social and environmental stress, isolation and exclusion from areas of social life such as employment (Allard, 2009; Rosenblatt, 2008). In the case of AS people, wellbeing also relates to a person's ability to experience ways of being that are compatible with their dispositions, without being forced to mimic non-autistic behaviours that can be confusing or bewildering to them (Bogdashina, 2001; Clarke and van Amerom, 2007; Milton, 2012). It is important therefore to understand the subjective significance of AS related experiences in relation to wellbeing, as these may not be immediately apparent, in particular to non-AS observers. Therefore, with respect to the present study, understanding pre-diagnostic experiences implies

not only exploring difficulties and coping strategies, but also those aspects of experience which are important for maintaining wellbeing. This is an epistemological concern that will be explored further in discussions of the theoretical (chapter three), methodological (chapter four) and analytical (chapter five) approaches I have adopted.

AS adults face a range of challenges and risks in relation to wellbeing throughout the life course; these include social isolation, education, employment, independent living, and mental and physical health. These are shaped not only by the fact that a person 'has' AS, but by the social and environmental conditions of life, resulting in a diversity of experiences and needs that may change across the life course. As indicated in the introduction, most AS diagnoses are now made in childhood, and awareness of AS has increased substantially since the condition was first introduced into the DSM and ICD in the early 1990s (Baron-Cohen et al., 2007). However, there remain people who are not diagnosed until adulthood (Baron-Cohen et al., 2007; Beardon and Worton, 2011), and for them the pre-diagnostic phase of life may be especially challenging, as they meet with difficulties in everyday life that often have no obvious causes. Understanding pre-diagnostic experiences has the potential to contribute to wider debates around understanding the diverse needs of AS adults, with existing studies indicating that these are often poorly understood (Rosenblatt, 2008; Allard, 2009; Burr et al., 2009; Griffith et al., 2011). This is of contemporary

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relevance to social policy, with the passing of the 2009 UK Autism Act leading to the publication of a national autism strategy (D.o.H, 2010), and further frameworks at the local level (for example, HAPB, 2012). The authors of these documents emphasise the need for continued efforts to understand and meet the diversity of needs within the ASC population (HAPB, 2012, 7, 15-16), in particular those of AS adults (Rosenblatt, 2008, 1-2; Allard, 2009, 9). My task now is to indicate why a particular focus on the pre-diagnostic experiences of AS adults who live for long periods without a diagnosis is a valid area for investigation. I begin by exploring research on the impact of having a diagnosis, and from here will discuss the potential challenges associated with living undiagnosed.

2.1.2 – Diagnosis and the self.

Existing literature indicates that getting a diagnosis is often a significant event in the life of an AS person in terms of understanding oneself and one's life, helping the person to access services and affordances, opening up new opportunities for social connection through contact with similar others, and granting access to legal protection from discrimination (for example, under the provisions of the UK Equality Act, 2010) (Attwood, 2007; Baron-Cohen et al., 2007; Baron-Cohen, 2008a; Baron-Cohen, 2009; NAS, 2011c). Social scientists have contributed to

understanding the impact of a diagnosis by exploring lived experiences, and while broadly supportive of the idea that diagnosis is often beneficial for the AS person, research indicates that its impact may vary both between people and across the individual's life course. In addition to its potential benefits, the experience of being diagnosed (or being told about an existing diagnosis if made in early childhood) can also involve shock and disruption to existing understandings of self.

For example, Molloy and Vasil investigated experiences of having a diagnosis, as part of their study of the relationship between AS, adolescence and identity, through comparative case study of six AS young people aged between twelve and eighteen⁴, using biographical interviews (2004, 7-11). The authors reported that while the initial response to the diagnosis could be one of 'shock and disbelief', it also provided resources for making sense of their everyday difficulties and life events (Molloy and Vasil, 2004, 114-115). They noted the variable impact of the diagnosis, with many older participants facing challenges in terms of sorting out 'which aspects of their personalities, interests and behaviours display AS traits and which have nothing to do with AS' (Molloy and Vasil, 2004, 121). This was linked to the danger of over-identification with static diagnostic criteria that may not adequately reflect individual differences (Molloy and Vasil, 2004, 123).

⁴ The age at diagnosis was between eleven and fourteen for all but one of the participants, who was diagnosed at age four (Molloy and Vasil, 2004, 24-27).

These findings were echoed in later work by Huws & Jones (2008), who explored the relationship between diagnostic criteria and young people's experiences of 'having [high-functioning] autism', through semi-structured interviews with nine students⁵ at an autism-specialist college (Huws and Jones, 2008, 100). Awareness of diagnosis was associated with a diverse range of feelings such as 'shock and disappointment', indicating that the experience of being diagnosed can involve qualitatively different feelings of difference from those encountered in the pre-diagnostic phase (Huws and Jones, 2008, 102). In addition, diagnosis also provided an explanatory narrative for making sense of everyday difficulties and life events (Huws and Jones, 2008, 102). The authors also noted that diagnostic labelling could have both positive and negative implications, for example, helping a person gain access to services, and/or marking them out for discrimination by others (Huws and Jones, 2008, 102). The impact of the diagnosis on the experiences of 'having AS' was therefore framed in terms of both disruptions to social life, and also opportunities for developing increased biographical coherence and understanding of everyday challenges (Huws and Jones, 2008, 103-104). The notion of the diagnosis having multiple effects has also been observed in relation to those diagnosed in adulthood by Singh, who described the case of 'Helen', a woman

⁵ Participants were diagnosed in childhood (Huws and Jones, 2008, 100)

diagnosed at age 32 (Singh, 2011, 249). Singh identifies the positive aspects of 'Helen's diagnosis as 'legitimation', 'relief' and 'coherence', alongside the 'upsetting notion that social interactions will always be difficult' (Singh, 2011, 249). These findings support the idea that the diagnosis can be important in understanding aspects of self and life events associated with AS; however, one should not assume that the diagnosis in and of itself results in an unproblematic experience of self.

While formal diagnosis can provide resources for making sense of everyday difficulties, differences and life events, the potential for actualisation of these resources in terms of developing a liveable sense of self is contingent upon wider social and biographical conditions. This is illustrated in Bagatell's case study of 'Ben', a 21 year old AS college student in the USA (2007, 414-415), in which the author describes a series of events through which he moved from experiencing his AS as something of which he sought to be 'cured', to an understanding of the condition as a legitimate and valued aspect of self. The research narrative takes place in light of 'Ben's recent history of suicidal thoughts, self-injurious behaviour, social exclusion, drug and alcohol use as self-medication for anxiety and depression, and the breakdown of his first romantic relationship (Bagatell, 2007, 416-422). Diagnosed at the age of 15, 'Ben' described being treated as an outsider for most of

his life and had begun to wish for a 'cure' for AS, hoping that science would one day provide this for him (Bagatell, 2007, 416-418).

However, shortly after the research began, 'Ben' attended a local autism conference where two significant events led to changes in his understanding of self. Firstly, he attended a lecture given by a neurologist on the neurobiology of autism, an experience which presented him with a new way of understanding AS, not as personal flaws, but as a set of neurodevelopmental differences (Bagatell, 2007, 418-419). Secondly, he met other AS people whose experiences offered the possibility of a liveable life without 'pretending to be normal' (Bagatell, 2007, 419). He began to adopt an 'Aspie'⁶ identity, and engaged with other 'Aspies' through online forums and physical meetings (Bagatell, 2007, 422). As a result, 'Ben' placed less emphasis on the norms of non-autistic behaviour, and instead began to judge his identity and self-worth by the norms of 'Aspie' culture (Bagatell, 2007, 421). Diagnosis did not give 'Ben' a ready-made or unproblematic identity, but rather provided resources for developing a more liveable sense of self. His ability to make use of these resources was however dependent upon changes in his social life (i.e. the new-

⁶ This is a term used by some AS people to describe themselves, particularly in online communities such as 'Aspie Pride' (NAS, 2012)

found 'Aspie' communities within which he found acceptance), and also in his understanding of AS as a set of neurodevelopmental differences.

This idea is supported by the fact that Ben's life did not suddenly become problem-free as a result of these changes; as Bagatell notes, tensions remained between 'neuro-typical' social arenas and those of 'Ben's newfound 'Aspie' culture (Bagatell, 2007, 422-423). His life became stretched across areas within which he was encouraged and obliged to 'fit in', and 'Aspie' spaces within which AS experiences were legitimate and accepted ways of being. What 'Ben's case illustrates is that simply having a diagnosis does not inevitably result in significant changes in identity or wellbeing. The impact of diagnosis on self and self-other understandings, as well as one's sense of life narrative, may depend upon how it is understood relative to the social and biographical circumstances into which it enters as a life event. This study also points to the importance of diagnosis not only in relation to understandings but also presentations of self, through the challenge of choosing whether or not to disclose one's AS identity to others.

Disclosure is a significant theme in the literature, and is a common everyday challenge throughout the life course for those with a diagnosis. For example, in their exploration of social inclusion for HFA children within mainstream classroom

settings, Ochs et al. (2001) note that the frequency and effectiveness of inclusive interactions with non-HFA children were linked to 'disclosure practices'. These related to teachers informing non-HFA children of the HFA child's aptitudes and limitations, a practice that was reported as the most significant factor in facilitating inclusion, irrespective of the IQ scores of the HFA children (these were expected to be a significant factor in mediating inclusion) (Ochs et al., 2001, 415-416). While in childhood disclosure may be managed by a teacher or caregiver, increasingly this can become a concern for the AS person themselves as they grow older. For example, Madriaga et al. (2008) explored the transition to higher education for AS young people, and highlighted a number of situations relating to disclosure, such as whether to disclose their AS status to flatmates and university lecturers, as well as a range of responses to these challenges (Madriaga et al., 2008, 28-30). For some participants, such as 'Alan', disclosure was 'not an issue', as he readily discussed his AS with flatmates; however, others such as 'Karen' were more guarded, choosing to conceal her AS status when seen leaving an exam room for disabled students (Madriaga et al., 2008, 29-30).

The pragmatics of disclosure have also been explored in the lives of adults more generally, in the work of Davidson and Henderson (2010a). The authors explored AS people's experiences of identity disclosure in everyday social encounters through examination of autobiographical narratives (2010, 155), observing a range of

strategies relating to concealment and disclosure in everyday exchanges. AS people often reported being able to 'pass' as non-autistic due to their intelligence and skills with language (Davidson and Henderson, 2010a, 155-156). 'Passing' was framed as a necessary strategy in order to protect against discrimination, ill-treatment or exclusion, and the authors identified a range of 'repertoires' for mediating these hazards (Davidson and Henderson, 2010a, 155). One of these was referred to as the 'qualified deception' repertoire, where a person's AS status was concealed from selected others within particular settings (Davidson and Henderson, 2010a, 157). For example, Toni Sano described her development of 'pre-programmed behaviours' as a way of negotiating the potentially destabilising social landscape of majority non-AS arenas (Davidson and Henderson, 2010a, 161). Qualified deception also functioned in relation to another prominent repertoire, which involved *keeping safe* through careful management of those to whom AS status is disclosed (Davidson and Henderson, 2010a, 158-160). Examples of this include Ruth Hane's use of worksheets for 'evaluating the pros and cons of self-disclosure' to different people (Davidson and Henderson, 2010a, 159). Hane's 'worksheets' and Sano's 'pre-programmed behaviours' are examples of the everyday efforts that many AS people undertake in managing their presentations of self. Sano's comment that her 'pre-programmed behaviours' represent a 'shell' indicates that 'passing' may involve not only performative effort, but also negotiation of confusion and

contradiction between understandings and presentations of one's identity (Davidson and Henderson, 2010a, 161).

The presentation of the self as an AS person can also depend upon how one understands the status of the diagnosis, and also how one believes others may view its significance. Clarke and van Amerom (2008) explored understandings of AS in parents and caregivers as compared with those diagnosed, through analysis of 60 blog websites (30 in each group) (85). The authors reported a substantial divergence of opinion between the 'cure focused' understandings of parents and caregivers, and the more positive view of AS presented by those diagnosed (Clarke and van Amerom, 2008, 100-103). While negative experiences and suffering were framed as being intrinsic to AS by parents and caregivers, those diagnosed argued that most of this was a result of discrimination and misunderstanding on the part of non-AS others (Clarke and van Amerom, 2008, 85). 'Aspie' bloggers also emphasised the importance of the internet in facilitating both the development of autistic culture and providing the resources for them to challenge both 'cure' and deficit-focused accounts of AS (Clarke and van Amerom, 2008, 93-94). This indicates that the significance of the diagnosis for understanding and presenting the self may well involve a critical engagement with diagnostic categories.

There are also indications that the pragmatics of identity disclosure involves other aspects of self, such as gender identities. Everyday challenges and experiences cannot be reduced to a single aspect of self, but involves different identities that intersect within various social settings. For example, in her exploration of the challenges faced by women on the spectrum, Faherty (2006) describes the view of a participant within an HFA/AS women's group with which she worked:

One woman explained that, from her perspective, there is a subtle interaction between these two sets of issues [being a woman and being HFA/AS]. "Problems related to the [autism] spectrum are combined with problems of society's expectations of women. How one looks, what one wears, how one is supposed to relate socially, that a woman is supposed to have natural empathy towards others, expectations about dating and marriage...". Women are affected by autism in the same ways as their male counterparts; however, they are doubly challenged by the assumptions that society places on the female gender (Faherty, 2006, 12).

Understanding and negotiating gender norms was a particularly significant topic for participants in this group, both in relation to understandings of self and to how they were perceived by others. Contributors to the group spoke of feeling that more

was expected of them in terms of adherence to social gender norms, when compared to their male counterparts, in particular those relating to 'feminine' intuition and empathy (Faherty, 2006, 13). Faherty also observes that for participants, being an AS woman was also linked to specific experiences of insecurity and risk, relating to difficulties in understanding implicit social queues and intuitive aspects of social interaction:

Interestingly, after discussing these issues, the first requested topic was how to read body language and how to tell if someone is trying to take advantage of you (Faherty, 2006, 13).

Having an AS diagnosis has implications not only for how a person sees themselves and their relationships with others, but also the potential insecurities and risks which they may face. Although the subject of having a diagnosis is not discussed directly here, all of the participants had been diagnosed, and the group itself was situated within a support centre for HFA/AS adults (Faherty, 2006, 10). This provides an example of how social resources for understanding and presenting the self, as well as understanding the intersection of different identities and their consequences for everyday life, may be mediated by having a diagnosis.

The impact of formal diagnosis, while apparently beneficial for many of those diagnosed, can be highly variable both between individuals and within individual biographies. Davidson and Henderson's (2010) work shows that presentations of self in relation to disclosure are closely related to the management of everyday risks people, such as potential discrimination or victimisation. Explorations of the impact of the diagnosis, in particular those relating to adults, also open up questions relating to the experience of living without a diagnosis. Increased biographical coherence may imply prior issues with making sense of one's life; feelings of greater self-acceptance may imply that these were not present or reduced in the pre-diagnostic phase; the importance of the diagnosis in formations of collective identities may also point to fewer opportunities for such involvement prior to diagnosis. Therefore, one may also ask: what might the consequences of not having a diagnosis be, in particular for those who go into adulthood undiagnosed?

2.1.3 – Living without a diagnosis

Narratives of AS people who have lived for long periods without a diagnosis offer indications that this can involve significant challenges. AS author Jerry Newport writes that the 'worst' AS-related experience of his life was 'not knowing about it'

(Newport, 2001, 119-120). In a published collection of interviews with AS college students in the USA, one participant ('Jim') observed that '[t]he trauma of knowing [about one's AS] does not even approach the trauma of growing up not knowing why the world is so difficult to comprehend' (Prince-Hughes, 2002). Pre-diagnostic experiences have received far less attention in research than the impact of the diagnosis; however, issues relating to pre-diagnostic life are indicated in a limited number of publications. For example, Singh's participant 'Helen' (discussed in 2.1.1) described 'constant misunderstanding' and 'feeling like an alien' as features of her pre-diagnostic life (Singh, 2011, 248) Elsewhere, in their explorations of risks associated with AS as a 'non-obvious disability', Portway and Johnson point to additional risks experienced by those who receive a late diagnosis:

The findings of this study indicate that early recognition of AS could have benefits in terms of ameliorating everyday and longer term risks identified with respect to participants who had only received their diagnoses in late adolescence and adulthood. Examples of harm associated with late diagnosis and low intervention include underachievement, high dependency on parents, negative feelings of low self esteem, high anxiety, depression and suicidal tendencies. It must be acknowledged this debate is not straightforward, and that amongst the undiagnosed and inaccessible population of people with AS there may be opposing viewpoints. It is

unlikely that everyone with AS will accept or need such a diagnosis, and further research is needed to measure any potential negative costs of such a labelling against the gains of diagnosis and intervention (Portway and Johnson, 2005, 81-82).

Here, it is suggested that living for a long period without a diagnosis can involve different experiences of risk when compared with those diagnosed in childhood. However, there is no detailed discussion of this in relation to their empirical material: no information was provided for the age of diagnosis of the participants, nor was this identified as a key issue in the design or discussed in the main report of findings. This leaves a gap not only in the comparison between early and late diagnosis, but also in terms of understanding the specificity of experiences of growing up undiagnosed. One aspect of further research invited by Portway and Johnson (2005) may therefore be to explore the challenges of pre-diagnostic life, in order to inform service provision for those who receive a very late diagnosis.

Elsewhere, in a report prepared for the National Autistic Society focused on the needs of adults with autism, Rosenblatt observes:

Many adults with autism, particularly those with Asperger syndrome or high-functioning autism, are only now seeking or receiving a diagnosis, as there was little awareness of the condition when they were growing up. Consequently, although autism is a lifelong disability, older adults are more likely to have received their diagnosis later in life, compared to younger adults (Rosenblatt, 2008, 11).

This suggests that exposure to risks may be associated not only with the timing of the diagnosis, but also the socio-historical situation of the person. Drawing on case knowledge from clinical practice, Baron-Cohen et al. observe:

[M]ost teachers, clinicians, social workers, and parents have now heard of AS, and thankfully many children with AS are being identified and diagnosed by middle childhood...But what of the generation who were born before 1980, who may have had AS but for whom there was no diagnosis available? No specialist clinical teams, not even the concept of AS. How did they fare? The answer is that they were overlooked, and struggled through their school years...they had trouble making friends or fitting in...many were bullied by the other children, both physically and verbally...many felt like “an alien in the playground”. The lucky ones managed to stay in school long enough to

get their SATs, and some got to university. But not without feeling their teens were an uphill struggle. By young adulthood many had suffered clinical depression and even felt suicidal...Some of them had enjoyed the closeness of an intimate relationship only for this to break down. Some had found employment only for them to run into problems in the work place through not understanding what the employer and other staff might expect of them...The unlucky ones succumbed to the low self-esteem that comes from a childhood of being bullied or feeling excluded and dropped out of school. In some cases, they were asked to leave because the school couldn't cope with their odd and disruptive behaviour in class. In other cases, the children themselves gradually truanted, because the lessons seemed pointless...Sadly, these unlucky ones left school by 15 years old, with no qualifications on paper, and many have been unemployed for long periods if not continuously, ever since...And then – somehow – they heard that AS exists. Maybe through a newspaper article, or a website, or in a poster on the wall in the GP/Health Centre waiting room. And for many of them, they describe that moment of feeling: “This is me” (Baron-Cohen et al., 2007).

Here, the authors highlight those born before 1980 as a cohort at particular risk of having lived for long periods without a diagnosis, and have also identified online communications as a common route to recognition of AS-related differences. For

this cohort, not only was the diagnosis not available, but also opportunities for connecting with similar others (such as AS communities online) were also restricted. This is a group whose access to resources (both in terms of the diagnosis and also understandings of AS within wider society) has been highly restricted for much of their lives. People in this cohort have been 'overlooked' both in the sense of not having access to specialist assistance or diagnostic services, and also through a lack of research engagement with their experiences. This gap is significant not only for those born before 1980, but also later cohorts of adults who may have grown up without a diagnosis in social settings where the condition is poorly understood. As Beardon notes:

Currently, if we believe published epidemiological studies alongside statistical data from local authorities, it would seem that there are a lot of people out there who would qualify for a diagnosis of AS but do not have one. If one has AS but does not know it, then there is the potential for major problems with identification of self and understanding who one is – and why (Beardon in Beardon and Worton, 2011, 9-10).

The pre-diagnostic experiences of those born before 1980 who were diagnosed in adulthood is an area that appears ripe for further investigation. While no studies in

social science have yet explored this issue specifically, there are indications in literature from elsewhere that social scientific study of living with undiagnosed conditions provides further evidence for potential social scientific contribution to this area of study.

Comparisons between AS and conditions clearly definable as illnesses must be made with great caution; here, this comparison is made only in so far as it shows some of social consequences of living without a diagnosis. For example, Juuso et al. explored the meanings of pain among women with fibromyalgia⁷, whom they characterised as facing a 'double burden' both from the physical pain itself, and persistent doubts by others of the legitimacy of their symptoms (2011, 7). This concept is useful for present purposes if one treats it as referring to both the absence of a diagnosis and the everyday challenges faced by AS adults more generally; the latter of which is understood to refer to the challenges themselves, and does not imply that AS-related experiences are inherently pathological. Elsewhere, Nettleton explored the experiences of neurology patients with medically unexplained symptoms (MUS) who lack a medical diagnosis. Participant narratives revealed common experiences of not being able to 'make sense' of their illness due

⁷ Fibromyalgia is a chronic pain condition of unknown aetiology. It is associated with fatigue, poor quality sleep, headache, stiffness, and perceived weakness (Juuso et al. 2011).

to the lack of a 'medical explanation' to engage with (Nettleton, 2006, 1165). As with Juuso's participants, legitimacy was a key issue for participants who expressed concerns about their illness being framed as 'imagined' or 'fake', and that psychological explanations offered to explain their symptoms carried less legitimacy than organic theories. Nettleton situates the experience of MUS within the context of wider social demands for accountability:

In an uncertain context the pressure of constantly having to account for oneself and remake ones identity can be relentless and unsettling. Having to be seen to be 'reflexively' making an effort to find solutions and restore physical and social coherence can be as intolerable as the symptoms themselves. One is not allowed to be anomalously 'ill'. Society does not readily give people permission to be ill in the absence of an 'accepted' abnormal pathology or physiology. Furthermore 'other people' and indeed society more generally is uncomfortable with, and indeed even fearful of such anomalies. Biomedical classifications are socially [sic] constructions which have the symbolic effect of stabilising identity and restoring coherence. *But they also generate ambivalence* (Nettleton, 2006, 1176 - emphasis added).

Here, Nettleton draws our attention to the social impact of living with an undiagnosed condition, and also to the negative effects of diagnostic categories on those who are excluded from them. Having a diagnosis can help a person to understand experiences of illness, and also provide credibility in terms of how they are seen by others. Conversely *not* having a diagnosis can generate ambivalence, both at the personal level of self-understanding, and the social level in which the person is continually called to account for the difficulties associated with their illness.

Research on adults who have self-diagnosed with Attention Deficit Hyperactivity Disorder⁸ (ADHD) presents a qualitatively closer comparison with AS, in particular because respondents often point to positive aspects of their condition. Henry and Hill Jones explored the experiences of older women who were diagnosed with ADHD in later years, including their experiences of pre-diagnostic life (2011, 246). The authors highlighted 'peer rejection' and 'feeling different' as key features of this phase, along with creative adaptation within the workplace where participants sought to mediate difficulties with repetitive or menial tasks (Henry and Hill Jones,

⁸ "The...DSM-IV-TR describes the essential feature of Attention Deficit Hyperactivity Disorder as a 'persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequently displayed and more severe than is typically observed in individuals at a comparable level of development'" (Henry and Hill Jones, 2011, 247)

2011, 256). The theme of 'creative adaptation' is of interest here because it indicates that while pre-diagnostic experiences of ADHD may lack the coherence provided by the diagnosis, participants did operate with understandings of personal dispositions later attributed to ADHD in this phase of life. This opens up questions as to how AS people understand their differences and difficulties in the pre-diagnostic phase of life.

In spite of a lack of specific research literature, there are indications that life without a diagnosis can be especially stressful for AS people, in particular due to the lack of coherent understanding of everyday difficulties as well as support for them. Baron-Cohen et al.'s observations from clinical practice point to a particular cohort who may be at increased risk of being diagnosed very late, and indicate that experiences may have socio-historical dimensions with respect to the resources and knowledge available during their lifetime. As indicated at the beginning of the chapter, recent policy-related literature points to the need for greater understanding of the diversity of needs within the adult AS population, of which those who have received a very late diagnosis are a part (Allard, 2009; Rosenblatt, 2008; HAPB, 2012). Although no specific research attention has been paid to AS adults' experience of living without a diagnosis, literature indicates some of the issues involved in living with an undiagnosed condition. Juuso et al.'s (2011) concept of the 'double burden' highlights the additional strain placed upon those living with

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an undiagnosed condition in relation to struggles for credibility. Nettleton (2006) points to the social context of living without a diagnosis, where the struggle for credibility also involves continual demands for accountability for one's illness to which the person is often not equipped to respond. Elsewhere, Henry and Hill Jones' (2011) work on older women diagnosed with ADHD in later years points to the existence of pre-diagnostic understandings of differences associated with the condition.

In all of the research considered in this section, the relationship between diagnosis and identity is a central theme. Further investigation of this topic can help to address a wider gap in research knowledge with regard to the needs and experiences of AS adults, and be of relevance to both researchers and service providers with interests in this group. In particular, it may also be of interest to diagnosticians in terms of understanding how pre-diagnostic experiences may affect the impact of the diagnosis. It can also contribute to debates around living with undiagnosed conditions, and to the nascent sociology of diagnosis more generally (Jutel, 2009; Annemarie, 2011; Jutel and Nettleton, 2011). However, this is potentially a very broad area, and attention to some of the wider themes in social research relating to AS can help develop more specific research questions.

2.2 – Investigating formations of pre-diagnostic identities (research questions).

Thus far my aim has been to demonstrate why there is a need for further investigation of the pre-diagnostic life experiences in relation to AS adults who were diagnosed in later life. In this part of the chapter, my task will be to derive some specific research questions from existing studies on the experiences of AS people more generally, in order to frame the present investigation.

2.2.1 – Understanding the dispositional self.

One common feature of AS people compared to non-AS others, is greater attention to detail and often intense interest in a narrow and/or repetitive range of stimuli. This is often attended by preferences for predictable, sequential ways of understanding and acting in the world, and discomfort in the face of ambiguity or sudden change (Attwood, 2007; Baron-Cohen, 2008a). The basis of these traits is believed to be neurodevelopmental, specifically in how the sensory information is organised in perception, and resulting in a range of dispositional strengths and limitations. In the social scientific literature, researchers have noted the implications of differences in dispositional engagements with the social world for experiences of everyday life. For example, Ryan and Räisänen explored experiences of social life through semi-structured interviews with 16 AS adults, and in some cases their non-AS partners (2008, 137). They argued that while non-AS people not

only learn social 'rules' but 'internalise' them as a taken-for-granted way of going on in the world, AS people typically do not, and continue to rely upon express rules as opposed to intuition in social life (2008, 137-139). As a result, participants in the study requested changes to the semi-structured interview format, preferring a more formal question and answer format over open-ended conversation (Ryan and Räisänen, 2008, 137). Their responses revealed constant efforts to 'fit in' with the norms of everyday life, which were often experienced as vague or confusing. AS participants also felt unable to grasp social encounters with non-AS others intuitively, instead relying upon learned and consciously enacted responses, as indicated in this response from 'Tim':

You do learn strategies from an early age I think and the problem is with people probably on the spectrum is that you have got a lot of information that you need to store away because you have to remember the strategies for those situations [um] because it doesn't come naturally so you have to pull that out of your little film cabinet that you have got in your head and play it quite quickly so you know what to do. It is not inherent really (Ryan and Räisänen, 2008, 140).

This is an example of what Ryan and Räisänen refer to as a 'different logic' for social agency, characterised by dispositions toward predictable, rule-based ways of

understanding over tacit, intuitive forms. This idea of a 'different logic' is supported elsewhere in the literature, for example in the work of Sterponi, who explored the construction of rules, accountability and moral identities of children with 'high-functioning autism' in spoken interactions (2004, 207). She argues that for the AS children in her study:

...social skills are linked with the capacity to operate with sequentially based understandings. Prior courses of action constitute for the autistic children the fundamental source for reaching an understanding of what is in the mind of other people, specifically their expectations and normative references, and subsequently for constructing their own lines of conduct (Sterponi, 2004, 222).

While these were seen as characteristic of AS children's dispositions towards understanding and maintaining accountability in communicative exchange, the 'dynamism and creativity typical of accountability practices [in non-AS people] constitut[ed] serious challenges for children with autism' (Sterponi, 2004, 221). In emphasising the practical nature of rule-following in language, Sterponi frames dispositions towards social coordination in terms of an opposition between sequential (AS) and creative/dynamic (non-AS) orientations to applying social rules (2004, 222-223). This is also reflected in the work of Ochs et al. (2004), who argue

that the aptitudes and limitations of high-functioning autistic children are illustrative of the important role that creative adaptation plays in non-autistic interaction (as well as its potential limitations) Drawing on anthropological linguistic research, they argue that:

Social life also entails the ability to construe and respond to fluid, contingent circumstances and indeterminate meanings...The social challenges of those with autism make plainly evident the importance of improvisational models that depict members as agents of social experience. Although the high-functioning children with autistic spectrum disorders who participated in our study exhibited improvisational strategies for taking part in conversational interactions, they also evidenced pronounced difficulties in grasping the range of socio-cultural dispositions, acts, identities, activities, and institutions indexed moment-by-moment by linguistic and other conventional semiotic features of shifting social situations (Ochs et al., 2004, 173).

This was reaffirmed by later work by Ochs and Solomon (2007) who argued that in co-present encounters AS children:

‘...strategically invert right there and then the practical logic of imminent social exigencies into the logical logic of patterned objective knowledge, reversing the default directionality of the logic of objective structures transformed into practical logic required for on-the-spot situational exigencies’ (Ochs and Solomon, 2007, 162).

In other words, while non-AS participants relied on a tacit ‘feel for the game’ as a means of going on in the social world, the AS children in their study made sense of interactions through systematic observation and construction of rules. This issue was taken up in later work by Ochs and Solomon (2010) on autistic sociality, informed by a decade-long programme of anthropological-linguistic research with children across the spectrum (Ochs and Solomon, 2010, 69). Drawing on Bourdieu’s concept of habitus - a ‘circumscribed yet transformable set of dispositions and situated logics that members of social groups employ to interpret and enact social practices’ - the authors situate autistic sociality within a wider human ‘range of possibilities for social coordination with others, influenced by the dynamics of both individuals and social groups’ (Ochs and Solomon, 2010, 69, 72). The authors argued that while autistic children faced significant difficulties in social interactions, these did not automatically exclude them from social life. Rather, in addition to their limiting aspects, autistic traits also include a range of orientations to social

interaction, including dispositions towards sequential, rule-based ways of engaging with the world (Ochs and Solomon, 2010, 69).

How one understands one's dispositional ways of being is also significant in terms of how they experience everyday life. For example, in Ryan and Räisänen's (2008) study, one participant ('Paul') spoke of his fear of committing 'social suicide' as an everyday anxiety related to 'being' AS; this involved saying something inappropriate, and then exacerbating the situation by making more problematic comments due to his anxiety at having made the original statement) (Ryan and Räisänen, 2008, 139). As a way of mediating these risks, 'Paul' reported relying upon mundane but predictable topics of conversation which Ryan and Räisänen (following Goffman) refer to as 'safe supplies':

I would, you know, find, even if it wasn't particularly interesting; "Oh look, butter, do you like butter?" "Yes, butter." And even if it was just like a two minute conversation I would just pick something randomly in the room, just like, talk about the microwave for five minutes and then realise I had talked about microwaves for five minutes, you know, and then it would, I would stop thinking about things in the room and then try and pick up I guess personality traits, or what people were wearing, or I guess if I noticed any

differences, like if someone had had a hair cut I would try, I guess, and make conversation about that (Ryan and Räisänen, 2008, 139)

The authors note that while the use of 'safe supplies' may also be a strategy familiar to non-AS people, the key difference was the frequency and intensity with which these were relied upon in the absence of taken-for-granted ways of interacting with non-autistic others (Ryan and Räisänen, 2008, 139). Elsewhere, in Madriaga's study of AS students in higher education, the participant 'Alan' noted that understanding his spatial sensitivity to crowds and noise helped him develop strategies for managing these in everyday life (Madriaga, 2010, 27). Diagnosed shortly before beginning his university course, 'Alan' describes how he went from not being able to tolerate crowds and noise during the society fair in the opening week of term, to being able to work and interact with others while working in a busy bar (Madriaga, 2010, 29).

It is important to note that not all understandings of dispositions relate to difficulties; in many cases those diagnosed emphasise the positive aspects of being AS, when compared with ways of being associated with non-autistic people. Brownlow et al. (2006) provide examples of this from their exploration of identity construction in online discussion forums; for example, one respondent (referred to

as 'Person 5') contrasted what they saw as problematic aspects of non-AS communication with a more direct style associated with AS:

Humans, even NTs, possess the linguistic ability to express concepts, ideas, and emotions verbally with clarity, but the NT brain seems incapable of actually doing so. They rely heavily on the animalistic means of body language. It's primitive and unnecessary, I think. Further, NTs can't seem to express thoughts completely. They use an irritating form of verbal shorthand, where significant gaps are left to be filled by the listener. It's absurd! If I were to design a communication paradigm to be applied to a sentient race of primates, it would be a lot closer to the AS way than the "normal" way (Brownlow et al., 2006, 319).

In a later comment, 'Person 5' goes on to explicitly reject the idea of their AS as a disability, and affirms the value of their AS-related qualities to their sense of self:

I won't use the term 'disability' to describe AS . . . I do not feel disabled or impaired. I am not broken and I do not need to be fixed or cured. If I were to become NT, I would not be 'me' anymore, and a lot of my good qualities would disappear (Brownlow et al., 2006, 319).

These examples show how a person's dispositional self can be understood and presented through the lens of the category AS as a valued and defended aspect of self. For those who have a diagnosis, understanding one's dispositional orientations to the world, and how this may affect relations with others, is one important effect of being diagnosed. In certain circumstances, knowledge of the person's AS status can also provide a basis for understanding on the part of others, with the potential for mediation of problematic aspects of social interactions. However, AS-related dispositions do not simply 'appear' when a diagnosis is made, and this raises the question of how dispositional aspects of self are understood and experienced in the time before one is diagnosed. Thus the first question explored in this thesis is - *How do AS people who are diagnosed in adulthood understand their dispositional selves in the pre-diagnostic phase of life?*

2.2.2 – Self-other relations and identity.

In addition to understanding the dispositional self, research indicates that understanding oneself through the category AS plays an important role in how one understands and presents themselves in relations with others, for example, who one identifies with or distinguishes themselves from, and why. One example of this

has already been demonstrated in Bagatell's case study of 'Ben', where changes in his understanding of dispositional self also led to changes in who he identified with, and the kinds of social relationships that were important for him. Having a diagnosis can affect not only how the person understands and presents themselves to others, but also the ways that they are 'seen' and treated by others. This can have implications for wellbeing, for example, in terms of having access to supportive relationships in order to mitigate risks associated with mental ill health (Rosenblatt, 2008; Allard, 2009). This was noted by Sirota, who explored the politeness practices of HFA children through ethnographic observation of interactions within 'naturally occurring family and community settings' (2004, 229). She observed that many participants were able to successfully negotiate tasks involving positive politeness practices in the presence of caregivers, who were able to mentor them in developing appropriate responses (Sirota, 2004, 230). Performance in naturalistic theory of mind tasks involving positive politeness was contrasted with poorer performance in clinical tasks by 7 of the 15 children involved, and Sirota observed that this may be due to the absence of social 'scaffolding' provided by the guidance and prompting of parents (Sirota, 2004, 245).

Elsewhere, Kremer-Sadik studied HFA children's responses to everyday questions (for example, 'what is the time?', 'what do you mean?') as 'naturalistic theory of mind tasks' in order to explore skills related to perspective taking (2004, 185). The

author observed that HFA children often did better in perspective-taking tasks when their parents are available to assist them in attending 'to predictable features and perceptual cues embedded in social situations to appropriately respond to and participate in social activities, as well as to better understand the internal dispositions of members participating in them' (2004, 200). Kremer-Sadik argues that a focus on interpersonal perspective-taking in lab-based theory of mind tasks may obscure socio-cultural perspective-taking practices in assessments of AS children's social competence (2004, 200). This was also supported by Sirota, who noted that for the children in her study 'participation in quotidian practices of positive politeness entailed a number of socio-culturally mediated resources that, although vital to the constitution of meaningful social discourse, generally have remained under-acknowledged and unavailable for study via experimental laboratory research' (2004, 245). Both of these studies suggest that aspects of social competence and perspective taking abilities may be linked to the availability of supportive relationships for HFA children.

The importance of relationships in meeting everyday challenges has also been observed in research relating to AS adults. For example, in Davidson and Henderson's (2010) work on disclosure, the authors noted the importance of finding 'allies...who can fully grasp the complexity and nuances' of AS people's experiences, for negotiating everyday interactions (Davidson and Henderson, 2010a, 159).

'Allies' were seen as important not only for their status as people to whom one's AS identity could safely be disclosed, but as sources of support and counsel in deciding how to present oneself within other social relationships (Davidson and Henderson, 2010a, 159). This was particularly relevant in relation to those whom the authors termed 'stigma coaches', or people who emphasised the importance of concealment and 'passing' in negotiating the non-autistic social world (Davidson and Henderson, 2010a, 158-159). Clinicians, parents, friends and other professionals were cited as examples of others who advised AS participants to conceal their diagnosis from non-autistic others, such as potential employers (Davidson and Henderson, 2010a, 158-159). Davidson and Henderson's work draws our attention to the social variability of disclosure, and the idea that the experiences of different AS people in self-other relations can involve variations in cultural and social context (i.e. where they are, and with whom).

Elsewhere, Rosqvist (2012) explored the impact of the diagnosis through ethnographic research in a 'Swedish educational setting', involving 12 AS participants who were diagnosed in adulthood (Rosqvist, 2012, 120). In common with the findings of previous studies concerning the impact of the diagnosis, participants framed it as an important life event in terms of self-understanding, collective identity and self-acceptance (Rosqvist, 2012, 122). Diagnosis was linked

to what the author describes as an 'ambivalent ideal of openness', where disclosure of one's AS identity was assumed to be the default course of action (Rosqvist, 2012, 122). However, participants also acknowledged that the pragmatics of individual social encounters may mean that this is not possible or desirable, and this was framed in terms of risks associated with ignorance or discrimination on the part of others (Rosqvist, 2012, 122). Participants also spoke of an active and critical engagement with diagnostic criteria and with the normative 'holders of knowledge' in biomedical and clinical sciences (Rosqvist, 2012, 122). These activities were framed as attempts to rebalance understandings of AS away from deficit-focused accounts, towards an appreciation of both strengths and limitations associated with AS differences (Rosqvist, 2012, 123-125). For participants, the diagnosis was taken as an imperfect concept, to be developed and contested, providing further evidence of potential variability and change in the relationship between the diagnosis and the self.

Differences in the quality of relations with others, as well as the wider norms and expectations that shape behaviour in different settings can influence how a person acts and is perceived by others. In the case of AS people, how they experience and deal with social and environmental situations may contrast with those prescribed by the social norms and demands of a given situation. These expectations may involve assumptions about 'normative' perceptual experiences of the social world that does

not hold in the case of AS people. Understanding the dispositional self can therefore involve intersubjective aspects, in terms of how one understands oneself in relation to others, and also how one is seen and treated by others relative to their presented self. Research indicates that throughout the lifecourse, having a diagnosis plays an important role in both of these aspects of self-other relations, notably through the challenge of disclosure. As indicated earlier (in 2.1.3), living with an undiagnosed condition has been associated with feelings of ambivalence and difficulties in understanding one's differences from others, in addition to everyday challenges associated with the condition (the 'double burden'). Not having a diagnosis may therefore involve particular challenges in relation to how a person understands and presents themselves to others, and also how they are seen by them. Therefore, the second question that I will pursue in this thesis will be: *How do self-other relations affect pre-diagnostic understandings of self?*

2.2.3 – Understanding and presenting the self in the management of everyday insecurities.

Another important feature of existing social scientific research on the lives of AS people is the presence of social and environmental challenges that can manifest in the form of everyday insecurities. Differences in the way one is disposed to engage with the social world can mean that many aspects of daily life appear strange or

confusing, and this insecurity becomes a perennial feature of everyday life. For example, Ryan and Räisänen reported participant experiences characterised by 'constant feelings of not belonging' in both social and environmental contexts (Ryan and Räisänen, 2008, 138). The authors frame these experiences in terms of an opposition between AS people's preferences for clarity and consistency, and what they see as problematic features of modern societies such as uncertainty, fluidity, individualism and weakening of social bonds (Ryan and Räisänen, 2008, 135). They argue that under these conditions, while many non-AS actors operate by 'maintaining an illusion of safety based upon trust and reciprocity' developed through 'a common sense attitude which reduces these concerns to the level of largely taken for granted and unremarkable', this is often not possible for many AS people (Ryan and Räisänen, 2008, 135, 141).

By contrast, AS participants were seen to 'move through social life with concern about the contingencies, risks and hazards that exist at a micro and macro level' in a state of constant vigilance and anxiety regarding potential breaches in the 'order' of interactions with others (Ryan and Räisänen, 2008, 142). The state of 'ontological security' which for non-AS people 'maintain[s] an illusion of safety based upon trust and reciprocity' and '...reduces [awareness of contingencies, risks and hazards in everyday life] to the level of largely taken-for-granted and unremarkable' was often

out of reach for the AS adults in this study (Ryan and Räisänen, 2008, 135, 141). This observation was reflected elsewhere in research by Portway and Johnson, who identified experiences of 'not quite fitting' (what they refer to as 'marginal normality') as common features of participants' lives (Portway and Johnson, 2005, 77).

Chronic insecurity also extends to experiences of social space, which can motivate practical strategies in response to challenges posed by the environment. For example, Ryan and Räisänen noted that AS participants were 'unusually sensitive to the presence and spatial practices of others in a way that most people are not' (2008, 142). This led to a common practice of making 'safe spaces', for example, one participant, 'Trisha' disliked having anyone but her children in her home, and described 'how one person visited her each month and she could not wait for her to leave because she felt so 'unsafe' when [this person] was there' (Ryan and Räisänen, 2008, 141). However, for 'Trisha' different spaces presented contrasting opportunities for managing socio-spatial issues, and despite her aversion to home-visitors she often welcomed local school children into her allotment where she felt safe and comfortable (Ryan and Räisänen, 2008, 141). This indicates how experiences of environments (and attendant insecurities) can vary within and between AS people, even within the same space, as observed elsewhere by Madriaga (2010) in his investigation of the transition to higher education for first

year AS students at a UK university. In this study, participants described common (though qualitatively variable) difficulties in gaining access to study, living and social leisure spaces (Madriaga, 2010, 23). For example, one respondent ('Louis') described the need to strike a careful balance between a lack of annoying sounds and complete isolation, in order to study effectively in the library; while another ('Lisa') was completely unable to work in this space due to annoying humming sounds from computer equipment (Madriaga, 2010, 29-30). Sensory issues also mediated opportunities for social exchange within leisure spaces, such as pubs and clubs, which became inaccessible in the evening due to crowding and noise (Madriaga, 2010, 27-29). Madriaga also observes a common dilemma faced by AS participants in dealing with problematic environments, specifically whether or not to withdraw in the face of problematic stimuli and risk further social isolation.

Everyday insecurities involve both social and environmental aspects of everyday life, for example, Davidson and Henderson characterise 'autistic lifeworlds' as those within which 'spatial and embodied coherence is challenged at every turn' (Davidson and Henderson, 2010b, 462). In their analysis of autobiographical narratives written by authors on the spectrum, Davidson and Henderson observe the frequent presence of 'travel analogies' that describe perpetual re-encounters with everyday environments; spaces that should ostensibly be familiar but never

become so due to difficulties with spatial orientation and change (2010b, 462, 472-473). In addition, what for non-AS people might appear as minute or trivial changes in the physical geography of places often caused profound confusion and stress for AS authors (Davidson and Henderson, 2010b, 472-473). The interrelation of social and environmental concerns in spatial access leads Davidson to frame this as a relational process, requiring reciprocal understanding by both AS and non-AS people of the dispositions and needs of the other (Davidson, 2010, 305).

Echoing the work of Ryan and Räisänen (2008), Davidson also observes that AS people are almost always compelled to make extraordinary efforts to both access everyday spaces, and to understand the unfamiliar behaviour of others (Davidson, 2010, 309-311). Drawing on evidence from autobiographical narratives, the author observes that spatial access for AS people often depends not on 'correcting' AS-related behaviours, but on appreciation by non-AS people of their sensitivities and coping strategies (Davidson, 2010, 305-307). This indicates that while dispositions towards sequential, rule-based ways of understanding the world can shape experiences of the social, they also involve environmental experiences. It also points to the need to explore experiences of insecurity in terms of both social and environmental aspects; for example, supportive relationships may help facilitate

spatial access; while changes to problematic aspects of environment provide better conditions for interactions with others.

Differences in dispositional ways of understanding and acting in social life, as well as sensory sensitivities, mean that AS people experience everyday situations differently from many non-AS others. Current literature indicates that for many AS people, everyday life can involve experiences of chronic insecurity, involving challenges to social as well as 'spatial and embodied coherence'. This can motivate strategies for managing insecurities, for example, making 'safe spaces' or through withdrawal from problematic situations. Given the discussion thus far in this chapter, in terms of how a diagnosis can help a person to understand their differences and relationship to the people and places of everyday life, we might ask how these challenges are met in the time before one receives their diagnosis. If, as existing studies suggest, a diagnosis can help the person to develop more coherent understandings of both the self and of life events, then the management of everyday insecurities in the pre-diagnostic phase could therefore involve confusion associated with the 'double burden' of living without a diagnosis. Furthermore, if managing insecurity is implicated in understanding and presenting the self in everyday interactions, then this constitutes another area of potential importance with respect to formations of pre-diagnostic identity. The third and final question

to be pursued in this thesis will therefore be: *How does management of everyday insecurities relate to formations of the pre-diagnostic self?*

2.3 – Summary

My aims in this chapter have been: firstly, to justify the broad focus of the thesis; secondly, to set out the specific research questions to be pursued. The main focus of this thesis is *to explore the pre-diagnostic experiences of AS people born before 1980 who were diagnosed in adulthood*, and the research questions are as follows:

- 1. How do AS people understand their dispositional selves in the pre-diagnostic phase of life?**
- 2. How do self-other relations affect pre-diagnostic understandings of self?**
- 3. How does management of everyday insecurities relate to formations of the pre-diagnostic self?**

All three questions relate to understanding and presenting the self in everyday life; however, they refer to different, though related aspects of this. The first question focuses on the experiences and processes that shape AS people's pre-diagnostic understandings of their dispositional selves, while the second question explores

how these understandings of dispositional difference affect how a person presents themselves to others in a given situation. The link between these two questions involves a shift from the personal to the intersubjective aspects of experience, and question three then moves to another level in terms of the context of everyday life. In addressing this question, I will explore how the practical management of everyday insecurities, including those relating to understandings of self and self-other relations, is shaped by social, cultural and environmental conditions.

Given that these questions are part of broader focus on pre-diagnostic experiences, my next task will be to set out how I have approached these questions conceptually, in order to link the three questions into an overall research narrative. I will explore the benefits and limitations of theoretical approaches used in existing studies, and draw on resources in phenomenological and sociological theory (in particular the work of Bourdieu) to establish a framework for exploring pre-diagnostic experiences. From here, I will move on (in chapter four) to discuss my methodological approach (life story analysis), and the sources of empirical material (autobiographies) that have informed my investigation. Once again, through a discussion of the strengths and limitations of existing approaches, I explain my decision to undertake a comparative case study using autobiographies. This will include a treatment of ethical and epistemological issues, and the value and limitations of my approach in terms of addressing the questions identified. I will also discuss the individual

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narratives in terms of their contributions to the questions identified in this chapter, and set out my approach to analysing the texts. I will then move on (in part two) to my analysis of the autobiographies.

3 – Framing and exploring pre-diagnostic formations of self (theoretical approach)

Having set out the focus and questions that frame the investigation, the aim of this chapter is to explain my theoretical approach to exploring pre-diagnostic identities. Identity is a contested concept, with a range of perspectives underpinning different approaches to framing and exploring this area (Lawler, 2008). However, as Lawler observes, the basic claim common to sociological perspectives on identity, is that the self (however defined) cannot be understood with reference only to the individual, but needs to be explored in relational terms (i.e. who a person feels that 'are' or 'are not', issues of sameness and difference, dis/identification with and positioning within particular collective and categories) (Lawler, 2008, 1-7). The relevance of this approach for present purposes has already been indicated in Hacking's conception of autism as an 'interactive kind', and in chapter two, where different sets of social and cultural circumstances were seen to interact with social and environmental factors in shaping experiences of 'being' AS (Molloy and Vasil, 2004; Portway and Johnson, 2005). My approach has been informed by Bourdieusian theory, drawing on developmental critiques of Bourdieu's original concepts, as well as some of his phenomenological influences. In this chapter, I will

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argue that Bourdieu's integrated concepts of practice, habitus, field and forms of capital, in combination with Bottero's approach to identity provide a useful framework for exploring formations of pre-diagnostic self. I suggest that this body of theory can be particularly useful as a way of framing connections between dispositional and social aspects of experience, and for accommodating a diversity of potential experiences relevant to formations of pre-diagnostic identity.

Existing literature indicates the potential utility of these ideas for exploring AS people's experiences of social life (Ochs et al., 2004; Ochs and Solomon, 2004; Ochs and Solomon, 2007; Ochs and Solomon, 2010); however, their use has hitherto been restricted to isolated concepts of practice and habitus, rather than application of the overall framework. This is significant for present purposes because a major strength of Bourdieu's work lies in his holistic approach to exploring relations between subjective, intersubjective and wider socio-cultural aspects of social life. This carries through into Bottero's identity framework, which seeks to go beyond purely reflexive or social constructionist approaches to identity (Bottero, 2010). Existing studies relating to AS people's identities have focused almost exclusively on these aspects, and none have sought to explore in detail links between dispositional, reflexive and collective aspects of self (Bagatell, 2007; Brownlow et al., 2006; Molloy and Vasil, 2004; Sterponi, 2004). However, before proceeding it will be necessary to explore some of the assumptions that Bourdieu makes about

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perceptual functioning in relation to social agency, and this will be my first task in this chapter.

Beginning with a discussion of how Bourdieu's 'logic of practice' can help us to better understand the 'different logic' identified by Ryan and Raisanen (2008), I will connect this with his ideas concerning intersubjective coordination (habitus) and wider cultural horizons (field, through the concepts of habitus, field and forms of capital. I suggest that Bourdieu's emphasis on habitual and tacit ways of understanding and acting in the social world need to be reconsidered, and propose that for AS people, reflexivity plays a much greater role in everyday life than his framework allows. These concepts provide one set of 'thinking tools' for exploring formations of pre-diagnostic identities; my next task will be to link them with Bottero's approach to identity, augmented by intersectionality theory, as a way of framing different aspects of identity and their interaction in pre-diagnostic formations of self. Finally, I introduce the idea that authenticity, accountability and legitimacy can be used as interrelated concepts in order to explore specific issues relating to the formations of pre-diagnostic identity. I will explore and expand upon this framework as I move through the analysis in chapters five, six and seven; however, for the purposes of clarity I will introduce them as part of the theoretical framework. I will begin by exploring the relationship between perception and the practice in Bourdieu's account of social agency.

3.1 – ‘Terms of engagement’ and ‘logics’ of practice – exploring the conceptual relationship between perceptual differences and sociality.

Existing studies point to a range of differences in dispositional orientations to social activity (Ochs and Solomon, 2010; Sterponi, 2004), or what Ryan and Raisanen (2008) describe as a ‘different logic’ for understanding and acting in the social world. Neuropsychological research literature (Tomchek and Dunn, 2007; Baron-Cohen, 2008a; Baron-Cohen, 2008b; Baron-Cohen et al., 2009; Schroeder et al., 2010), as well as descriptions of first-person experience from AS writers (Lawson, 1998; Lawson, 2009; Milton, 2011; Williams, 1994), point to a range of perceptual experiences that may differ from those typical of many non-autistic people. Thus as a starting point, we need to appreciate how differences in a person’s perceptual ‘terms of engagement’ with their surrounding world shape dispositions towards social agency.

3.1.1 – AS differences in perception and their significance for dispositional orientations to social action.

Bourdieu's theory of social agency is grounded in the work of Merleau-Ponty, whose account of the relationship between perception and experience underpins the former's concept of the 'logic of practice' (Crossley, 2001; Dreyfus, 2007). As Dreyfus observes:

[W]hat interests [Merleau-Ponty] is coping...how you are able to respond to the particular situation...the way your body has of immediately grasping the gestalt of what's going on, or failing to and doing it better next time (Dreyfus, 2006).

For Merleau-Ponty, the experience of 'lifeworld' as a taken-for-granted experience of everyday situations and environments arises from the body's 'constant conversation' with the surrounding world, in which objects of perception are 'grasped' as both physical and meaningful entities (Thompson, 2007). Perception is not the same as sensation, nor is it a neutral reporting of an unreconstructed physical world; rather, perception involves the organisation of sense data in interest-relative and context specific ways (Thompson, 2006). Interest and context are mediated by the *meaning* and *purpose* that the perceiving body attaches to them, where 'meaning' refers to the significance of perceived objects to the perceiving body, and 'purpose' involves the intentional relationship which that body has to the objects of perception (i.e. what things are *for*) (Crossley, 2001, 65).

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Meaning and purpose are not products of conscious action; they are principles upon which sense data are organised to produce a progressive, meaningful and interested experience of being-in-the-world (Crossley, 2001, 69).

One grasps the world not as a series of separate, discrete sensations but as an overall or *gestalt* picture of what is going on (Dreyfus, 2006). Gestalt perception arises from the interplay of sensory information, where stimuli in particular sense domains are rendered meaningful not only in the sense of their own particular qualities but also in combination with experiences in others (Crossley offers the illustrative example of the role of music in film, altering the mood of scenes which may remain unchanged in visual terms) (Crossley, 2001). The perceptual organisation of stimuli (what Merleau-Ponty refers to as *the gaze*) is not fixed, but evolves in response to its on-going experiences of environment (Crossley, 2001, 72; Merleau-Ponty, 2002, 263-4). The gaze of perception is 'never disinterested'; it is always directed towards some phenomena or *intended* object (Crossley, 2001). Meaningful and purposive relationships with the objects of perception motivate actions and responses which alter the gestalt, generating new perceptual experiences, which in turn generate new responses, and so on, creating a feedback loop which Merleau-Ponty refers to as an 'intentional arc' (Merleau-Ponty, 1962, 14). Perception is thus revealed as:

...an outcome of the process in which the organism interrogates its worldly surround, guided by both biological sensitivities and behavioural-perceptual schemas, thereby creating for itself a subjective 'milieu' or 'lifeworld' (Crossley, 2001, 71).

For Merleau-Ponty, the emergence of the 'lifeworld' in perception involves a process of habituation in relation to familiar environments and situations, through which the perceiving body develops an 'equilibrium' with the surrounding world (Merleau-Ponty, 1962, 153). In this view, habitual familiarity with the people, places and practical challenges of everyday situations allows a person to skilfully cope with them, and thereby feel 'at home' in doing so. For Merleau-Ponty (and for Bourdieu) it is through this process of habituation that a person's taken-for-granted experience of everyday life arises; however, as we have seen, for AS people many everyday situations cannot be taken-for-granted in the same way as for many non-AS people, and can involve different experiences such as 'resonance' with aspects of the physical world, and/or chronic insecurity in problematic environments (Ryan and Räisänen, 2008), as well as challenges to 'spatial and embodied coherence' (Davidson and Henderson, 2010b, 462). Merleau-Ponty's work indicates the importance of perceptual dispositions in shaping orientations to acting in the world,

and Bourdieu takes up this view of human agency in his account of social agency through his account of the 'logic of practice' (Taylor, 1995; Dreyfus, 2007).

For Bourdieu, most of what people do, most of the time involves 'doxa': tacitly enacted and largely unconscious activities that become habitual through repeated enactments, out of which a 'practical sense' of appropriate behaviour arises within a given social context (Bourdieu, 1990b, 66-67). Doxic forms of practice allow similarly disposed actors to synchronise with each other, and for their exchanges to develop a rhythm and tempo that is central to the meaning of everyday interactions (Bourdieu, 1990b, 86-87). The flow of conversation, reciprocal comportment of the body in interactions, and the length of utterances are all examples of how practices shape and are shaped by experiences of temporality (1990b, 91). In this view, coordination between actors in terms of how they synchronise with each other and develop this rhythm and tempo is shaped by a tacit 'feel for the game', which Bourdieu refers to as the 'practical sense', through which people learn to do the 'right thing, in the right way, at the right time' (Bourdieu, 1990b, 82; Dreyfus, 2006). This intuitive sense of what must be done in order to go on in the world develops as the progressive result of encounters with wider social and cultural regularities in particular forms of life. Bourdieu's account of the logic of practice provides a useful starting point for framing social agency in AS people, precisely because many of the assumptions in this model are problematised by AS-related differences in

perception. Given these differences, how then might we use this account of practice as a way of understanding the impact of dispositional differences on orientations to sociality?

3.1.2 – Perception and the ‘different logic’ – theorising the relationship between AS-related differences and practice.

One important difference in AS people’s terms of engagement with the social world has to do with the organisation of information in perception, involving a range of associated strengths and limitations. For example, Murray et al. (2005) describe heightened attention to detail and issues with gestalt awareness in people on the autism spectrum as features of a ‘monotropic’ perceptual style. This is where a person’s attention tends toward local, specific features of people or objects rather than the overall picture of a situation (Murray et al., 2005, 145-150). Elsewhere, Mottron et al. observe that a key feature of the Autism spectrum is what they refer to as Enhanced Perceptual Functioning (EPF), supported by superior performance by autistic people in local processing of information vs. non-autistic controls (2006, 39-40). Baron-Cohen et al. (2009) have also argued that strong dispositions towards systematic ways of understanding and acting in the world are rooted in sensory hypersensitivity (Baron-Cohen et al., 2009, 1380). While local processing and detail focused attention appear to be dispositional strengths relating to the autism spectrum, dealing with sudden change, ambiguity and making gestalt connections between different experiences are also common difficulties (Bogdashina, 2003).

This is significant because gestalt processing and intuitive understanding are central to Bourdieu's understanding of how agents develop a 'feel for the game', and his emphasis on doxic forms of activity may therefore need to be adjusted in relation to AS people.

Bourdieu's rejects the idea that human sociality operates according to sets of express rules, which can be understood in totality and stated explicitly by actors. He argues that such approaches obscure the immediacy of social life and the spontaneity required to negotiate emergent nature of practical exchanges (Bourdieu, 1990b, 86-87). This aspect of his thought reveals the influence of Wittgenstein (1968), who argued that absolute reliance on express rules could not be the foundation for people's use and understanding of language. Wittgenstein claims that such a basis is implausible because it would require total understanding of all possible conditions for application of a particular rule, including its relationship to all other rules (Bourdieu, 1990b, 9, 10, 18). For each additional layer of conditions for application of the original rule, a new set of conditions would need to be added in order to understand their application, and so on, *ad infinitum* (Taylor, 1995, 166-167). Therefore, Wittgenstein's conclusion is that at some point people must necessarily 'stand' on an incomplete, inarticulate sense or understanding of how to use language (1968, 211, 217).

The implications of Wittgenstein's argument for Bourdieu are that express rules, far from being the basis of human agency, can only emerge, be understood and provide guidance for action on the basis of an inarticulate, practical grasp of the world which actors develop through experience (Bourdieu, 1990a, 9; Taylor, 1995). In this view, express rules are 'brought to life' through practical activity and enacted within the broader context of embodied social 'know how' (Taylor, 1995, 178). The phrase 'know how' here describes a form of knowledge which is tacit and intuitive, as distinct from *knowing that*, which denotes formal, conceptual knowledge (Ryle, 2000, 28-32). *Knowing that* one should, for example, make eye contact with other people during conversation, is different from *knowing how* to perform this action; even where a set of express rules may be available for such a task, mere conceptual knowledge of these rules carries no guarantee of their successful enactment (Ryle, 2000, 28-32).

In Bourdieu's thought, doxa are those forms of know-how that allow a person to coordinate socially with others, and to feel 'at home' in everyday social situations. Although these two ways of knowing are framed as common features of human activity, it is Bourdieu's emphasis on doxa as a way of going on in the social world

that is potentially problematic in relation to AS people. Drawing on Garfinkel, Milton argues that:

[Non-AS] [p]eople have a tendency to ‘fill in the gaps’ in their perception in order to gain what they think is a full or whole picture. Due to differences in the way autistic people process information (whether it be monotropism, a weak drive toward central coherence, a lack of mirror neurons, or a lack of long-range connectivity in the brain), this ‘filling of gaps’ tends not to occur (at least to the same extent). Autistic people have a tendency to be more literal, and work upon what is tangible and present, thus conclusions are reached through available information (without ‘filling in the gaps’) (Milton, 2011).

Given the findings of existing research, suggesting that everyday spaces can often remain unfamiliar despite repeated encounters (Davidson and Henderson, 2010b) and that AS people often have difficulties with ‘internalising’ social rules (Ryan and Räisänen, 2008, 137-139), what are the implications for re-framing the ‘logic of practice’?

What appears different about the 'different logic' (when compared to Bourdieu's original doxic account of the 'logic of practice') is how AS people are disposed to understand, make sense of and act in relation to the everyday world, due to their different perceptual 'terms of engagement' with it. For this reason, many everyday social and environmental situations that may be unproblematic for non-AS others represent significant challenges for AS people. While this helps to describe orientations to social practice, one also needs to appreciate the affect that this can have on the qualitative experience of everyday situations in terms of their affective significance. While AS people may have difficulties in feeling 'at home' within some of the social and environmental situations of everyday life, this does not mean that AS lifeworlds consist only of challenges to 'spatial and embodied coherence'. For example, Davidson has noted strong emotional connections to the physical environment, in particular feelings of 'resonance' and connection to elements of the natural world, in her analysis of AS women's writing:

Williams [an AS autobiographer]...experienced social pleasures in her own autistic world: 'I was a social kid: social with the dirt, the trees, the grass . . . I felt the world deeply and passionately. I was cheerful in my own world and I had a fascination with anything that was not directly confrontational and which would allow me to simply be' (Davidson, 2007, 668-670).

Differences in AS people's perceptual terms of engagement with the world should therefore not be assumed to be pathological; rather, if we accept the underlying ontology proposed by Merleau-Ponty, perception is the basis upon which connection to the world (sensory, practical, affective) becomes possible *at all*. This has ethical significance given, as Davidson (2007, and elsewhere Davidson and Smith, 2009) have noted, whether or not a person can freely experience these forms of connection (referred to as 'autistic emotion') has implications for wellbeing. Elsewhere, Hodge notes that investigations of different lifeworld experiences have the potential to guard against deficit focused descriptions or analyses by seeking to preserve a more holistic view of experience (2007, 31-32), and this will be particularly significant in the exploration of understandings of dispositional self (in chapter five). For now, I will briefly summarise the main arguments in this section.

1. Bourdieu's idea of the 'logic of practice' is based on the development of habitual familiarity with everyday situations and environments, through an inarticulate 'grasp' rooted in the perceptual relationship that a person has with the world.
2. For AS people, their practical 'grasp' of the everyday situations obeys a 'different logic', one that can involve a variety of dispositions towards sequential, rule-based ways of knowing, arising from different perceptual

‘terms of engagement’ with the world. This can affect not only the explicitly practical business of coping with social exchanges and environmental challenges, but also experiences of meaningful and affective connection.

Thus far I have used Bourdieu’s concept of the ‘logic of practice’ to understand how differences in AS people’s perceptual terms of engagement with the world shape dispositions towards practical coordination. However, social activity and its implications for formations of identity cannot be reduced to the actions of individuals, but need to be understood in intersubjective and wider social cultural contexts. My next task will therefore be to relate the preceding discussion to Bourdieu’s concepts of habitus, field and capital.

3.2 – Framing self-other relations - Habitus as a ‘situated intersubjectivity’.

While dispositions to act, as well as individual patterns of activity (whether habitual or consciously willed) can be seen as properties of the agent, these activities ‘extend beyond agents’ predispositions’ to encompass the constraints and demands which shape and bring forth such activity (Bottero, 2010, 12). For many AS people, what is not given to their experience of social life through lifeworld must often be understood in other ways, for example through express rules, which can result in

'asymmetry' in the interactive styles of those engaged in joint practice (Ochs et al., 2004, 173). This asymmetry can lead to breaches in social coordination, both in the qualitative content of interactions, and also their temporal structure (i.e. the rhythm and flow of exchanges) (Ochs et al., 2004; Ochs and Solomon, 2007; Ochs and Solomon, 2010). Bourdieu's concept of habitus has been used previously in the work of Ochs and Solomon (2010), to explore these issues in terms of differences in dispositions towards spoken communication that shape parent (non-AS) / child (AS) interactions. I argue that Bottero's developmental critique of this concept can also help us understand not only how dispositions to act affect social coordination, but how the regularities of social coordination in given settings also shape dispositions to act and understandings of self. I will begin by outlining the concept and its relationship to practice, before considering its relevance for present purposes.

If the practical sense can be understood as an individual actor's grasp of 'what to do', then habitus is that which connects personal understandings together at the intersubjective level. Habitus is not a property of individuals but arises through exchanges between actors, which shape and are in turn shaped by dispositional understandings of context-appropriate activity (Bourdieu, 1990b, 53). These produce what Bourdieu refers to as 'systems of transposable, durable dispositions' through which a shared sense of social regularities is created, not as a set of express rules, but as 'generative principles' for going on in the world (Bourdieu, 1990b, 52).

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For Bourdieu these 'generative principles' operate as 'structured structures' shaped by the meeting of actors in practical exchanges within given sets of social and environmental circumstances (Bourdieu, 1990b, 53). They also function as 'structuring structures' by providing means for social agents to engage in context-appropriate activity through adaptable understandings (Bourdieu, 1990b, 53). In this view, habitus does not involve a closed system of operations which one is able to predict, but rather consists of and produces general guidance for developing and amending social practices (Bourdieu, 1990b, 87). However, Bottero argues that, rather than Bourdieu's notion of habitus as a 'socialised subjectivity', it is more useful to think in terms of a 'situated intersubjectivity' 'circumscribed by a particular cultural horizon' (Bottero, 2010, 17). In this view, a person's sense of what is appropriate and 'what one can get away with' are produced through exchange within particular cultural contexts (Bottero, 2010, 16). Thus while individuals may have personal understandings of social regularities (i.e. their practical sense), these are (Bottero argues) animated, sustained and amended through social exchange, and as such habitus is neither separate from nor reducible to individual agents.

In her critique of habitus, Bottero introduces two ideas which can help us frame how dispositional differences may constrain opportunities for social coordination between differently disposed actors. Firstly, she argues that dispositions to act are

always oriented and adjusted by 'calls to order from the group', or those engaged in joint practice, which involve expectations and influences of other actors in concrete networks (i.e. situated sets of relations between specific people) creating a space for indeterminate features of interaction such as ambivalence and irony to shape social relations (Bottero, 2010, 16). This is significant for AS people because if social regularities are affirmed and negotiated through ironic or ambivalent exchanges then the ability of an AS person to understand these 'calls' may be limited. Secondly, Bottero argues that agents continually provide a 'commentary' on their activities in social interaction, whether through overt statements or other tacit forms of communication, which indicate qualities of intention, and in so doing 'routinely expect and provide' accountability as a basis for social coordination, but also for sustaining a shared sense of what they are likely to do in the future (Bottero, 2010, 16). 'Calls to order' are therefore not about enforcing social rules, but signalling demands for accountability. In a general sense, this means being available to others through mutually understood means of interacting, so that a person is able to maintain a degree of connection with the "logic" of what the other is up to, and what they are likely to do in the future' (Bottero, 2010, 16). Accountability thus refers to the conditions of possibility for successful exchange between actors, but implies nothing of the practical forms which calls to order may take.

AS people's dispositions toward sequential, rule-based ways of knowing may violate dispositional understandings of appropriate conduct which are consensual within majority non-AS groups by, for example, making explicit that which is understood as needing to pass unspoken. This also highlights the temporal consequences of dispositional differences in terms of coordination through habitus, but also opens up the potential for framing how these difficulties may be overcome practically. The difference between *knowing how* and *knowing that* is significant in social relations, because the 'logic' of many practical encounters rests on the timing and coordination of responses. If one's dispositional connection to habitus rests on knowing how rather than knowing that, then this can put the person at a disadvantage in social situations where, for example, improvisation and spontaneity are required aspects of participation. However, the ability of AS people to *know that* certain forms of practical exchange are going on around them that may be dispositionally difficult, even if they may not *know how* to participate, suggests that the possibility of renegotiating the practical demands of habitus may be one route to successful coordination in AS/non-AS interactions. Thus, while accountability may not be about 'enforcing social rules', more explicit forms of social exchange may enable better and more equitable conditions of accountability in exchanges between differently disposed actors (i.e. AS/non-AS). Finding a way of connecting with differently disposed others in ways compatible with one's own dispositions can thus be seen as an important challenge for AS people (Ryan and Räisänen, 2008);

however, this possibility is mediated by the wider 'cultural horizons' which frame habitus being hospitable to such processes.

3.3 – The 'cultural horizon' of fields and the relevance of capital forms.

For Bourdieu, social fields are relational networks brought to life through practical exchanges between actors, or what he describes as 'a network, or a configuration, of objective relations between positions...' (Bourdieu and Wacquant, 1992, 97). For Bourdieu, the character of modern 'highly differentiated' societies is of a 'social cosmos' made up of 'relatively autonomous social microcosms which contain specific logics that are irreducible to other fields' (Bourdieu and Wacquant, 1992, 97). For example, online forums, pubs, family homes and places of worship are all imbued with regimes of practical social and cultural exchange – how to speak, how to dress, what to say, regimes of bodily comportment, and so on. Following Bourdieu's analogy of the social as a game, we may understand the concept of field as follows: if the practical sense is an understanding of how to play, and habitus denotes agents' shared understanding of the regularities which shape the game, then fields are structuring horizons that define the limits of play. Fields thus provide the 'cultural horizons' for specific interactions. This does however leave out

one crucial component – what is played *with*? To answer this one needs to understand how Bourdieu conceptualises the ‘stakes’ of the field as forms of *capital*.

In Bourdieu’s view what defines a field is not any regime of social regularities (this belongs to habitus) but rather what is at ‘stake’ in it (Jenkins, 1992, 85). Fields are relational networks within which social resources - for example, educational qualifications, prestige, and/or economic resources – are negotiated, contested and actualised in social life (Jenkins, 1992, 85). Bourdieu frames these resources as forms of *capital* where, in addition to economic capital, he conceptualises two other value forms. *Social capital* refers to the strength, range and number of social relationships which a person has, through which they may be able to access collectively held resources and partake of the ‘credit’ to which the relationship entitles them (Bourdieu, 1986, 51). Access to information, economic resources, and introductions to disparate others are all examples of how one’s social capital can be actualised in the exchange and accrual of different social resources.

Another type of resource is *cultural capital*, which in Bourdieu’s schema can take three forms. The *embodied*, which refers to ‘long-lasting dispositions of mind and body’ that have value and utility for the bearer within particular social fields, for example, knowing how to speak or act in particular interactions (Bourdieu, 1986,

47-48). The *objectified form*, which inheres in material objects, for example, as art works, books, instruments or technical apparatus, items that confer value upon the owner or bearer in particular cultural contexts (Bourdieu, 1986, 50). The value of this resource lies not in legal ownership of an object but by awareness of its cultural value and understanding how this may be actualised in social situations. Mere possession of a painting, for example, does not actualise its value as capital; however, discussing it with guests in one's home may do so if the cultural conditions are appropriate (i.e. that the guests accept the value of the painting as a marker of taste or status). Finally *institutional* cultural capital refers to a form of value that inheres in attachment of the bearer to a particular social institution, complete with the historical lineage as well as the social and legal guarantees of competence that this involves (Bourdieu, 1986, 50-51). For example, an academic qualification in the form of a certificate may constitute a form of *objectified* capital, but it also links the bearer to the life and history of an institution, the legacy of which may confer particular forms of value.

Bourdieu's notions of field and capital allow for an appreciation of some of the wider conditions which shape AS people's experiences of social life beyond the dispositional and intersubjective. In social fields, what is crucial to the operation of the symbolic economy (i.e. what social and cultural capital forms are worth and how they may be actualised) are degrees of understanding and acceptance of the

value of what is at stake. Just as habitus requires a degree of dispositional alignment in practical understanding of how one should act within a particular exchange, so the life of fields requires a sense of the significance and value of different resources within the network of relations that constitute them. Once again, if these forms of value and their actualisation involve tacit, unspoken or ambivalent performances then the ability of an AS person to participate in the social life of fields, and to access potential resources therein, may be limited. This is significant not only for participation but also for understanding relations of domination and power, where the ability of the AS person to accrue and actualise different symbolic resources may be mediated by dispositional differences in understanding the symbolic economies at play within different fields. The potential for inclusion on the basis of appropriate practical conditions, and the practical and social conditions that make this possible, is something which Bourdieu's account of *reflexivity* can help explore.

3.3 – Reflexivity as a disposition.

In phenomenological terms, reflexivity can be understood as a type of intentional activity in which a person 'stands back' from taken-for-granted experience, in order to re-encounter in a more circumspect fashion that which otherwise passes

unquestioned in everyday experience. This is something which also needs to be understood through Bourdieu's ideas of domination. For Bourdieu, relations of domination – of a particular individual, social/ethnic/religious group, or gender – are made possible not only through violent oppression, but through control of the conditionings of habitus which shape the practical senses of actors (Bourdieu, 1990b, 128-131). What is acceptable, what one should do in a given situation, and what one 'can get away with', are all understandings which shape relations between actors, and that therefore have the potential to privilege actions that serve the interests of particular individuals, groups or institutions and/or to suppress or exclude those of others (Bottero, 2010, 17). These forms of domination do not require conscious projects of oppressive activity, but can result from and/or be sustained by the tacit everyday activities of actors occupying unequal social positions (for example, being a non-AS person in an exchange with an AS person, where the practical sense of the former reflects the dominant habitus).

Reflexive consideration of what is tacitly accepted in the practical sense, in habitus or within the cultural horizons of social fields offers human beings the potential to resist these forms of domination, and/or to see how they are implicated in one's own practices and understandings of cultural regularities. Reflexivity is for Bourdieu the 'margin of freedom' which occupies a figurative space

between doxic experiences and the regularities of habitus which shape them (von Holdt, 2010, 1). This brings to our attention two important issues regarding reflexivity, firstly its centrality to negotiating social relations for many AS people, and secondly its value as a potential route to overcome social exclusion by renegotiating the practical conditions of exchange with differently disposed others. If, as I have argued thus far, AS people are often rely on express rules as means for understanding that which is not given intuitively in social interactions, then this would also imply that reflexivity may be a normative, rather than exceptional, way of interacting with the world for people in this category. The idea of reflexivity becoming dispositional under certain circumstances for non-AS people more generally has also been proposed elsewhere by Sweetman (2003); however, I argue that this has special relevance for AS people given differences in dispositions towards social interactions. As discussed in chapter two, being AS in a largely non-AS world can involve the need to be aware constantly of life 'over there' in the non-AS world, and for 'constant vigilance' (Ryan and Räisänen, 2008) in the face of persistent challenges to social as well as 'spatial and embodied coherence' (Davidson and Henderson, 2010b). However, it can also involve feelings of attachment and resonance with aspects of the world that others may take for granted or experience as mundane (Davidson and Smith, 2009), as well as strengths associated with detail focused attention (Baron-Cohen et al., 2009; Mottron et al., 2007). What cannot be achieved through doxic activity must be dealt with

reflexively, and this is significant for understanding AS people's dispositions not as a uniform 'absence' of sociality, but part of a wider continuum.

Bourdieu's framework provides a useful set of 'thinking tools' for exploring how dispositional, intersubjective and wider cultural aspects are implicated in the formation of social experiences. Having set out these concepts and discussed their relevance to AS people, my task is now to explain how they inform the approach to identity used in this investigation.

3.4 – Framing a neo-Bourdieuian approach to identity

As indicated in the previous chapter (2.1.2), identity has been a significant focus of social scientific research relating to AS people; however, the majority of these studies have focused on the conscious construction of identity and presentations of self as reflexive projects either in online discussion groups, forums and blogs (Jones and Meldal, 2001; Brownlow et al., 2006; Clarke and van Amerom, 2007; Clarke and van Amerom, 2008; Brownlow, 2010b; Brownlow, 2010a), or in co-present exchanges with non-AS others (Bagatell, 2007; Huws and Jones, 2008; Madriaga et al., 2008; Ryan and Räisänen, 2008; Bagatell, 2010; Madriaga, 2010), both of which have centred around the negotiation of the diagnostic label. Existing approaches

present two important theoretical gaps which need to be addressed; firstly, with respect to the need for a broader perspective on identity beyond the diagnosis itself, and secondly, how one might go beyond purely reflexive experiences of identity to explore relationships with other aspects of self. This something which Bottero's approach can help provide, by connecting an account of identity with the perspective on social agency already established thus far.

Bottero's approach involves three different aspects of self. *Dispositional* identities, which are those 'expressed through implicit modes of being' rooted in agents' taken-for-granted and dispositionally conditioned ways of acting in the world (Bottero, 2010, 20), *reflexive* identities that refer to those which are explicitly affirmed and expressed through conscious identifications (Bottero, 2010, 4), and *collective* identities relating to those which arise in the behaviour and mobilizations of groups of actors (2010, 7). Dispositionality and reflexivity are here not framed as binary oppositions, but as conceptual poles between which much 'slippage' may be present (Bottero, 2010, 10). In this view, a person may have 'multiple reflections' upon 'multiple dispositions', and that may in turn be shaped by their position within particular social groups and wider fields (Bottero, 2010, 10). In this way, Bottero seeks to preserve the advantages of a Bourdieusian approach to identity in terms of going beyond purely positional or constructivist notions of self, while retaining a critical awareness of his tendency to emphasise homogeneity and reproduction

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over difference and diversity (Bottero, 2010, 10). Bottero's schema helps frame different aspects of identity as objects of analysis, while the Bourdieusian framework provides 'thinking tools' for exploring the social and cultural aspects of pre-diagnostic formation. In addition, it is also important to recognise that just as different aspects of self (dispositional, reflexive and collective) may interact in formations of identity, so too may qualitative aspects of self.

In the work of Molloy and Vasil (2004 – discussed in 2.1.2), it was noted that as the AS teenagers in their study grew older, and began to deal with other aspects of identity beyond their AS labels (such as political and sexual identities), that these processes affected both their overall sense of self and experiences of 'having' AS (Molloy and Vasil, 2004, 124). This illustrates the significance of intersectionality as a component of identity formation (McCall, 2005, 1775-1778). Intersectionality is a nebulous term, with multiple theoretical interpretations that have been used to explore and conceptualise relations between different aspects of identity, and also contestation and difference within social groups who claim a similar identity (McCall, 2005, 1771-1772). Here, I adopt what McCall refers to as an *intercategorical* understanding of intersectionality, which involves examining how AS people's existing aspects of identity combine in different situations and at different points of life (McCall, 2005, 1785). For example, we have already seen how the categorical aspects of AS and gendered selves were significant for women in the support group

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observed by Faherty (2006, 12 - discussed in 2.1.2), where management of AS identity was linked to understandings of prevailing gender norms, and also management of everyday insecurities relating to unwanted sexual attention. Therefore, it is important to keep in mind that different qualitative aspects of self may interact, in addition to the dispositional, reflexive and collective elements identified by Bottero. Concerns expressed by AS women around being made to 'fit in' with prevailing gender norms that force them to adopt what are often confusing and dispositionally inappropriate performances in everyday interactions, leads us to the final aspect of my theoretical framework, the interrelated concepts of *authenticity, accountability and legitimacy*.

These concepts will be used to frame particular sets of issues that emerge in negotiation of pre-diagnostic identities, and will be developed further as I move through the analysis in chapters five, six and seven. However, for the purpose of clarity I will introduce them briefly here. *Authenticity* is a term that I use to refer to dispositionally appropriate ways of understanding, experiencing and acting in the world compatible with the forms of 'autistic emotion' identified by Davidson and Smith (2009). The ability to experience ways of being that feel authentic is often crucial to wellbeing, and conversely can be restricted by unfavourable social conditions in which a person is compelled to 'pass' as non-autistic or otherwise engage in dispositionally appropriate ways of being (Davidson, 2010; Milton, 2012;

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Milton and Moon, 2012). This is significant because one's sense of dispositional identity, and also their wellbeing, may depend on their ability to access dispositionally appropriate ways of being (this theme will be discussed further in chapter five). *Accountability* has already been defined (in 3.2) as the conditions of possibility for successful exchange between actors, maintained through 'calls to order' (Bottero, 2010). It has also been indicated as an issue with respect to the 'double burden' of living with an undiagnosed condition, where a person may be unable to account for their difficulties as demanded by the dominant habitus (Nettleton, 2006 - see section 2.1.3). However, as I will argue (beginning in chapter five), accountability has special relevance for formations of pre-diagnostic identity not only due to practical difficulties in understanding implicit calls to order, but not understanding why these issues arise. One important feature of life without a diagnosis is that one may not be able to account for their differences and thus make claims of others for renegotiation of the practical conduct of problematic interactions. The quality of accountability relations, particularly those that involve unequal relations of power, can mediate a person's ability to experience dispositionally appropriate (and authentic) ways of being, and also influence how these are understood in relation to the self (this will be discussed in chapters five and six). This leads to the issue of *legitimacy*, which refers to reflexive judgement as to whether or not the way a person acts in the social world is understood appropriate and acceptable, and this can refer to oneself as well as others (i.e. the

way that people view the actions of an AS person, or how the AS person understands either their own actions and/or those of others) (Milton, 2011). Legitimacy can thus be something that is conferred upon (or denied to) the AS person by others or themselves, with implications for formations of identity and for wellbeing. These concepts overlap and interplay with each other in a range of ways in negotiation of pre-diagnostic identity, and this will be expanded upon in the analysis (chapters five, six and seven).

3.5 - Summary

In the previous chapter, I set out the questions that frame my investigation; my objective in this chapter has been to set out my theoretical approach. Identity remains a contested concept within sociology, with a range of approaches to its study, and I have argued that Bourdieusian theory offers a useful perspective for situating dispositional orientations to social life relative to intersubjective and wider cultural facts that shape and are shaped by them. Beginning with the relationship between perception and practice, I have argued that Bourdieu's framework can help go beyond individual accounts of social experience by connecting the dispositional with intersubjective and wider cultural aspects of pre-diagnostic experience. This approach informs Bottero's approach to framing identity as involving dispositional, reflexive and collective aspects of self which, in addition to

an intercategory intersectionality perspective, can help explore formations of pre-diagnostic identity. Finally, I have introduced the idea that authenticity, accountability and legitimacy represent a set of related concepts that can help frame issues arising from my analysis (these concepts will be discussed later in the analytical chapters). Having set out my conceptual approach to exploring formations of pre-diagnostic identity, my final task in part one will be to explain the methodological design of the project, how sources of empirical material were selected and analysed, and how these analyses were organised into the discussion in part two.

4 – Exploring pre-diagnostic identities through life stories.

Existing research has explored the lives of AS people through a range of methodological approaches and analytical frameworks. In this thesis, I have adopted an approach based on life story analysis using autobiographical monographs as sources, the rationale for which will be discussed in this chapter. Firstly, I will discuss the value and limits of existing methodological approaches, and my decision to adopt a life story approach using autobiographies. Secondly, I will describe the process by which the specific autobiographies were identified and selected; thirdly, I will describe how the autobiographies were analysed and discussed in relation to the questions, and discuss interpretative issues in relation to this. Finally, I will introduce each of the autobiographers and give a summary of their contributions to the discussion that will follow in part two.

4.1 – Rationale for a Life Story approach

My aim in this thesis is to explore the pre-diagnostic identities of AS adults. As indicated in the previous chapter, identities and the social conditions in which they emerge are not fixed, and may change over the life course in response to different life events (Molloy and Vasil, 2004). Therefore, the approach that I have taken is one that looks to explore these questions biographically across the pre-diagnostic phase, rather than focusing on individual events. I will discuss the limitations of

existing approaches before outlining my decision to take a life story approach using autobiographies.

4.1.1 – Comparative life story analysis

Existing studies in social science have drawn on a range of data sources in order to explore the lives of AS people including semi-structured interviews (Molloy and Vasil, 2004; Jennes-Coussens et al., 2006; Ryan and Räisänen, 2008; Madriaga, 2010; Singh, 2011) as well as co-present (Ochs et al., 2004; Sirota, 2004; Bagatell, 2007; Ochs and Solomon, 2010; Rosqvist, 2012) and online ethnography (Jones and Meldal, 2001; Brownlow et al., 2006; Clarke and van Amerom, 2007; Brownlow, 2010b). All of the aforementioned approaches have made use of interesting empirical material through which authors have been able to develop new perspectives on AS people's lives in a variety of contexts. However, many of these (with the exception of Molloy and Vasil, 2004) have taken either entirely synchronic approaches in order to explore specific themes through cross-sectional analysis, or taken place within a restricted time frame (for example, three months in the case of Bagatell, 2007; and a year for Madriaga, 2010). Given that, as existing research has shown, AS people's identities are changeable relative to variations in the environments and situations of their lives (Molloy and Vasil, 2004; Bagatell, 2007), a diachronic approach appears appropriate. The question now before us is: *which particular approach should be adopted for present purposes?* I will begin my answer

by assessing the strengths and limitations of existing approaches, before setting out my case for a life story approach.

Ethnography involves contemporaneous observation of specific people or groups over a period of time, and is therefore impractical for exploring pre-diagnostic experiences from a biographical point of view (Mason, 2002). In the case of semi-structured interviews, while it may be possible to obtain relevant material, the biographical range and qualitative depth of the material may be limited by practical and ethical constraints involved in researching AS people's lives. This approach relies to a large degree on the interaction between researcher and participant evolving over the course of the encounter, where a researcher's questioning may be guided by core themes, but they are free to explore other aspects of the research topic with the interviewee (Mason, 2002; Hammersley, 2008). This may be a fruitful approach, so long as the practical dispositions of researcher and participant share some synchronisation in habitus, something which cannot be presumed in the case of AS people. For example, Ryan and Räisänen (2008) have noted the limitations of the semi-structured interview method for participants in their study, who were resistant to open questions and requested a more formal question-and-answer format (Ryan and Räisänen, 2008, 137). Thus the ability to explore life stories in detail within this format may be constrained by practical issues, especially given the open nature of the research questions.

This method also presents ethical issues for this type of study, for the rendering of life events in the breadth and level of detail needed in order to explore pre-diagnostic identities within a biographical frame would require a considerable commitment by participants, both in terms of time and the potential breadth of issues to be explored (Silverman, 2008, 337). Reflective research always carries an element of risk, and as the space for reflection (i.e. the range and depth of what is explored) increases so may the potential hazards in terms of mental and emotional distress (Merrill and West, 2009, 175). This is a particular concern in the case of people who are already indicated to be at risk across a range of different aspects of wellbeing (Rosenblatt, 2008, 2; Silverman, 2008, 336-337; Allard, 2009, 5-12). Therefore, both ethnography and semi-structured interviews were deemed unsuitable.

The method which I chose to adopt was life story analysis, drawing on the productive application of this method in Molloy and Vasil's (2004) work on AS, adolescence and identity. This was used to explore the lives of six AS adolescents in terms of the relationship between their experience of 'having' AS and other aspects of identity. As indicated in chapter two (2.1.2), their work indicates that the position and importance of one's AS status within an overall sense of identity may

change over time, something highlighted by their biographical approach (Molloy and Vasil, 2004). Their approach draws on the work of Goodley (2000), who describes a life story as:

[T]he product of the reminiscences of one narrator that are structured together chronologically or thematically in a storied fashion. The life story relies on the accounts of a primary narrator...[and] can be written or told to others who collaborate in writing (Goodley, 2000, 48).

Molloy and Vasil (2004) contrast life stories with clinical 'case histories'. In this view, investigations of the latter type attempt to produce a 'report of behaviours or actions' with little reference to their subjective rationale or meaningful significance for the person, and present these observations as the objective 'truth', used by professionals to determine appropriate types of 'treatment' (Molloy and Vasil, 2004, 158). Life story approaches, by contrast, explore how the world is experienced and dealt with not only practically but also meaningfully (Molloy and Vasil, 2004, 158). Life histories invite readers to explore personal experiences of everyday life, including the abstract aspects of meaningful and affective connection that are not readily given in reports of observed behaviour (Goodley, 2000). Part of the difficulties in communication between differently disposed (i.e. AS/non-AS) people

identified in existing literature has been in terms of the ‘different logic[s]’ (Ryan and Räisänen, 2008) of actors in social coordination. Furthermore, it has been noted that while AS people are often very aware of life ‘over there’ in the non-AS world, this understanding is often not reciprocated (Ryan and Räisänen, 2008). As Pellicano writes:

More often than not, the onus is on the autistic person to meet the demands of others...Rarely, however, are the expectations reversed, where the onus is instead on the non-autistic social partner to engage with the autistic person via his or her unique modes of communication and ways of interacting. Exchanges with autistic people are therefore often largely asymmetric – you could even say unequal – in nature (Pellicano, 2013, 131).

One important epistemological strength of life stories is that they offer access to ‘hidden spheres’ (Thompson, 2008, 20), not only in terms of internal subjective experiences (e.g. emotions, thoughts etc.), but also to the more private fields of the social world (e.g. the family home). In the case of AS people this is valuable because readers are invited to explore what may be hitherto unfamiliar experiences, and to glimpse (however partially) into the ‘logic’ of observable behaviours, offering new opportunities for practical coordination. In so doing, they help to ‘circumvent

biomedical check points' (Davidson and Henderson, 2010b, 462) and offer the possibility of seeing differences as rooted in meaningful and valid experiences of being in the world, rather than automatically classifying them as 'bizarre' or 'strange' (Davidson and Henderson, 2010b, 462), and/or as evidence of deviance or pathology (Molloy and Vasil, 2004). In terms of the present project, this also applies to understanding the challenges faced by AS people in pre-diagnostic life, in terms of how they come to understand and negotiate different aspects of their identity. Having set out my rationale for adopting a life story approach, I will now discuss the source of empirical material used in this study, autobiographies, in terms of their suitability for exploring pre-diagnostic identities.

4.1.2 – Autobiographical monographs as sources of material for life story investigation.

Autobiographical writing has been significant in changing public understandings of Autistic people and their experiences, in particular by challenging overly deterministic or categorical representations (i.e. based around narrow interpretations of diagnostic criteria). As Shore writes:

These stories of disclosure began to move the societal construct of the person on the autism spectrum from the nonverbal, antisocial, self-abusive child flapping his hands in the corner of the room to somebody who is capable of contributing to society (Shore, 2001, 137).

Elsewhere, Hacking (2009) has noted the effect that autobiographical materials can have not only on representations of individual people, but on the wider processes through which the language in which Autistic experiences and people are framed as discussed is formed. Here, he points to how autobiography has enriched both conceptual understanding of autism, and the language through which it is discussed:

Different kinds of item influence each other in complex ways. Novelists study autobiographies, whose authors learn from theorists. Parents pick up ideas from novels when they are thinking about their children. We all watch movies and documentaries. A 'thick' kind of human being is coming into being, where once there was only a 'thin' one. The autistic thin man of yore, or rather the thin child, when not having a tantrum, was a silent self-absorbed creature, alone with bizarre habits (Hacking, 2009, 1467).

As indicated in chapter two, autobiographical monographs have been used productively as sources of empirical material in previous social scientific research on the experiences of AS people. For example, Davidson et al. have used them to explore experiences of spatial access, gender identities, and affective connections with environments (Davidson, 2007; Davidson, 2008; Davidson and Smith, 2009; Davidson, 2010; Davidson and Henderson, 2010a; Davidson and Henderson, 2010b). Engaging with self-authored life narratives also offers a perspective on subjective experience, offering the kind of phenomenological detail (including affective forms of connection) (Davidson and Smith, 2009) that is often obscured in observations of behaviour or clinical case reports:

While autistic behaviour may seem strange when viewed from the outside... it makes a perfect kind of sense when seen in the context of the perceptually overwhelming life-worlds...Through close reading of their own words, it becomes clear that ASD 'symptoms' are often necessary tactics for emotional or environmental protection, and perhaps even survival. Such behavioural differences can therefore be more faithfully understood as inherently meaningful (Davidson, 2010, 307).

The 'thick' people who come into view through autobiographical accounts are those whose voice has largely been silenced in accounts of AS based upon clinical case histories (Waltz, 2005). As Waltz observes, 'people with autism are denied primacy, and even agency, in all but the least-mediated personal texts', a description that indicates the value of autobiographical texts as sources (2005, 432). As I observed in chapter two (2.1.1), in some social scientific studies that have engaged with the qualitative experiences of AS people, researchers have framed these in terms of pre-determined indicators or assumptions in relation to areas of wellbeing, without exploring their congruence with the subjective experiences and preferences of participants. Attention to narratives over which the AS person has the majority of control thus offers the opportunity to explore formations of pre-diagnostic identity, and their relationship to wellbeing.

While Davidson and colleagues have explored these texts hitherto through synchronic, cross-sectional approaches, I argue that they also provide suitable material for the type of diachronic life story work undertaken by Molloy and Vasil (2004). In their exploration of risks associated with 'having' AS, Portway and Johnson (2005) suggest that undiagnosed AS people were by definition 'inaccessible' to their study. This may be true in terms of immediate person-to-person access; however, this does not mean that pre-diagnostic life is entirely 'lost' or unavailable for exploration. Reflective materials can offer insights into pre-

diagnostic experiences, and autobiographical narratives represent what appear to be the only publicly available sources of qualitative material for an investigation of this type. In the course of developing my methodological approach, I made enquiries at the British Library, the British Archives, the Economic and Social Data Service (ESDS) Qualidata Archive, the Autism Diagnostic and Research Centre (ADRC, Southampton), the National Autistic Society (NAS) *Research Autism* database and the Autism Research Centre (ARC, Cambridge), none of which held, or could provide information on ways of obtaining relevant material. However, there are also practical, ethical and qualitative advantages to their use.

From a practical perspective, the process of autobiographical writing appears to mediate some of the difficulties in generating qualitative data through methods that rely on spontaneous and/or emergent processes such as semi-structured interviews. For example, Davidson has observed that this may be for some the only way in which detailed information about life experiences can be communicated effectively, and appears a practically appropriate way for people in this group to give accounts of their lives (2007, 662). Autobiographical writing appears compatible with many AS people because it gives the author time and space to order their reflections in narrative, and to produce an account of life experience in conditions favourable to their practical dispositions (Davidson, 2007, 663). It is also a process over which the author has a large measure of control, both in terms of the

practicalities of production and also over what is rendered in narrative, something that helps mediate the potential hazard of unforeseen emotional and mental distress emerging during semi-structured interviews (Waltz, 2005, 432-433; Merrill and West, 2009).

There are also questions regarding the status of AS people's narratives within the wider body of research literature. As Silverman observes, the voices of AS people have historically been excluded in the production of knowledge on autism, something which has contributed to a homogenised view of AS-related experiences that have been challenged by authors on the spectrum (Silverman, 2008, 328-330; Milton and Moon, 2012; Milton, 2012). For example, the centrality of sensory and perceptual issues has only come to prominence in clinical literature in the last five to ten years, despite its clear presence in the published narratives of AS people over a much longer period (Bogdashina, 2001, 1). This is indicative of a comparative lack of both biographically informed knowledge and research attention paid to the lives of adults (Davidson, 2007, 659). Autobiographies therefore represent a source of material that is appropriate for life story investigation, and for exploring formations of identity over broad periods of life.

Autobiographies (as with all sources of empirical material) have limits in terms of their epistemological value, something that is noted in existing literature and needs to be acknowledged here (Davidson and Smith, 2009). One limitation is the particular quality of diachronicity offered by the narrative, in that while they contain accounts of specific events across broad periods of life, the level of detail cannot be expected to be the same as more contemporaneous methods of recording, such as co-present ethnographic observation. Autobiographies involve recollections of life events which are then re-presented as a storied sense of self in narrative (Erben, 1998, 13). They can be thought of as 'situated knowledges', meaning that the texts are 'produced in specific circumstances and that those circumstances shape [them] in some way' (Rose, 1997, 305). For the researcher, these are contingencies to which one can only have partial access through 'traces' – fragments of past events and experiences which are then re-presented (Erben, 1993, 19). These traces relate not only to life experiences, but also the epistemological status of the material produced in terms of how it has been shaped by processes and conditions of production (Erben, 1998). Beyond the fact that all first person accounts are necessarily situated perspectives, rather than omniscient representations of events, there are other contingencies to consider in relation to the limits of autobiographies in terms of the selection, rendering, and ordering of life events.

Selection of life events first implies memory, for what one is able to select is dependent upon remembrance of it (Stanley, 1993; Erben, 1998). Events in the distant past may have fallen from memory, been neglected or, particularly in the case of traumatic experiences, have been suppressed or intentionally left out of the narrative (Thompson, 2008, 24). What is recollected can also be influenced by the mode of remembering, or the practical processes through which life events are recalled and objectified (Erben, 1998; Goodley, 2000). What a person remembers can be influenced by the reasons for remembering, and as such recollected events can be influenced by the period of life or themes of experience that structure these processes (Scott, 1998). These are limitations of which one can have only partial knowledge, perhaps through traces in the text where an author indicates that an event has been left out, or through internal inconsistencies or disputations arising from external sources (Stanley, 1993). Finally, the ordering of life events relates to the narrative structure of autobiographies, something which may not follow chronology, but at times necessarily violate it (Erben, 1998). How an author orders what is selected will depend upon the type of narrative one wishes to provide, and the points of life that they wish to emphasise. This does not automatically imply distortion or untruth, but recognises the status of autobiographies as *re-*presentations of self, situated at a particular point in time. Having set out my rationale for using autobiographies as sources of empirical material, I will now

discuss my approach to analysis, and in particular how positional, interpretive and ethical issues were managed.

4.2 – Investigating the monographs: interpretative, ethical and analytical approach

4.2.1 – Positional concerns and reflexive practice

Having set out some of the ethical advantages of using autobiographies over other sources of empirical material, it is important to discuss some of the potential hazards of using these materials, and how they were managed in the research process. One of these relates to the re-presentation by a non-autistic author of life stories, which can be framed using Sinclair’s concept of the ‘self-narrating zoo exhibit’. This term was coined in 1994, to refer to how Autistic people are routinely used by non-AS people (primarily clinicians and professionals) in conferences or publications, typically in an attempt to show ‘Autism from the inside’ (Sinclair, 2005). However, this often constitutes a form of tokenistic involvement where autistic people are expected to provide their experiences as material to be analysed by non-autistic professionals (in Sinclair’s terms, AS participants are expected to ‘speak when spoken to’ by non-autistic others) (Sinclair, 2005). Use of autobiographical narratives goes some way to mediating this hazard, in terms of using sources over

which AS authors have the majority of control. However, this still leaves issues of selection and re-presentation, in what will be necessarily thematic (and therefore, selective) discussions of broader life stories. Management of these issues requires attention to issues of positionality and reflexive practice, which are now discussed.

One important question relates to my position as a non-AS sociologist exploring the dispositions, reflections and subjectivities of people whose dispositional ways of being may differ in a variety of ways from my own. In the majority of literature on AS experiences, people in this category have occupied a curious position as (in Merton's terms) *insiders* in terms of their status as 'native experts' (Bogdashina, 2001, 1) on the lived experience of ASCs, but have been positioned as *outsiders* with respect to their exclusion from the processes of academic knowledge production (Merton, 1972; Silverman, 2008). This is an issue that social scientists have begun to address by drawing explicitly on first-person accounts of experience as sources of empirical material for understanding sociality (Waltz, 2005, 13; Ryan and Räisänen, 2008). However the fact that these investigations are still mediated through the analytical lens of the non-AS researcher requires understanding the relationship of this body of knowledge to my own position in a number of respects.

In providing a perspective on formations of pre-diagnostic identity, my analyses will necessarily involve a reconstruction and interpretation of them, most notably through the theoretical perspective set out in chapter two. One concern here involves the use of language, in particular the relationship between what Schutz calls first and second order constructs: the former denote the language and terms used by authors, while the latter involve concepts that the analyst may use to analyse and interpret them (Schutz, 1962, 220). This is a practical challenge, in terms of being able to make this relationship visible to the reader and thereby preserve something of the distinction between the original source and my own perspective. I have attempted to address this issue through my use, wherever possible, of the original language used by the authors to describe specific events, as well as being clear when my own terms are at play in the research narrative. This is important because in one sense, as Arnold argues (drawing on McLuhan) 'the medium is the message' (Arnold, 2010) with respect to representations of experience. Autobiographies are sources in which the authors' choices of how to order and describe their stories can bring to the fore themes and perspectives that might not be obvious to a non-AS reader. This brings into view questions of how first order constructs are understood and interpreted through my own dispositional understandings.

Flyvbjerg notes that analytical intuition, even that which is considered and ordered reflexively, necessarily involves dispositional forms of practical, inarticulate know-how (2006, 218). While these types of understanding are, by their very nature, only partially visible through practical activity, one can gain an indirect appreciation of the context for these understandings by reflecting on one's own biographical situation. I explore these life experiences through their rendering in autobiographical narratives, bringing my own understandings and assumptions to this work, as well as areas of ignorance. I am very much an 'outsider' in understanding these processes, not only in dispositional terms but also in social, environmental and biographical contexts (Merton, 1972; Stanley, 1993). For example, one of the themes I will explore (in 6.1.2) relates to Jen Birch's experience of different iterations of gendered and sexual self (heterosexual, lesbian, bi-sexual and 'unlabelled') (Birch, 2003). As a heterosexual non-autistic person, my purchase on these issues is mediated not only by conditions of access through language, but also by differences in social and embodied experience which form the basis for interpretive judgement – my own dispositional ways of knowing and being. This is not to state that the experiences of people different from my own are unintelligible to me, or that it is impossible for me to say anything of value about them. Rather, it is to recognise that I come to these texts from a position qualitatively different from those of the authors, who themselves are attempting to bridge this gap through language. In these texts, there are passages communicating experiences of, for

example, elation or suffering, in addition to descriptions of perceptual renderings and embodied performances, understanding of which I can only approach through my own approximations (Davidson and Smith, 2009, 898). Reading autobiographies draws on a range of emotional, sensual and intellectual experiences arising in response to the engagement with the texts, but that does not of course mean that it is the same as the experience of the author. The question thus becomes, how have I attempted to manage these contingencies in my reflexive practice?

Reflexivity is a central concern in contemporary sociological research, and this is particularly apparent in Bourdieu's concepts of practice, habitus and field as 'thinking tools' in the production of knowledge. Commitment to rigorous and ethical social science implies an intention to avoid harmful distortions or oversimplifications of experiences, and thus that reflexivity be incorporated into the practice of sociological research (Bourdieu and Wacquant, 1992; Plummer, 2001; Mason, 2002). This is not something that gives unmediated or transcendental access to one's own position, for as Rose observes, acts of reflection are always situated, thus one can have multiple reflections providing different perspectives on sociality (1997). Access to our dispositions and the wider regularities of habitus (e.g. the institution within which I conducted this PhD) and field (e.g. the wider discipline of sociology) are not in any sense transparent, but involve socially situated perspectives that evolve over time (Rose, 1997, 316).

Initially, as someone unfamiliar with the world of autism but with a theoretical interest in the relationship between mind and brain sciences I was drawn to questions of how differences in neurodevelopment could impact upon social agency. In the beginning I was therefore very attentive to the writings of those in the clinical and neuropsychological sciences, in particular categorical descriptions enshrined in diagnostic criteria. This was not an unwise or 'bad' move, for it provided me with some basic understandings or 'rules' which, as a novice in the field, were necessary to make sense of it. However, as the months went on I came into contact not only with the autobiographical writings of AS people, but also met individuals in this category whose experiences and reflections indicated to me a need to move beyond categorical understandings of their lives (i.e. diagnostic schemas). In the early stages of the project, I recall hearing the phrase that 'when you've met one person with autism, you've met one person with autism', signifying the diversity of experiences within that AS people may have. Contact with a range of different life stories bore out the importance of this observation, opening up a more detailed and diverse range of experiences than had been readily visible through categorical understandings of AS. Through engagement with these life stories, I was able to explore a different kind of knowledge in the forms of 'know how' that AS people, as 'native experts' (Bogdashina, 2001, 1) develop as they go on in the world.

Throughout the project, I have sought to engage with a range of different perspectives on AS people's experiences, not only those described in published literature (both peer-reviewed and lay texts) but through exchanges with AS people whom I met along the way. In the development of both theoretical and methodological approaches, I have engaged with other social scientists on the spectrum (such as Damian Milton and Larry Arnold at the University of Birmingham), and was also joined by Tony Brown (consultant clinical psychologist at the Autism Diagnostic Research Centre, Southampton) who acted as a project advisor. I also continued to develop my practical understanding of AS people's social experiences through voluntary work with the National Autistic Society through their e-befriending service. While this role was not directly related to the existing research, the desire to become involved with this stemmed from a wish to develop my knowledge of autistic people's experiences through practical social exchange, as well as contributing to an area of public need. This describes some of the reflexive processes involved in the constitution of knowledge on autism in general. What I will now do is outline how these were managed in the practical processes of analysis and construction of the analytical discussion.

4.2.2 - Description of the analytical process and structure of discussion.

The perspective provided by this thesis is not intended to override the original narratives of authors, or to establish an authoritative reading of their texts. Rather,

my aim has been to explore comparatively different formations of identity represented in the monographs and, through the conceptual approach set out in chapter three, and to connect these together within a holistic theoretical frame that contributes to knowledge. The positional and reflexive concerns discussed thus far in this chapter have informed my approach to analysing the texts, and in particular my concern with preserving as far as possible the original language used by authors in the thematic analysis of sources. This does not mean uncritical acceptance of the claims of authors (Thompson, 2008, 23-24); as discussed in the previous chapter, I have attempted to explore where possible the integrity of the monographs (as discussed in 4.1.1). Rather, it indicates my understanding of how my position has affected the limits of what I have been able to do with these sources in terms of producing new knowledge.

Thus far, I have argued that reflexivity is an important part of sociological research and is something that needs to be managed continuously within the research process. Therefore, my first act in the analytical phase was to create a research diary for recording observations on the development of my practice, and as a resource for reflection on my relationship to the material and research questions. The second step was to develop a method of organising my observations that would allow me to produce comparative analyses, while preserving the context of the cases. While guidance from the methodological literature and existing studies

hitherto discussed was useful for informing this approach, the process was not something that I was able to take 'off the shelf' in totality, but emerged as a process of practical problem solving. As Erben observes, understanding autobiographical texts involves a process that involves a relationship between particular events and their place within the whole of the narrative (1993). This follows the logic of the 'hermeneutic circle', where the text (in this case a life narrative) is encountered as a whole, analysed in terms of its particular events and their relationship to each other, and these observations are then re-interpreted within the context of a wider life narrative (Malpas, 2009). The researcher seeks to understand the life as presented, then to analyse particular aspects (in this case the themes underpinning the three research questions identified in chapter three) and then to understand how these aspects are contingent upon their relationship to wider aspects that make up the whole (Erben, 1993; Malpas, 2009).

Broadly, there were three stages to my investigation of the monographs. In stage one, the autobiographies were read through in their entirety, so that I could familiarise myself with the broad context of each source, during which particular observations relevant to each of the three research questions were noted. Once each monograph had been read in full, these observations were typed up into an electronic document, creating a second 'pass' over the observations in which errors or omissions could be spotted (e.g. mis-readings or incongruent observations), and

also findings reassessed in light of my understanding of the 'whole' of the narrative. In stage two, these documents were loaded into the NVivo qualitative data analysis software package for coding, something which had a number of practical advantages. Firstly, it allowed for a large amount of text-based data to be indexed in such a way that material could be organised thematically across cases. Approximately 19,000 words of notes were generated, and so this assisted greatly in working with this material (Mason, 2002, 152). Secondly, the different narrative structures of the autobiographies meant that observations relating to a particular theme sometimes appeared at different points within the monograph. Coding in NVivo allowed material both within and across cases to be organised in relation to themes, and also for observations to be indexed according to their relevance to each area as well as sub-fields within them. This is important because observations can then be arranged and re-arranged according to the emergent structure of the analysis as one moves through the texts. Using this software helped to maintain and develop a clear understanding of the relationship between the chronological order of life events, and their ordering in narrative.

In practical terms the first step in the process was to create a project file in Nvivo, beginning with each research question as a base node (highest level tree node), and then further child nodes (core nodes) corresponding to themes within each area. Each base node produced an output summarising the individual observations

relating to each individual source, which then allowed me to explore sources in terms of their relevance to specific questions. The autobiographies varied in terms of themes discussed, and this process was helpful in organising sources for analysis and discussion. For the first two questions, individual narratives were selected in relation to relevant themes within the monographs, which were explored individually and then discussed comparatively (this process also informed the structure of chapters six, seven and eight). For question three, my approach differed with respect to the organisation of the discussion into sub-themes, within which individual life experiences contributed to a more general discussion of understandings and negotiations of risk (this is reflected in the structure of chapter seven). My aim was thus to explore different lives in context and identify specific themes relevant to each question, and then to discuss them in detail, before a comparative discussion at the end of the chapter. This approach was chosen over discussion of the autobiographies cross-sectionally for the reasons stated hitherto (in 4.1.1).

Secondly, focusing on individual lives prior to comparative discussion allowed for more detailed exploration of the particularities that affect individual lives, and for appreciation of the factors that may affect individual lives. This is important because my approach to discussion of each of the autobiographies was to begin with early experiences of dispositionality, and then explore how these developed in relation to life events and other aspects of self, in relation to each of the themes

discussed. For example, in chapter six (6.1.2), I explore how Jen Birch came to understand her AS-related dispositions in the pre-diagnostic phase in relation to regularities of gender and sexuality operating within different fields. Here, I begin by setting out how Birch came to understand her dispositions in early childhood and from there trace how they developed in relation to other aspects of self with respect to different manifestations of her gendered and sexual self. This allowed me to explore biographically, how her sense of self in relation to these aspects of identity developed across broad periods of pre-diagnostic life. The life stories will be explored individually before being discussed comparatively at the end of each chapter (or at the end of each section in chapter seven). Here, I explore how the different life stories, and the themes they present in relation to each of the research questions, can help contribute to understanding of formations of pre-diagnostic identity, and help develop the interrelated concepts of authenticity, accountability and legitimacy as a way of understanding them. Having set out my approach to managing positional, reflexive and ethical issues in the practical process of analysis, I will now discuss the specific autobiographies, first in terms of their selection, and secondly in relation to the particular contribution that each monograph will make to the discussion in part two.

4.3 – Identification and selection of source material

4.3.1 - Identification process

The starting criteria for identifying suitable materials was any published (having an ISBN or ISSN number) self-authored autobiographical monograph produced by a person over the age of 18 at time of publication, born before 1980. On the basis of these criteria, an initial long-list of materials was identified through a number of searching strategies:

- *Search of the Jessica Kingsley publications database* – Jessica Kingsley Publishers (JKP) are the largest publishing house for AS-authored and relevant texts in the English language, both by and for people with autism, their families and professionals. The search strategy for this repository involved an item-by-item exploration of all materials listed under the ‘Asperger’s Syndrome, Autism and other Syndromes’ (478 items returned) and ‘Fiction and Memoirs’ sections (79 items returned). The latter section contains materials, either fictional or autobiographical, that have been authored by people on the autism spectrum. According to JKP these are classified together in order to bring together different works by authors on the spectrum, which may be either personal accounts of experience or fictional narratives (within this section individual items are identified as such).

- *Search of the Autism Asperger's Publishing Co. (AAPC)* – this involved a search of the AAPC catalogue section 'Personal Accounts' subsection 'Individuals with ASD' (18 items returned).
- Search of the Copac catalogue (incorporating over seventy major research libraries in the UK and Ireland including the British Library).
- Appointment with a social sciences librarian at the British Library to search specialist collections.
- *Search of the Google Books online database* – Google books is an online repository of print materials – currently the largest publicly available database. The Google Books search involved the use of an advanced search with the parameters 'include all words' – Books (as type of material) – 'autism' (as Subject) Search strings 'autism autobiography' (156 items returned) and 'Asperger's autobiography' (109 items returned) were used on each of these services.

- Other relevant materials were included after identification through bibliographies of existing research publications.

The respective searches returned a large number of duplicate items; however, multiple searches were beneficial in identifying relevant items that were missing or miscategorised in other databases. This was notable in the JKP search, where my initial plan was to examine only the 'Fiction and Memoirs' section of the catalogue; speculative exploration of the 'Asperger's Syndrome, Autism and other Syndromes' section revealed a number of items which were suitable for inclusion but had not been categorised as memoir (and thus the decision was taken to widen the search within this catalogue). This also led to a search of *Google Books* system which serves as a meta-catalogue of printed materials from a wide range of general and specialist publishers and book sellers including JKP, AAPC, Amazon, Barnes and Noble and others. The Google Books search was intended to provide a wider literature search beyond the specialist publishers, and through which a number of suitable publications were identified which were not revealed by searches of JKP and AAPC or other databases.

This led to an initial long list of nineteen monographs, from which a further seven were excluded after further investigation revealed that their diagnosis was either of

classic Autism, or a dual diagnosis of AS with ADD (Attention Deficit Disorder) or ADHD (Attention Deficit Hyperactivity Disorder). The decision to exclude those with a dual diagnosis was taken on the advice of a project advisor, Dr. Tony Brown (a consultant clinical psychologist at the Autism Diagnostic Research Centre, Southampton), in order to preserve a degree of comparability within the group of monographs identified. Dual diagnosis is a complex and contested issue within the study of AS, and while this would certainly qualify as an additional area of complexity worthy of investigation, I felt that I would not be able to accommodate this within the confines of the present project. It is important to note that dual diagnosis exclusions pertained only to those who, at the time of writing, had multiple standing diagnoses in relation to a major neurological or mental health issue and did not exclude those who had been misdiagnosed in earlier life with another condition (i.e. schizophrenia in the case of Wendy Lawson)

4.3.2 – Selection of final sample.

From the initial long list of nineteen monographs I looked to identify a range of cases that would provide adequate material for investigation. While not in this case looking for a representative sample, I was looking for a range of different life experiences within which to explore the general and particular aspects of life in relation to the three research questions identified in the previous chapter. Molloy

and Vasil's book-length investigation of the identities of six AS teenagers provided a rough guide as to the amount of material that I could analyse in sufficient depth, given the constraints of the thesis. I sought to identify a range of different individuals, experiences and life circumstances through which to explore comparatively different formations of pre-diagnostic identity. I chose to exclude two of the monographs by more well-known authors, these being Temple Grandin and Donna Williams. Given the restrictions of the thesis, my challenge was to include (as far as possible) a diversity of voices such that could be discussed in detail. Grandin and Williams' accounts have become virtually ubiquitous within the wider research literature on autism, and their narratives are already part of the fabric of contemporary AS research. Both of these authors' narratives are referenced frequently in the life stories of those who published after them (Shore, 2001, 213-214; Birch, 2003, 208; for example Purkis, 2006, 9-10), and so I took the decision to exclude these more well-known authors in favour of those whose narratives had received less attention hitherto in research literature.

The monographs were assessed according to three of Scott's four criteria for assessing documentary sources – authenticity, credibility, meaning and representativeness (Scott, 1990a). The authenticity of the sources – 'whether [they are actually] what [they purport] to be' – was ascertained through web-based research. My aim here was to find indications that the authors of the works were

who they claimed to be. As each case was a formal publication by a recognisable publishing house, there were in all cases clear indications, often from a number of sources, that the purported authors were identifiable with those of the text. There were also often corroborating observations, such as interviews in print or other media, recognition by voluntary agencies (such as the UK National Autistic Society) or other indications of authenticity.

In relation to the credibility of the sources, Scott advises that the researcher assess documentary sources for evidence of sincerity and accuracy (Scott, 1990b). One limitation of autobiographical materials is that the former is often easier to ascertain than the latter, as the knowledge gained through autobiographies is often involves 'traces' of events otherwise lost in time. For example, it is not possible in many cases to detect errors of memory or missing details because there will be no 'trace' of these occurrences, such that they might be intelligible to the researcher. Thus accuracy in many cases can only be assessed through constant vigilance as to the status of specific claims and by considering internal consistency and concordance with other known details of the authors' lives. Certain claims— where authors lived, who they worked for, where they studied – could in most cases be explored through background research online, although in many cases only in the negative sense, i.e. by checking for evidence of falsification or contradiction, rather than confirmation. This was an iterative process that evolved as I became aware of

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details within individual monographs and was able to move through the process of checking them. No traces of inaccuracy were found within the sources in the final sample; however, there were issues with sincerity in relation to one of the authors in the long list.

Dawn Prince-Hughes' *Songs of the Gorilla Nation* was rejected after the initial reading, because of concerns regarding the academic and professional credentials claimed by the author, and doubts about the circumstances surrounding their award. These concerns arose after online research into the awarding institution (Universitat Herisau) for the author's doctorate revealed it to be a diploma mill. In addition the circumstances described in the book surrounding her study with this institution appear doubtful in light of the institution's dubious status. Although this did not invalidate her entire narrative, it was felt that significant doubts had been cast with respect to the accuracy of the author's account, such that the monograph should be excluded. To be clear, this not merely a question of inaccuracy, as the detail provided by the author appeared in direct contradiction what I was able to discern about her awarding institution. It appeared extremely doubtful that events could have unfolded as she had claimed in the book, and these doubts were compounded by a curious absence of external evidence to verify her professional history or subsequent activities. Similar checks were made to explore the sincerity

of claims made by the remaining authors, with no evidence found to cast doubt on their sincerity.

While representativeness was not a major concern in this study due to my stated aim of looking to exploring different formations of pre-diagnostic identity in relation to the three research questions identified, an important criterion for assessing the utility of the monographs was their meaningful content – did the autobiographies provide suitable material of a sufficient quantity to facilitate a detailed investigation? One way of doing this was to identify different categorical aspects of author identity as potential indicators of biographical variation, for example ensuring that both men and women were represented in order to broaden the scope for exploration of issues relating to different experiences of gender and sexuality. I also looked to identify authors with a range of ethnic and cultural backgrounds, as well as differing socio-economic class positions, although my success in these respects was limited by available material. The sample consists of five female and two male authors. Two of the authors were US nationals, one from the UK, one from Sweden, another from New Zealand and the remaining two were UK nationals who subsequently migrated to Australia. The authors were all born between 1955 and 1974, while their age at publication ranged from thirty-one to forty-six (mean=41.1 years) and their age at diagnosis ranged from nineteen to forty-three (mean=29.1 years).

Author	Year of Birth	Sex	Nationality	Age at diagnosis	Age at Publication	Education
Lawson, W	1954	Female	UK/Australia	42	46	Higher Degree
Birch, J	1955	Female	New Zealand	43	46	Undergraduate Degree
Robison, J.E	1957	Male	USA	39	50	Secondary/High School
Willey, L.H	1959	Female	USA	37	40	Higher Degree
Gerland, G	1963	Female	Sweden	29	40	Secondary/High School
Hadcroft, W	1970	Male	UK	30	35	Secondary/High School
Purkis, J	1974	Female	UK/Australia	19	31	Higher Degree

Table 1 - Autobiographical monographs

All of the authors were of white European ethnicity. One of the autobiographers had been educated to undergraduate level at the time of publication, four had obtained higher degrees, while the remaining three had completed secondary/high school education and the remaining one had withdrawn before completing secondary/high-school education. In terms of socio-economic status, my approach was to assess this through self-identification or markers evident in descriptions of lives. Only one author, Will Hadcroft, self-identified as 'working class' (2005, 119) while the majority of other authors did not overtly identify with a particular class position (excluding Jeanette Purkis, who identified herself as 'middle class') (2006, 177

162). Nevertheless, beyond categorical differences there remained a range of different dispositional, social and environmental as well as biographical narratives within the final sample to support a productive discussion. The qualities of each monograph are now discussed.

4.4 - Biographical summaries

As Davidson observes, one of the qualities of autobiographies is to offer an insight into the subjective experience of life events and behaviours that may seem 'strange' or 'bizarre' to differently disposed (i.e. non-AS) observers. To this I would add that autobiographies offer not only insights into individual behaviours, but as storied representations of self offer insights not only into differences but also similarities. Many of the themes and situations of these life stories are perennially human stories – marriage, friendship, loneliness, disappointment and fulfilment. What differentiates them in parts from the stories of many non-AS others is the role of dispositional differences, and their interplay with the social and cultural circumstances of everyday life.

In this section, I introduce each of the autobiographers in order of appearance in the coming chapters, and highlight the aspects of their narratives to be discussed.

As indicated earlier, I do not claim to represent the totality of their stories, and what is discussed here are specific themes relevant to each of the questions identified. Furthermore, not all of the autobiographies will be discussed in relation to each of the themes, although some narratives appear in two chapters. Again, this is due to the constraints of the project, and my desire to discuss each of the autobiographies in detail. Finally, I would also like to add that although the focus will be on the pre-diagnostic phase of life, post-diagnostic experiences will be discussed in places where this serves to contextualise or otherwise provide evidence of the significance of not having a diagnosis. It will therefore necessary at some points to compare accounts of pre-diagnostic experiences with those that came after diagnosis was made, in order to indicate the relative importance of living without a diagnosis for different aspects of identity.

4.4.1 - Gunilla Gerland (A Real Person)



Image 2 – Gunilla Gerland (<http://www.tankbart.se/guni.jpg>)

Gunilla Gerland was born in Stockholm, Sweden in 1963, the younger of two sisters. Her monograph contributes to two of the discussions in the coming chapters, the first of which explores how she came to understand her dispositional self in childhood. From a young age, Gerland's experience of AS involved issues with coordination and motor function, synaesthesia which manifested in her experience of affective connections as 'colours', and difficulties understanding of others' actions and use of language (Gerland, 1997, 11, 14-15, 20, 22). She describes having to rely in early years on her sister (three years her elder) as a 'bridge' to the world of others, and a 'model' for how one should act in social situations (Gerland, 1997, 22). Although academically proficient, she faced difficulties in her school years, where her spatial sensitivities and social differences marked her out for

bullying by her peers, and led to her being seen as 'insolent' by teachers (Gerland, 1997, 22, 150-151). In 6.2.1, I will explore how Gerland came to understand her dispositions in terms of strengths and limitations, how these were understood as differences through comparison with the behaviour of others, and how this related to her lifelong feelings of not feeling like a 'real person'. At the end of chapter six (6.2), this will be discussed in relation to the wider theme of 'legitimacy', in terms of how her experience of dispositional self as not being 'real' was shaped by the conditions of habitus and field in early years.

The second point of contribution of Gerland's monograph is to the discussion of managing insecurity in the workplace, in chapter seven. After leaving school, Gerland moved through a number of low-paid jobs before becoming a nursery worker, an experience which she describes as 'fulfilling' but 'tiring', not only due to the sensory demands of her job but also having to deal with her mother's 'psychotic break' (Gerland, 1997, 189-193). This precipitated a period of depression, during which she recalls that 'the will to live had withered within [her]' (Gerland, 1997, 193). In 7.3.2, I will explore this experience of managing sensory challenges in the workplace, and how associated feelings of insecurity left her vulnerable to the negative effects of unforeseen life events on her physical and mental wellbeing.

4.4.2 - Wendy Lawson (*Life Behind Glass*).



Image 3 – Wendy Lawson (<http://www.mugsy.org/wendy/wendy2.jpg>)

Wendy Lawson was born on the South East Coast of England in 1954, and later moved inland to the Avon/Somerset region at age four (Lawson, 1998, 24). In her autobiography, *Life Behind Glass*, she describes her experience of distance from other people, in particular the ‘mystery’ of affective experiences such as ‘love and feelings’ (Lawson, 1998, 84). In addition, she describes the challenge of distinguishing between different emotive states such as ‘anger, fear, frustration, anxiety or disappointment’, as well as the practical strategies used to mediate these challenges in social life. Lawson’s narrative explores long-held feelings of being ‘misunderstood and alienated’ from the world around her, and her emotional connection to the events of her life (Lawson, 1998, i-ii). Sensory sensitivities, perceptual differences and dispositional differences in understanding interactions with non-AS others intertwine in her struggle for a sense of belonging, through

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experiences of family life, work and motherhood (Lawson, 1998, 75). This also includes her experience of institutionalisation within a psychiatric hospital following a suicide attempt, during which she was diagnosed with schizophrenia (a label that would stand for 25 years until her diagnosis of AS in 1994) (Lawson, 1998).

In the coming chapters I will discuss Lawson's narrative in relation to two of the research questions, the first of which will be in chapter six where I focus on the relationship between lifeworld, dispositionality and practice. Lawson's narrative will be discussed (in 6.2.2) in terms of her ability to experience dispositionally appropriate ways of connecting with the world, and how this was mediated by the conditions of habitus and field in the pre-diagnostic phase. The second use of her monograph will appear in chapter eight, in which I explore her management of insecurities experienced as a new mother in terms of risks associated with both her dispositional ways of being and her label of schizophrenia.

4.4.3 - Lianne Holiday Willey (Pretending To Be Normal)



Image 4 – Lianne Holiday Willey

<http://www.aapcpublishing.net/images/authors/edb29e65d137b8b89c95b45d8e3dcf33e58d5386.jpg>

Lianne Holiday Willey was born in the USA in 1959 and raised as an only child. Aware of her differences from an early age, she describes feeling ‘removed’ from the domains of others, as well having an attraction to ‘safe spaces’ (for example, a ‘swimming pool’ and a ‘large tree’) and experiencing social life as something which ‘...[she] could jump in when [she] felt like it, slip away if that fit, or sit back and observe...’ (Willey, 1999, 26-30). During her school years, Willey found that while issues with social interaction, sensory sensitivities and motor coordination restricted her participation within certain spaces, the social structure of high school groups ‘defined by shared interests’ provided accommodating circumstances for her

differences (Willey, 1999, 32). However, this would become problematic as she moved away to college, where she found it difficult to make friends and to conform to 'expectations of normality' (Willey, 1999, 51-53). The dynamics of social events, such as parties, were examples of situations in which communicative aspects involving 'subtext and innuendo' were problematic and led to feelings of exclusion and isolation (Willey, 1999, 54-55). Willey's narrative will inform the discussion in chapter six where (in 6.2.4) I will explore how the value of particular practical strategies varied in different fields across her life, and the implications of this for her understanding of dispositional self in pre-diagnostic life.

4.4.4 - Will Hadcroft (*The Feeling's Unmutual*)



Image 5 – Will Hadcroft ([http://q-ecx.images-amazon.com/images/G/01/ciu/07/72/b4e1e03ae7a0a5cd05482210.L_V192188220_SX200 .jpg](http://q-ecx.images-amazon.com/images/G/01/ciu/07/72/b4e1e03ae7a0a5cd05482210.L_V192188220_SX200.jpg))

Will Hadcroft was born in 1970 and grew up on the Kenyon Way estate in Little Hulton, Greater Manchester, England (Hadcroft, 2005, 19). While social motor coordination issues were a problem for Hadcroft in early childhood and primary school years, it was not until the second year of high school in 1982 (at age 12) that his differences ‘stood out’ socially, making him a target of bullying by his peers. After leaving school, Hadcroft’s experiences of work-place fields were marked by isolation and ridicule from co-workers, leading to prolonged periods of loneliness and depression. In 1993, he met his future wife Carol who he describes as ‘filling the massive chasm of loneliness and despair’ that he had experienced for much of his life up to that point, and they were married in August of that year (Hadcroft,

2005, 171). Over the next few years he would struggle with anxiety and panic attacks that would affect his ability to work, lasting one month in a part time job at a retirement home in 1999 (Hadcroft, 2005, 216). During this time he also began psychotherapy sessions, a process that would lead to his eventual diagnosis in 2003. He also began developing his skills as a writer, taking classes in creative writing and preparing a manuscript that would later be published in 2002 as *Anna Droyd and Century Lodge*.

Hadcroft's autobiography informs two of discussions in the coming chapters, the first (6.1.4) relates to how his understanding of dispositional self developed in the pre-diagnostic phase of life. In particular, I will explore how Hadcroft's dispositional self was configured through his cultural values in relation to problematic relations with others in school and the workplace. I also discuss how the progress of three life events – his marriage to Carol, becoming a published author, and his eventual diagnosis – changed his understanding of dispositional self in relation to others. The second use of Hadcroft's narrative will be in the comparative discussion of orientations to fatherhood (in 8.2.1), which will be contrasted with John Elder Robison's experience. In this case, Hadcroft's reflections provide a perspective on the decision not to become a father, and how this was informed by understandings of risk linked to dispositional and biographical factors.

4.4.5 - Jeanette Purkis (*Finding A Different Kind Of Normal*)



Image 6 – Jeanette Purkis (<http://www.jkp.com/blog/wp-content/uploads/2010/08/Jeanette-Purkis-300x200.jpg>)

Jeanette Purkis was born in 1974 into what she describes as a ‘middle class’ Christadelphian (a minority Christian denomination) family in South East England, moving to Australia in early childhood (Purkis, 2006, 11;93;162). Purkis’ narrative will be the first to be discussed in chapter six, where I will explore how her experience of pre-diagnostic self underwent several changes as she moved through different social fields. I will explore how her dispositions combined with the cultural and practical conditions of habitus in the production of her different ‘selves’. From an early age, she experienced spatial sensitivities in the presence of other children, as well as issues with social interaction, communication and coordination (Purkis, 2006, 12-13;16). Between the ages of seven and eight, she became increasingly

active in the Christadelphian church, developing an affinity for the 'rules' provided by this organisation (Purkis, 2006, 17). While at high school, Purkis began to question her Christadelphian faith and became increasingly interested in the politics of the far left. She would go on to become an active member of the Communist party in Melbourne, wherein the writings of Marx and the 'authority of the party' became her new source of 'rules' for acting in the world (Purkis, 2006, 43-65).

Her consumption of recreational drugs, particularly amphetamines and marijuana, increased during this period, as did her self-described 'obsession' with 'the darker side of life', manifested most prominently in her involvement with violent demonstrations (Purkis, 2006, 78-81). This 'obsession' culminated in what she describes as 'inadvertent' involvement with an armed robbery planned by a then-friend, leading to her first term of imprisonment (Purkis, 2006, 87). During this time Purkis was first diagnosed, at the age of twenty, with Asperger's Syndrome by a prison psychologist. Although the diagnosis was vital in the eventual reduction of her sentence, she did not accept the diagnosis at this time, and instead took on another identity based around the rules of prison life – 'Jeanette the Criminal' (Purkis, 2006, 101). The final shift in Purkis' identity occurred just after her final stay in prison, with her enrolment on an undergraduate arts course, and acceptance of the diagnosis as a valid description of her differences. Purkis' narrative will contribute to the discussion of how self-other relations affect pre-diagnostic

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understandings of self. In 6.1.1, I will contrast her description of her most recent 'self' with descriptions of her previous 'selves', in terms of how the former incorporated feelings of meaningful connection to the life of the field (in addition to practical compatibility and social legitimacy) that hitherto been absent.

4.4.6 - Jen Birch (*Congratulations! It's Asperger Syndrome*)



Image 7 – Jen Birch (<http://www.aspergers.co.nz/images/bannerPic.jpg>)

Jen Birch was born in 1955, and diagnosed with Asperger's Syndrome at the age of forty three, an event which she describes as a 'revelation'. Birch's narrative will be the discussed in chapter six (6.1.2), where I explore how the intersection of her dispositions with different cultural landscapes in relation to gender and sexuality shaped her identity. The author describes her experiences of growing up in rural New Zealand, and the impact of AS-related differences on her gender identity as a child (Birch, 2003, 116). Married in her early twenties, and divorced five years later, Birch discusses the breakup of her marriage in terms of a conflict between her dispositions and those qualities that she felt proper to motherhood (the decision not to have children was significant in the divorce) (Birch, 2003, 146-149). Gender and sexuality issues also come through as strong themes in terms of her experiences as a teenager and young adult, including her explorations of relationships with both men and women, and her 'lifelong' feelings of androgyny

(Birch, 2003, 120). She also held a number of jobs in which she often came up against difficulties in understanding and negotiating the implicit regularities which shaped social relations within these fields. These experiences will be explored in chapter seven (in 7.2.1) in relation to how Birch's dispositions combined with changes in the conditions of habitus and field to shape particular risk conditions within the world of work. Here, I will explore her negotiation of the 'hidden' regularities of workplace fields, as part of a wider discussion of negotiating everyday insecurity in the workplace.

4.4.7 - John Elder Robison (Look Me In The Eye)



Image 8 – John Elder Robison

<http://blogs.plos.org/neurotribes/files/2011/05/robison.handsome.jpg>

John Elder Robison was born in 1957 into a suburban household in Massachusetts, USA (Robison, 2008, 7, 19). From an early age he describes difficulties in interacting with other children, as well as ways coping with different experiences of lifeworld in terms of how information about other people was organised. As a child, he describes difficulty understanding the emotional responses of non-AS people, contrasting his 'logical' responses with the emotional reactions of others (Robison, 2008, 38). He also writes of difficulties with issues such as making inappropriate facial expressions, and describes (in later life) the development of practical strategies for managing social exchanges with differently disposed others (Robison, 193

2008, 189). Robison's narrative contributes to two of the discussions in this thesis. The first of these appears in chapter six where (in 6.1.3) I discuss his idea of 'logical empathy' and how he contrasted this with the affective responses of differently disposed others. I will explore how this concept operated as a form of distinction in the formation of his identity through self-other relations. In contrast to Lawson's account, this example illustrates how opportunities for renegotiation of the practical conditions of interactions can be restricted by the cultural horizons of particular social fields. The second use of Robison's narrative will appear in chapter eight where (in 7.1.1), I compare and contrast his orientations to fatherhood with those of Will Hadcroft, who decided not to become a parent. In this discussion I will explore how the respective authors framed fatherhood in terms of associated insecurities in relation to their dispositional selves.

4.5 - Summary

The aim of this chapter has been to explain and justify my methodological approach to exploring formations of pre-diagnostic identity in this thesis. Existing literature (discussed in chapter two) indicates that the relationship between AS and identity is subject to change across the life course (Molloy and Vasil, 2004; Bagatell, 2007; Davidson and Henderson, 2010a), and I have therefore chosen to adopt a comparative life story approach. In 4.1, it was argued that this is an appropriate

approach for exploring formations of pre-diagnostic identity across lives, as well as exploring the 'hidden spheres' (Thompson, 2008) of phenomenological experience and social life that have often been hidden from third party accounts of AS people's experiences (in particular, clinical descriptions) (Waltz, 2005). The sources of empirical material for this investigation are autobiographies, which as argued in 4.1.2 may be the only source of available qualitative data for exploring pre-diagnostic experiences. Epistemological and ethical advantages to the use of these sources were also discussed in terms of the degree of control that the AS person maintains over the structure and description of their account. Following on from an understanding of autobiographies as situated knowledges, management of interpretive and positional issues was discussed with respect to how these were managed in reflexive practice during the research. In 4.3.2, I explained the process of analysis using the NVivo CAQDAS software package, and how this relates to the structure of the discussion in part two. Finally, I have given an introductory summary of each autobiography in terms of its relevance to my investigation of pre-diagnostic identities.

This chapter also marks the end of part one of the thesis, in which I have sought to frame my investigation, beginning with an exploration of how I understand AS as an object of study, drawing on Hacking's concept of the 'interactive kind'. In chapter

two, I established the broad focus and specific research questions that have structured my investigation:

- 1. How do AS people understand their dispositional selves in the pre-diagnostic phase of life?**
- 2. How do self-other relations affect pre-diagnostic understandings of self?**
- 3. How does management of everyday insecurities relate to formations of the pre-diagnostic self?**

As indicated in 2.2, these questions follow a conceptual progression that moves from a focus on formations of dispositional identity, to consider how these relate to other aspects of identity as they arise in self-other relations, and finally to explore the interplay between management of everyday insecurities and pre-diagnostic identities. The literature discussed in this section (2.2), and the questions arising from it, point to the importance of social and cultural conditions on formations of pre-diagnostic identity, and in chapter three I argued that a Bourdieusian approach to identity can help to explore these issues. Through a discussion of how assumptions about perceptual functioning inform Bourdieu's original concepts of practice, habitus, field and forms of capital, I have sought to reframe aspects of this framework in order to accommodate AS related differences. Using Bottero's schema (augmented by intersectionality theory), I have framed identity in terms of a relationship between dispositional, reflexive and collective aspects of self. Finally,

I have introduced the idea that the concepts of authenticity, accountability and legitimacy can help us to frame specific issues relating to pre-diagnostic formations of identity for AS people. These concepts will be developed further in the analytical chapters that follow, beginning with my exploration of dispositional identity formation in the pre-diagnostic lives of four of the autobiographers.

Part Two - Exploring formations of pre-diagnostic identity

5 – How do AS people understand their dispositional selves in the pre-diagnostic phase of life?

In this chapter, I will explore how four of the authors – Gunilla Gerland, Wendy Lawson, Lianne Holliday Willey and Will Hadcroft – came to understand their dispositional selves in the pre-diagnostic phase of life. The discussion will focus on each author in turn, exploring a particular theme from their narrative in relation to the question above, the order of which also reflects a progression in terms of the overall discussion. Gerland’s narrative will introduce two themes, firstly, in relation to early understandings of dispositions in terms of strengths and limitations, and secondly, how these may be configured as differences through social encounters in different conditions of habitus and field. The discussion of Lawson’s autobiography will take up these themes and explore them in relation to the author’s ability to experience dispositionally appropriate ways of being, compatible with the idea of ‘autistic emotion’ identified by Davidson (2007). Following on from this, Willey’s narrative will be discussed in relation to how her dispositional ways of being shaped practical strategies and aptitudes, how these were valued in different fields (positively in the school drama group, less so in college), and the implications of these experiences for her understanding of dispositional self. Finally, I will explore Hadcroft’s experience of moving from conditions of chronic isolation, to those within which he could develop a liveable sense of self. His autobiography will be explored last, as it provides a contrasting example to the other narratives here

discussed, in terms of how Hadcroft framed his dispositional self in relation to others. For Gerland, Lawson and Willey, problematic encounters in social life led them to question the legitimacy of their dispositional ways of being, and also to mimic others as a way of negotiating problematic exchanges. In contrast, Hadcroft's response involved a rejection of what he saw as the illegitimate habitus and cultural horizons of his later school years and early working life. This will illustrate the potential variability of responses to problematic encounters in the pre-diagnostic phase, and their implications for understandings of dispositional self.

Analysis of the autobiographies will inform the discussion (in 5.2) in which I will highlight several themes emerging from them: the development of dispositional self in relation to strengths and limitations, configuration of these understandings as differences, importance of variations in habitus and field in shaping the dispositional self, and the implications of this for a person's ability to experience authentic ways of being. I propose that these issues point to some more general concerns in formations of pre-diagnostic self that can be theorised in terms of the relationship between authenticity, accountability and legitimacy as a way of exploring issues associated with the 'double burden'. These themes will carry over into the next chapter, where I will move from exploring understandings of dispositional self, to examine its relationship to reflexive and collective aspects in self-other encounters in pre-diagnostic life. The findings of this chapter will then be

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considered in terms of their relevance to management of everyday insecurities, in chapter eight.

5.1 – Understanding the dispositional self in pre-diagnostic life (Analysis).

5.1.1 – Understanding the dispositional self in childhood (Gunilla Gerland).

In this section, I will explore two themes relating to the formation of Gunilla Gerland's sense of dispositional self in childhood; firstly, her experience of dispositions as strengths and limitations; secondly, the relationship between her dispositional traits and reflexive understandings of self in the development of everyday practical repertoires, and their role in coming to understand dispositions as *differences* through social encounters. These themes will be discussed in relation to an experience of the 'double burden' that relates not only to practical difficulties, but to issues of 'legitimacy' in relation to the dispositional self.

Gerland frames her narrative in terms of a lifelong struggle to become a 'real person': an idea of how one should be, linked to aspects of self which she observed in the behaviour of others and saw herself as lacking. The author recalls that, from

her early childhood, understanding and navigating the everyday world was often a bewildering experience:

I always felt that there was something I didn't really understand. That feeling was constant and followed me everywhere. Even when I understood quite a lot, there was always something left – the actual way it hung together...Sometimes it was all so incomprehensible, I couldn't even find an end in the tangle to pull at. Then I would turn in on myself, knowing neither the question nor the answer...My state was just one colour inside myself. I was the only one who had the colours: I had an internal colour system which became a way of connecting information about different worlds, about the nursery world and the garden world. Everything became a colour inside me – people, words, feelings, atmospheres. Not understanding was faintly orange, a pale orange with sunlight coming through it. Tiredness, what I hadn't the energy to try to understand, came and laid a dark green on top of the orange light and put it out. The dining-room world, the kitchen world and the hall world – none of these had anything to do with each other until a colour made me connect. If my mother said something in a violet coloured way in the kitchen and two months later used that violet tone of voice in the bathroom, I suddenly realised that the kitchen and the bathroom had something to do with each other, so I could begin to find other similarities

such as that there was water in both rooms. But the first connection was always via colours (Gerland, 1997, 21).

Gestalt understanding ('the way it all hung together') was a particular area of difficulty for Gerland, and a cause of significant stress throughout her life. While her synaesthesia ('the colours') provided some contextual connections between places, people, emotions and other experiences, this was attended by the feeling that there was 'always something that [she] didn't really understand' (an example of the chronic unease discussed in chapter two) and an experience of lifeworld compatible with the idea of 'spatial and embodied coherence [being challenged]' (Davidson and Henderson, 2010b). From earliest childhood, Gerland's sense of dispositional self involved feelings of insecurity and precariousness, in terms of how far her perceptual impressions could be trusted. Her sense of which experiences could be relied upon in everyday situations developed as she grew older, and shaped practical strategies, such as theorising what could be observed by sight:

As my visual impressions were very clear and sharp, I connected whatever happened with what I could see. To me, everything boiled down to what I saw, and sight was the most reliable of my senses. It was as if my sight was tangible. I desperately wanted to understand, and this led to theories: if

everything looked in a certain way in the living room – the sun shining through the curtains, the ash-tray on the table with a newspaper beside it – and if Kerstin [her sister] then came back from school...I thought that everything had to look exactly the same the next day, for her to come back from school. It quite simply had to be like that. And in fact, it often was (Gerland, 1997, 26).

Making theoretical connections between different visual elements of her lifeworld provided a route to understanding what was not given to her intuitively; however, the need to ‘consciously sort [her] sensory impressions’ was something that, although practically necessary, could also be demanding and tiring (Gerland, 1997, 193). Another important development in understanding her dispositional traits as a child, was Gerland’s ‘discovery’ of what she refers to as ‘behind’ and ‘inside’: the idea of things existing beyond visible external appearances:

It was an enormous discovery, with equal parts of joy and pain, and it completely took my breath away. I was seven, maybe eight, and it was spring or early summer and fairly warm. I was out in the garden tickling the neighbour’s cat with a piece of grass...The cat, who was called Higgins, was lying almost in the hedge on the neighbour’s garden side. I had to reach in

among the leaves and twigs to get him. I looked up, and I saw the hedge separating our garden from the neighbours; then I looked out over the whole area. As our house was at the top of the hill, I could see a long way, and I glimpsed far off a large handsome house like a palace. It was an old people's home, I'd heard someone say. I saw the houses and the trees, and suddenly light dawned. There's something behind everything! I at once knew how things were inside as well, and that this too applied to everything. Everything has an inside! (Gerland, 1997, 98).

Her 'discovery' of spatial and contextual connections between different places and things had a significant impact on how she came to understand her relationship to everyday environments. In light of her sense that certain aspects of experience were more 'reliable' than others, the idea that 'everything' must have a 'behind' and 'inside' became a rule that was applied globally, as a way of trying to fill gaps in intuitive understanding:

I had previously found it difficult to generalise, and to apply an experience from one area of life to another. I now began to generalise exaggeratedly. I deduced that as behind and inside applied to everything, this was sure to be where the centre of understanding was. It was a matter of taking with you

what you knew. The compartments were not separate. Everything went together. What happened here could also happen there. It was important to try to maintain a thread from one situation to another. This soon became more than a theory – it became a truth that would have consequences for my way of trying to understand the world in the future (Gerland, 1997, 117-118).

These extracts provide examples of how understandings of dispositional self in relation to environments can develop and change over time and generate new ways of understanding and engaging with the world. Both dispositional (e.g. her sharp vision and synaesthesia) and reflexive elements (e.g. her understanding of their ‘reliability’) shaped her practical orientation to social and environment situations, and thereby affected her sense of dispositional strengths and limitations in relation to everyday challenges. This led to the formation of practical repertoires, such as her ‘colour and theory’ system (Gerland, 1997, 27), where her synesthetic impressions formed the basis for theoretical understandings of everyday settings. This evolved over the course of her life, through childhood and adolescence and into adulthood, incorporating new practical strategies; for example, as a child, learning to write provided Gerland with a mode of expression and comprehension which she found easier than speech, offering new strategies such as ‘labelling’:

I enjoyed writing and being good at it. Expressing words in writing was much easier for me than taking the long way round, as I experienced it, via speech. I used to write labels for various things. I wanted everything to be orderly, clear and separate. This was not some way of keeping an inner chaos under control, but an attempt to arrange the external world according to the same system as the inner world, a way of establishing a slightly better accord between me and everything else. Inside me were already closed compartments with labels attached for events, rooms and worlds. Like a computer, these did indeed have a great many ramifications and sub-departments, but the cross-connections were few. Clearly, the worlds outside me would be easier to relate to if I was able to sort them out in a similar way. So I made labels which said what everything was and where it belonged (Gerland, 1997, 53).

‘Labelling’ allowed Gerland to connect her experience of lifeworld (with its clearly ordered connections and ‘closed compartments’) with the external world of objects and places. Learning new skills, finding things that one is ‘good at’ and remaking space in accordance with one’s own dispositions and preferences are activities that are not specific to AS children; however, when viewed in the context of Gerland’s

terms of engagement with the world, these practices have particular significance in terms of learning to cope with everyday situations. Gerland grew up having to deal with social and environmental challenges over and above those typical of non-AS children, and this affected the development of her dispositional self in terms of her practical relationship with the everyday world. In addition, she grew up without a clear understanding of why these difficulties arose, an example of how the idea of the 'double burden' may relate to experiences of pre-diagnostic life for AS people. As well as aptitudes, Gerland's experience of using her practical repertoires also shaped her understanding of her dispositional limitations, for example, in relation to theories, the success of which was dependent upon the stability of what was being theorised:

Of course, there were sometimes exceptions that made me doubt my theory. That doubt was a painful feeling, and I wanted to understand. I was a mental marionette hanging on strings of theories. When the theories didn't fit and I could find nothing new to hang on, I was unable to move mentally. So I had to create new theories all the time (Gerland, 1997, 27).

Theorising was thus not experienced as an unproblematic strength, but as fallible and associated with feelings of precariousness and insecurity (e.g. 'a mental

marionette'). Theorising also involved affective experiences, as indicated by the 'painful' doubts which arose when aspects of the world did not fit with her theory. Her need to understand a world that was often 'so incomprehensible' required a great deal of mental exertion, and the stress associated with this activity increased as the author began to inhabit more varied and complex social and environmental settings (Gerland, 1997, 21). As a young child, strategies such as labelling had allowed Gerland to make sense of the physical world by re-organising it in order to fit her dispositional understandings. However, as she grew older and moved into the field of school, the limits of these strategies became apparent:

[W]hat I saw was what happened, neither more nor less. On these occasions when my theory was sabotaged by things not turning out as I'd anticipated, I had to start a new one...Strangely enough, my theories quite often fitted, although naturally they were entirely wrong. Later on when I was an adolescent, and then an adult, this ability to link situations with visual impressions, or arrange them inside my internal colour system, led to my being able to discover connections long before I saw them – though without being able to explain them. So, of course, in the world of school they became invalid (Gerland, 1997, 27).

Here, Gerland describes changes in her experience of the dispositional self in relation to the everyday world. From an early age, the author had relied upon her 'colour and theory system' and associated practices as a way of navigating problematic environments. This shaped her development of practical repertoires, such as labelling, through which she sought to remake the surrounding world in accordance with her own internally ordered sense of it. However, the success of this strategy was limited by the stability of the environment, and her ability to exercise control over it. When faced with the 'the world of school', with its room changes (1997,127-128), different sets of toilets for boys and girls (1997, 117-118), and noisy classes in which she could not concentrate, the success of these strategies was diminished (1997, 122-123). What had been functional understandings that seemed to 'fit' with the external world suddenly became 'invalid', and this experience had implications for her understanding of dispositional self. So long as Gerland's ways of understanding the world functioned adequately, they were not questioned in terms of their validity; however, in settings where her practical strategies suddenly became problematic, and where others continued to cope without the social and spatial difficulties that she encountered, Gerland began to question not only the strategies themselves but also aspects of her dispositional self. She frames her move into school, and the feelings of confusion and 'invalidity' associated with this experience, as one particular example of not feeling like a 'real person':

I...made a great effort to get rid of particular characteristics, such as my taste for certain clothes. I wanted to be as little different as possible, so I tried to smooth away and bleach out the stronger parts of my personality...I became slightly more accepted at school, but unfortunately this signalled the beginning of a slow change in my view of myself, a kind of poisoning of my self-respect. Previously, when I hadn't thought of myself as a real person, I'd had some sense of belonging, but to a different species. Now I didn't feel like a real person – rather a poor imitation of other people, a kind of faulty copy (Gerland, 1997, 127).

In the 'world of school', Gerland became 'painfully aware' of her dispositions not only as strengths and limitations but as *differences*. Legitimacy thus became an issue in understanding her dispositional self, one that was negotiated with reference to the observable norms of non-AS habitus. The author describes trying to rid herself of dispositional traits that were associated with the idea of not being a 'real person', shaped by her observations of others' behaviour, the 'logic' of which remained elusive. This experience points to a tension in the development of self between conformity with the demands of habitus (i.e. practical demands of social and cultural norms within the world of school) and a sense of an authentic self.

Here, Gerland faced a dilemma, in terms of imitating or conforming to the behaviour of others, or remaining 'different' but faithful to her dispositional ways of being. Imitation and conformity also carried the risk of encountering breaches in social exchanges with others, especially in situations where she was unable to grasp the 'logic' of the behaviours she was imitating. One example of this comes from her relationship with her older sister, Kerstin, in early childhood:

Kerstin was one of the good things in my life. I could play with her, although otherwise I found it difficult to play with other children. I had no clear grasp, even, of the fact that other children existed. Kerstin was older than me, and could guide me a little at play as well as in the world. I could sometimes use her as a model. Out there in the world, I was always half a step behind her and trying to do what she did, and in that way I often succeeded in fitting in a little better. Sometimes I really did walk just behind her and did exactly what she did (Gerland, 1997, 37).

Having Kerstin as a 'model' gave Gerland some practical strategies to hold on to in otherwise confusing social situations; however, it also affected her sense of difference through comparison with her sister's ability to be an 'ordinary child':

[A]s I couldn't be with children I occasionally tried to be with adults.

"Run away and play", they said. But I could neither run nor play.

"Run away and play", they said, as if I were any other child. So I tried to be any other child. No 'any other child appeared', only me pretending to be any other child. I sensed the difference. Oh *how* I sensed the difference, screeching like chalk against a blackboard inside me...I tried and tried and tried. I tried much harder than I really had the energy for. I made such an effort to be another child, an ordinary child – a Kerstin child...I wanted to so very much (Gerland, 1997, 41 - emphasis in the original).

In the 'world of school', imitation carried the benefits of greater 'acceptance' at the cost of 'poison[ed]...self-respect'; with Kerstin, guidance and the 'model' she provided was weighed against the risk of exposing her dispositional limitations, and the painful feeling of difference from her sister as the 'ordinary child'. We can only speculate about what may have happened if Gerland had grown up at a time when the diagnosis was available, in terms of how this would have affected her sense of dispositional self. However, given Ochs et al.'s (2001) work on the importance of managed disclosure in classroom inclusion for HFA children (discussed in 2.1.2), having a diagnosis may have consequences for both self understanding and the way the child is treated by non-AS others.

Gerland's narrative points to two different ways in which the dispositional self may come to be understood in early years for children without a diagnosis. The first of these involves coming to understand dispositions as strengths and limitations, in terms of how 'reliable' different aspects of experience are for dealing with everyday situations. Developing a sense of the body and its aptitudes is of course not something unique to AS children; however, what Gerland's narrative points to is the challenge of coming to understand the dispositional self in relation to a world where one often feels ill at ease. This may be especially relevant for AS people who have grown up without a diagnosis, and in particular those who grew up before knowledge of AS was widespread. Developing a practical relationship to the world is something that all children can be expected to experience, albeit in different ways with respect to variations in environment, culture and biology. However, AS children such as Gerland face additional challenges in terms of practical coping that have implications for understanding the dispositional self. Early formations of self understanding, such as those feelings of 'invalidity' identified in the worlds of school, have consequences for the development of the self in later life (i.e. adolescence and adulthood) (Gerland, 1997, 249). In Gerland's case, this meant internalising feelings of differences as deficiencies which had to be overcome, associated with lifelong feelings of not being a 'real person'.

The second aspect involves a combination of dispositional traits and reflexive understandings in the formation of practical strategies for dealing with everyday challenges, and the implications of these strategies for understanding dispositions as differences. What was not given to Gerland's experience, 'the way it all hung together', had to be approached through conscious organisation of her synesthetic impressions, what she calls her 'colour and theory system'. The development of this strategy in turn shaped her sense of dispositional self, in terms of how that she felt able to deal with the surrounding world. Growing up not knowing why the world was 'so incomprehensible' meant that her resources for understanding were limited to trial and error, or imitation of the 'model' provided by others such as her sister. The success or failure of practical repertoires in everyday settings, and comparison of these outcomes with the observable experiences of others, also shaped Gerland's understanding of her dispositions *as differences*. Moving into different social fields, with changing environments, as well as cultural norms and practical demands of habitus, presented various challenges that could de-stabilise previously successful ways of interacting with the world. This was not only a practical issue, but one of personal and emotional significance, both in terms of how she framed her dispositional self in relation to others, and the type of person she wanted to 'be'. Here we can see an example of how for AS people, the 'double burden' of growing up without a diagnosis can involve both practical challenges and a struggle for a 'legitimate' sense of dispositional self. The author's experiences of

dispositions-as-differences emerged as a result of her comparisons with the experiences of others; her sister as the 'normal child' who could 'go and play' at will, and others who 'fitted in' with the dominant habitus of school, who could navigate its sensory environments seemingly without problem. In the absence of a diagnosis, or any other narrative through which to understand her differences and their impact on daily life, Gerland internalised her daily struggles as evidence that she was 'not a real person', like other people. This is not to state that Gerland's eventual diagnosis removed her desire to be a 'real person'; reflecting on her diagnosis she describes her 'ambivalence' at being diagnosed, indicating that while this had practical benefits, there remained 'at times' this desire:

I am quite ambivalent when it comes to my handicap. I'm happy with what I've got and sad about what I lack. Though sometimes an ability I'm happy to have and which not for the life of me would I want to be without – my sharp vision for instance – can also have a dark side that saddens me. I'm capable of feeling 'I don't want to be like you' and of thinking I have the right to be different, that I like being otherwise. And at the same time, I still want to be a real person through and through and can wish that I could be transformed or that I had been born someone else (Gerland, 1997, 249).

While confusion and feelings of illegitimacy may be aspects of pre-diagnostic experience, being diagnosed will not necessarily remove these issues; however, in Gerland's case, it may offer new ways for her to understand her differences from others, and their implications for her understanding of dispositional self.

5.1.2 – Negotiating the dispositional self at different stages of life (Wendy Lawson)

Gerland's narrative points to the potential impact of changes in environment and habitus on the success of practical repertoires, and their implications for formations of dispositional selfhood in early years. It also highlights the issue of legitimacy in relation to understandings of dispositional self, as indicated by her experiences of not feeling like a 'real person'. In Wendy Lawson's autobiography, legitimacy is also an issue in relation to her ability to freely experience dispositional ways of being that appear highly compatible with notions of 'autistic emotion', highlighted in the works of Davidson (Davidson, 2007). The discussion here will focus on the role of habitus in mediating opportunities to experience dispositionally appropriate ways of being, and the implications of this for understanding the dispositional self in the pre-diagnostic phase of life. Writing of her experience just prior to publication of her autobiography, Lawson describes her lifeworld in terms of a primacy of sensual connection with the physical environment, as well as feelings of removal from the intersubjective realm of differently disposed others. She identifies lifelong feelings

of distance from other people in terms of her meaningful understanding of everyday environments and social situations:

Much of time life is like a video, a moving film I can observe but cannot reach. The world passes in front of me shielded by glass. On a good day, I can smell the flowers and taste the inviting aromas. What I cannot do is fully participate in the complexities of apprehension, interpretation, communication and comprehension (Lawson, 1998, 1).

In common with Gerland, Lawson's dispositional ways of understanding the world involved reflexive as well as dispositional elements, such as her drive to understand puzzling aspects of her lifeworld through study and reason:

Being quite academic and possessing a love for books, poetry and study, I have an insatiable appetite for knowledge. This need to understand the world around me drives me to interact with people and constantly explore their reasoning for what they do, think and feel. (Lawson, 1998, i)

This understanding of dispositional self involves a clear sense of strengths and limitations, and how these aspects of dispositional self made her different from others:

I do not see the world as others do. Most people take the routines of life and day-to-day connections for granted. The fact they can see, hear, smell, touch and relate to others is 'normal'. For me these things are often painfully overwhelming, non-existent or just confusing, but when an experience or emotion is attached to some form of connecting stimuli, such as colour and fragrance, I am more likely to relate to it. My friends tell me most people do not stop and take time to notice the bright colours around them: the colour of a door they are about to open, a wall or sign that happens across their path. They don't stop and stare for ages, lost in the wonder at the 'feeling' the colour evokes (Lawson, 1998, 3).

Here, Lawson describes an experience of the world that is not merely a field within which to perceive and act, but a form of affective connection through which the author inhabits the world meaningfully. The distance which Lawson describes in social encounters with non-AS people is contrasted with the quality of her attachment to the physical world, an experience that is valued and defended in the

narrative. This is indicative of a struggle throughout her life to freely experience these forms of 'autistic emotion', and to understand them as legitimate aspects of her dispositional self. Writing of her early years, Lawson describes her feelings of perceptual and affective connection to aspects of the physical world:

As far back as I can remember, I have been distracted and absorbed by repetitious sounds and movements. I remember on my eighth birthday I received a new red bicycle with shiny silver mudguards. I was oblivious to the birthday tea and celebrations, nor do I remember being excited about my birthday, but I do remember those mudguards. The light gleaming from the silver mudguards seemed to go on forever. It was so intoxicating and I felt so alive. To have that feeling interrupted by so much as a word or an action evoked extreme irritation and anger in me. I hated being disturbed or interrupted when I was involved with some repetitive action that gave me delight. I felt a sense of connection as I watched the shiny mudguards. It belonged to me and I to it (Lawson, 1998, 1-2).

This example illustrates how different perceptual and affective attachments can shape a variety of dispositions towards acting in the world, revealing a 'different logic' that may not be obvious to non-AS observers. In pre-diagnostic life, this

difference in Lawson's dispositional ways of coping with the world had implications for both her practical orientation to social interactions, and for how these experiences shaped her sense of dispositional self. For example, in adolescence, her ways of connecting and relating to others could often be problematic, as she writes:

[S]ometimes at school, especially during my teenage years, I formed strong attachments to certain girls, following them everywhere just to be close to them. The tone of someone's voice or the shape of their smile could lull me. Sometimes it was simply the length of their hair that attracted me and how it shone when the sun's light touched it. Certain people fascinated me, but they were few and far between. Unfortunately, my fascination and need to be close to certain people was not shared by the individual concerned and I was often asked to go away (Lawson, 1998, 40).

In these encounters, dispositional differences shaped qualitatively different practical orientations towards social coordination between Lawson and others. The above is one example of what she refers to as her 'clumsy' attempts at friendship building, for which she lacked the 'know how' (her terms), and which often 'ended in trauma' (Lawson, 1998, 18). Lawson's way of connecting with

others, through 'fascinating' physical traits, put her at odds with the dominant habitus of her peers. At this point in her life, her differences marked her out as 'weird' and 'strange', and she was often excluded from social life (Lawson, 1998, 40-42). Not understanding why this was the case was a source of considerable stress for Lawson (as for Gerland), and the 'cultural horizon' of what was practically appropriate within the dominant habitus remained elusive in many such encounters. This had implications for both her sense of dispositional self and wellbeing, as her growing need for 'connection and friends' in adolescence and adulthood contrasted with distance she felt from others in terms of her ability to connect with them socially.

Lawson's growing sense of distance from others, and increasing difficulties in dealing with the social and environmental situations of everyday life, was intersected by another important factor in her pre-diagnostic experience of dispositional self, which was her diagnosis of schizophrenia as a young adult. Upon leaving school, she found her career choices 'restricted' by difficulties with social interactions, eventually deciding to become a nurse (Lawson, 1998, 64). While this provided her with a sense of 'meaningful' work, Lawson describes problems with integrating into the professional habitus of nursing due to practical issues, for example, dealing with sudden change, and eventually was forced to leave the profession (Lawson, 1998, 72). Having to leave the nursing field was a painful

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experience for Lawson, which heralded the onset of her first mental health crisis, resulting in a suicide attempt and hospitalisation within a psychiatric institution (Lawson, 1998, 75).

In post-diagnostic life, knowledge of her AS-related differences as such presented opportunities for understanding and negotiating breaches in social interactions, an example of which comes from her time as a mature student at university, during practical role-play exchanges in a communication studies module:

“So, Sheila. How do you think that session went?” The words left my mouth in a confident manner. There was a moment’s silence – but it seemed to go on forever.

“Actually, Wendy, it felt like you had no interest in what I was saying at all!” Her words startled me.

“Oh...ummm...can you please explain to me why you felt that way?”

“Look, I know we are only practising and this counselling session is not for real, but what I shared with you is still a real problem for me and yet you seemed not to care. I am feeling quite hurt at your lack of attention and interest!” I felt surprised because I had tried so hard to listen to her.

“Why did you think I was not interested in what you were saying to me?” I replied, trying to stay calm and in control.

“It was very obvious because you did not look at me throughout the session.” Sheila was looking at the ground.

“So, if I look at you while we talk, you feel I am listening, but because there was little eye contact, you felt I was not interested in what you had to say?”

I was finally beginning to understand what she was saying, although the concept was not new.

“Sheila, I’m really sorry you felt this way. Please be reassured that I am interested in you and in what you have to say. The problem here is one of communication. I actually hear you better when I am not looking at you! However, because this is a problem for you I would like you to be patient with me while I learn to work on my lack of eye contact.” Sheila smiled, thanked me for my honesty and said she would not take it personally in the future. She also encouraged me to at least give the appearance of making eye contact during counselling sessions. It was explained that this could be done without necessarily looking at another person’s eyes but rather attempting to look in their general direction now and then, with occasional eye contact at other times. This advice has proven to be an enormous

advantage to me and has been a great helping strategy (Lawson, 1998, 10-11)

What Lawson was able to do in this situation was to renegotiate the practical conduct of a problematic exchange, by rendering that which had hitherto passed as implicit *explicitly*, and thus make it a topic for reflexive renegotiation with Sheila. While changes in her understanding of dispositional self and associated ways of being opened up new ways of approaching social coordination with others, it is important to consider the wider conditions in which this exchange took place. Both parties appear to have displayed interest in and commitment to amicable resolution of a communicative difficulty, and this reciprocal concern was vital in shaping the outcome of the encounter. In addition the cultural horizons of the field appear hospitable to reflexive renegotiation, such that both actors were able to pursue this as a legitimate form of exchange within this setting. In most of the settings she had inhabited up to this point, this does not appear to have been the case.

Reflecting on changes in her understanding of self over the course of her life, Lawson writes of the impact that understanding her AS differences as such had on her orientations to practical activity:

I have begun to realise that my outlook on life is vastly different to that of most other people. I had always assumed everyone operated as I did, and felt about things as I do. Intellectually, I realised that people are individual and different, but it has only just occurred to me *how* extensive is that difference. Over the years, I usually tried to contain my excitement and joy over life's happenings and watched to see what makes other people happy or sad. If they laughed or were unmoved, then this was my signal that it was all right for me to do likewise. This process was hard work and although it helped me to be more observant of others, it robbed me of spontaneity and enjoyment of the richness of my own experience. Today recognition of this fact has freed me in many ways and I now allow myself the choice (Lawson, 1998, 116).

In this passage, the author highlights the impact of changes in her perception of dispositional self, in relation to both her practical orientations to everyday situations, and to her ability to freely pursue and experience her particular ways of connecting with the surrounding world. Previously, she had sensed her difference from others through connections with the physical world and her orientations to social life, for example, as she writes of difficulties in family settings as a young adult:

I could not explain my world to my family and I could not function in theirs (Lawson, 1998, 65).

The role of the diagnosis in this process is difficult to isolate, as while the event is referenced it is not discussed in detail, only general reflections on changes in self-understanding which occurred afterwards are given. The structure of the narrative does provide some indirect evidence of the importance of the diagnosis: examples such as the exchange with Sheila, as well as her reflections on changes in her understanding of dispositional self (1998, 116), all appear chronologically at points after Lawson was diagnosed. Equally however, changes in other aspects of her everyday life also appear to have been significant in this regard, such as entering the more supportive field of the university within which she could renegotiate problematic interactions (Lawson, 1998, 10). Given these circumstances, and the fact that she continues to identify as 'autistic', it appears that the diagnosis had a significant impact on her understanding of self; however, its specific operation in terms of the development of dispositional self relative to other life events, is difficult to isolate.

Like Gerland, Lawson's narrative reflects processes of coming to understand one's dispositions, and how these came to be framed as differences in later years. What

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Lawson's narrative adds to the discussion is a perspective on how a person's understanding of their dispositional ways of being can be mediated by the conditions of habitus and field. In particular, it illustrates how the resources available to differently disposed actors for understanding behaviours that conflict with the dominant habitus can shape opportunities for social coordination. In Lawson's case, her pre-diagnostic experiences in school and the workplace contrast with those such as her interaction with Sheila in post-diagnostic life, in terms of the author's ability to overcome practical difficulties in social interactions. Practical issues in social coordination also mediated opportunities for her to experience the perceptual and affective forms of connection to the world that appear vital to her wellbeing. While it is difficult to isolate its precise impact, being diagnosed appears to have been significant in terms of increased self-acceptance and self-awareness, indicated by its positioning within the narrative. What can be stated is that other factors also appear significant, such as her entrance into fields where she was able to renegotiate practical social encounters, and could offer herself the 'choice' to explore the 'richness' of her perceptual and affective connections to the world. For AS people in the pre-diagnostic phase of life, how they come to understand dispositionally preferred ways of connecting with the world can be mediated by the social context in which one is situated. This relates to both the conditions of habitus and field, in terms of whether or not one's dispositional ways of acting are accepted, and also the resources that both parties have to frame practical

difficulties that arise in everyday interactions (e.g. as something that shapes exclusion, as in the example from Lawson's school days; or as a challenge to be addressed together, as with Sheila).

5.1.3 – Practical strategies, fields and the dispositional self (Lianne Holiday Willey)

In both Gerland and Lawson's narratives, formations of dispositional self involve a sense of strengths and weaknesses in relation to the everyday world. In addition, we have seen how related forms of attachment and coping may be understood in relation to the dispositional self, in terms of difference and their legitimacy within different social settings. Lianne Holiday Willey's narrative presents another example of the variable value of dispositional strengths in different settings, and the implications of this for understanding the self. In particular, it shows how changes in the value of different practical strategies within different fields can affect a person's understanding of the dispositional self. For Willey, an important way of coping with problematic interactions was imitation, something to which she was disposed from a young age:

My mother tells me I was very good at capturing the essence and persona of people. At times, I literally copied someone's look and their actions. For

instance, if a schoolmate began wearing glasses, I would sneak my aunt's so that I too could wear glasses, even though they nearly blinded me. If someone broke their arm, I would come home and complain my own arm was broken, until my mother finally cast it in flour paste (Willey, 1999, 22).

This disposition towards imitating other children was attended by feelings of distance and separation from her peers, in addition to which the effect of her imitations on other children was not immediately understood by the author:

Until I was somewhere around ten years old, I held myself separate from others. I never really compared who I was to who they were. It didn't dawn on me to see myself as a fellow third grader or as a member of a team. I felt almost like I was invisible. I was conscious of the fact that other people could see me and hear me and talk to me, but still I thought I was removed from their domain. I didn't contemplate that they ostracized me; rather, I chose to shut them out. I could stare at them all I liked, never thinking this might annoy them. I could take in parts of who they were and never worry that I was a copy cat... (Willey, 1999, 23).

Though her early and middle school years were marked by problems in relating to others, in high school her experience improved as she discovered new social groups 'defined by shared interests', within which the cultural horizons were clearer (Willey, 1999, 32). For Willey, the performing arts groups provided a setting in which she could experience belonging and involvement with others who accepted her differences. In this arena, her dispositions towards imitation operated as a form of embodied cultural capital, actualised through her talents as an actress, a role which was valued by others within the field and provided Willey with an important sense of belonging and acceptance:

I think cultural and performing arts types must be Aspies. If not, they are surely the next best thing. They are at least amenable friends of Aspies. I found great acceptance among my drama peers, most of whom were extremely tolerant and appreciative of diversities and personal visions. I was able to flourish in such a warm and supportive environment, finding it to be the best place for me to turn many of my AS traits into real and viable assets. In those classes I was inspired by other eccentric thinkers who taught me to think of language as more than a means for expressing simple needs. Finally, I had found a natural place for me to be (Willey, 1999, 35).

The positive experience of life within the performing arts group contrasted sharply with her later experiences in college, where the cultural horizons of social fields again became vague, and her differences marked her out for bullying by peers:

I must have thought the people I would meet in college would fall into my life just like those from my hometown did. But what I never included in my grasp for understanding was the fact that my hometown was more than a group of randomly placed people. It was a group of cohesive friends who had learned, over the course of a good many years, to accept one another for all our quirks and idiosyncrasies. I gave no thought to the possibility that I would move to school and end up any differently than I had ever been, a well-received young woman with some strong academic skills and the respect of my peers. I had no way of knowing college students would be so cruel to those who did not fit in the circle of their normal (Willey, 1999, 42-43).

What had been accepted and valued within the high school field of performing arts was not so within the college environment and this had implications for the practical strategies that Willey adopted in social situations. For example, after graduation, Willey describes a growing sense of needing to 'fit in' with others' ways

of being, and to 'mask' her differences (Willey, 1999, 63). Though beginning to develop a grasp some of the 'rules' which appeared to govern activities in the non-AS social world, their 'logic' remained elusive and as such she was not always able to respond to their demands:

When I hit my mid-twenties I was somewhere between the bright new college graduate and the slightly off-beat lady who talks to pigeons in the park. Truth is, I was both. By then I was fully aware that I would need to mask myself, as best I could, according to the set of circumstances that sat before me. I knew for instance, that I could not talk to myself during a job interview. I knew I would have to dress a certain way in order not to evoke long stares. I understood that it was inappropriate around certain circles to bring up the fact that my home was a zoo filled with dogs and cats. I was beginning to see life more objectively, to realize that though I did not see the purpose in most rules, or more important, the harm in my breaking so many of them, I needed to follow them as best I could. Occasionally I would find someone who would let me make things up as I went along but for the most part I knew people expected me to merge with them as inconspicuously as possible. By my twenties I knew these premises were true; trouble is, I still did not have the mechanisms to comply as often as I might have (Willey, 1999, 51).

Awareness of implicit regularities and demands for accountability, as well as problems in responding to them intuitively, were major concerns for Willey as she entered the field of the job market. While the author was confident in her intellectual abilities, the means by which these competencies and skills were assessed and could be made visible to employers, was a source of concern. In particular, this was an issue in interviews and meetings with unfamiliar others that were often attended by sensory and spatial sensitivities:

People, particularly people I never saw or thought of unless they were sitting in front of me, unraveled [sic] me. They unhooked the calm in me and let loose too many thoughts, too many images, too many questions. My mind would melt amid the noise and the light and the voices and the asymmetrical patterns and the smells and the images, as I desperately tried to attach meaning to every word every person uttered (Willey, 1999, 56).

The sensory and social challenges of unfamiliar situations often required great mental efforts from Willey, as she attempted to maintain a coherent sense of both the physical environment and behaviour of others. In these situations, the author

employed a number of strategies in order to maintain her place in an interaction, for example, during her time as a teacher at the University of Houston:

[B]ack when I taught, I had to fight with myself to stay on track. I would try to keep my eyes very still, concentrating intently on people's faces, but not their gestures. Gestures took on dialogues of their own, making it even harder for me to keep up with the conversation. I would take notes, hoping that if I wrote down everything that was said, I could later piece everything together like a puzzle. Or, I would completely take over the meeting, asserting my own thoughts and ideas, as if I were the self-appointed expert (Willey, 1999, 56-57).

In situations where the dominant habitus involved intuitive sense-making, Willey relied on dispositionally appropriate strategies, such as note taking. While as a sense-making practice this helped her to understand experiences that had been confusing in the moment, the value of this particular strategy in terms of her ability to 'keep up' with the tempo of interactions was limited. The author was then forced to fall back on her 'fitting in trick', as a strategy for holding her space in an interaction:

[W]hen all else failed, I used to rely on a 'fitting in' trick that is nothing more than a sophisticated form of echolalia. Like a professional mimic I could catch someone else's personality as easily as other people catch a cold. I did this by surveying the group of people I was with, then consciously identifying the person I was most taken in by. I would watch them intently, carefully marking their traits, until almost as easily as if I had turned on a light, I would turn their personality on in me. I can change my mannerisms and my voice and my thoughts until I am confident they match the person I wanted to echo. Of course, I knew what I was doing, and of course, I was somewhat embarrassed by it, but it worked to keep me connected and sometimes that was all that concerned me. It was simply more efficient for me to use the kinds of behaviors other people used, than it was for me to try and create some of my own (Willey, 1999, 57).

From the material presented, one cannot be sure of the effect that this strategy had on others, and therefore how 'successful' it may have been in terms of her being able to hold her space or conceal her dispositional differences. What does appear clear is that this was a strategy that Willey used in situations where the social and environmental conditions made it difficult for her to connect with others. This points to a particular understanding of the dispositional self in relation to everyday challenges, in which there is an apparent tension between the ability to cope (in the

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sense of 'hold[ing] her space') and being able to engage meaningfully with the situation at hand. In these situations, her 'mimicry' represented an asset to the extent that it allowed her to cope, but the need to use this strategy also points to her vulnerability to being 'unravelling' by problematic social and sensory experiences. In this way, Willey's narrative provides an example of how understandings of dispositional self may vary within as well as between, different fields and social settings.

As the author's earlier experiences in the drama group indicate, there may be areas of social life into which AS people can enter (with or without a diagnosis) where their dispositional ways of being are accepted, valued, and integrated into the practical life of the field. However, there may also be fields where these same practical strategies and ways of being are incompatible with dominant understandings of habitus, and/or the cultural horizon of fields within which these understandings operate. In such situations, particularly those where the rhythm and tempo of interactions overtakes understanding but calls for timely response, AS people may fall back on strategies which are deployed out of necessity, rather than ideal choice. Understanding the variable success of different strategies in different areas of social life may therefore be a key challenge for AS people, particularly in the pre-diagnostic phase of life. This will have implications for how one comes to understand the dispositional self in relation to different everyday settings. In

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addition, the absence of a diagnosis may restrict the ability of the person to make claims for renegotiation of the practical conditions of social exchanges. This could be, for example, in the context of understanding one's differences and being able to actualise the diagnosis as a form of institutional cultural capital, that confers legal rights (such as those granted by the UK Autism Act, 2009) (Pellicano and Stears, 2011).

5.1.4 - From isolation to a liveable sense of dispositional self (Will Hadcroft)

Thus far, we have seen how encounters with different conditions of habitus and field have affected understandings of self, in terms of how these are framed as differences. For Gerland, Willey and Lawson, these experiences were bound up with issues relating to the legitimacy of the dispositional self, and shaped practical strategies aimed at conforming to what were often confusing social and cultural regularities. Will Hadcroft's narrative provides a contrasting example of how understanding dispositions as differences shaped his relationship with habitus and field. As the final autobiography to be discussed in this chapter, it indicates the possibility of framing the self as a legitimate actor, within a world of illegitimate others, and the potential influence of social and relational conditions on the development of a liveable sense of identity. The discussion here covers two aspects of Hadcroft's narrative, the first in which he maintained a sense of dispositional self

in the face of chronic isolation and bullying, and the second in which three life events (including his diagnosis) allowed him to develop a liveable sense of self.

The author writes that as a young child he was 'perpetually nervous, frightened of everything' (2005, 22), and experienced 'a slight cerebral pause' between perception and action, which led to him being labelled as 'slow' (Hadcroft, 2005, 20; 67). In addition, his dispositional need for clarity and consistency in social situations was significant in many of his social difficulties:

Instant change in speech and behaviour completely baffled me. I would puzzle over the way my peers could be so polite and helpful in the presence of a teacher, and then seconds later be "effing and jeffing" with the best of them. I simply could not get over how easily they turned it on and off. One minute they were in primary-school mode, the next they had metamorphosed into pseudo-teenagers (Hadcroft, 2005, 58).

Hadcroft's early school days were, in comparison with later life, relatively unproblematic, as for him '[b]eing eccentric at that age was not a problem' (Hadcroft, 2005, 29). However, as he grew older, his dispositional ways of being

came up against changes in the habitus and cultural horizons of school, leading to isolation and bullying in his middle and senior school years. One important source of comfort during this period was his faith as a Jehovah's Witness, and in particular his identification with the figure of Jesus Christ:

The serialized film *Jesus of Nazareth*... had me spellbound. The personality of Jesus as depicted in the series was a potent one. I was struck by his charisma and the way he taught. Most of the time he was gentle and loving, but on occasion he would get angry and shout, most notably at the hypocritical religious leaders...[his] death in this film is depicted in a realistic fashion, and the overall message of the story hit home: If you're going to be different and go against the tide, the world will hate and reject you. I took the principle to heart because deep down I knew I was different to my peers. It wasn't just my religious ideas, but my interests and obsessions. I had quite a lot of friends during this period of my life but sensed I was slightly at odds with them. I felt like an alien, as though I had come to earth from somewhere else (Hadcroft, 2005, 36-37).

For Hadcroft, the figure of Christ was someone with which he could identify through his reflexive understanding of virtue, as well as a life story that resonated with his

own experiences of isolation, misunderstanding and rejection. In addition to the personal figure of Jesus, the cultural field of the Jehovah's Witnesses helped him to develop a sense of collective identity and community, within which he could experience a sense of belonging:

[T]he appeal for me at the age of 12 was the pure defiance they showed in the face of orthodoxy. I despised and loathed the system of the world, with its fashions and trends and flimsy ideas and philosophies, its media and social conditioning. The idea of a heavenly father watching over me was also potent. It put paid to the notion that we were so small in the universe, that we were insignificant. It also helped me cope with the bullies. [An older Witness] encouraged me to pray for the strength to endure, and she gave me a Bible text to meditate upon as a means of comfort...I felt at home with them. They were my people. I was safe with them (Hadcroft, 2005, 79).

This is one example of how his dispositional ways of understanding the social world combined with the cultural values of his religious and home life, in shaping not only his practical sense but also his reflexive understanding of appropriate behaviour. In this way, Hadcroft's identity developed both in relation to his dispositional sense of

self and his reflexive identification in both individual and collective terms with the religious life of the Jehovah's Witnesses. Notwithstanding episodes of bullying, and moments in which his differences were rendered acutely 'visible' in interactions with his peers (2005, 91), school life also provided positive situations within which he could experience a liveable sense of self, such as his friendship with another boy, Ian (2005, 90-91). However, his experience of 'rowing against the other boats' in everyday social interactions intensified as Hadcroft entered the world of work, as he writes of his first job at a local superstore:

I was very conscious of the girls sniggering and pointing. They were in their late teens or perhaps their early twenties, plastered with make-up, hair bleached white, and poisoning the air with their foul language. I was a laughing stock again, and on that very first day the awful truth dawned on me: the working world was actually no different to that of school. I had been looking forward to joining the outside world because I thought it was the world occupied by my grandparents, my aunts and uncles, and my mum and dad: a world where people are responsible and civil, where being "different" is readily accepted as part of the tapestry of life. But I had been duped. This was definitely not the world where people watched their Ps and Qs, and I began to realize, slowly but surely, that the illusion presented by the adults in my family was precisely that, an illusion (Hadcroft, 2005, 121).

Hadcroft's move from school into the world of work marked the beginning of a problematic period of life, during which he experienced frequent ridicule from others at work, and also chronic isolation. While aspects of school life had provided a counter to experiences of bullying and his sense of difference from others, few such opportunities arose in working life, and this experience needs to be understood in relation to both his dispositional and cultural aspects of self. In the field of the superstore, reflexive (i.e. his cultural beliefs and values) and dispositional (i.e. his difficulties with coordination and the slight 'cerebral pause') elements of self combined both in his distinguishing of himself from his colleagues, and how he was framed by others. These played out in relation to both his practical abilities (e.g. he was labelled a 'balloon' – someone who 'holds others up' due to their slow pace of working) and cultural values (e.g. his behaviour he was labelled a 'virgin', and his masculinity and sexuality were questioned and mocked by women in the workplace) (Hadcroft, 2005, 121-122) .

Hadcroft's experiences in the world of work also point to the potential importance of class cultures in developing understandings of self. Hadcroft self-identifies as 'working class', describes having grown up on a council estate, and is writing of his experiences in workplaces that typically involve semi or unskilled employment. In

addition, the values and interests that were valorised within the cultural field of the superstore, such as, drinking, football, and being 'quick' to grasp the hidden meanings and double entendres of workplace banter (Hadcroft, 2005, 119-123), are consistent with those observed in other working class cultures of work at the time (see Willis, 1977). There is little direct evidence in terms of overt displays of class culture (for example, explicit use of class-related language) in Hadcroft's discussions with colleagues; however, this is perhaps unsurprising given that, as argued in chapter three, habitus can often function through tacit understandings and performances, with which Hadcroft describes difficulty. Notwithstanding these limitations, the circumstances of Hadcroft's life and the observations he makes regarding the processes of distinction and teasing that he experienced, point to the potential significance of class culture in this process, not only as a factor in itself but also in terms of its intersections with other aspects of habitus such as gender norms:

For the first few weeks I was a subject of idle mockery, with various staff members commenting on my crippling shyness, the fact I was still a virgin, the fact that I didn't share any of their interests. A lad not passionate about football? How strange. He still watches Doctor Who at his age? Even stranger. The girls would encircle me and ask me embarrassing questions.

“Is it true you’re still a virgin?”

Just look at the floor.

“Yes, that’s true.”

“Even though you’re 17?”

“Yes.”

“Why?”

Just look at the floor.

“Beck’ll let you go with her, won’t you Beck?”

Beck’s shaking her head in mock denial. Just look at the floor.

“Haaa! He’s blushing!”

I wish I were dead (Hadcroft, 2005, 121).

The nature of the bullying and teasing to which he was subjected appears to suggest transgression of cultural norms relating to heterosexual masculinity (Hadcroft, 2005, 149, 27, 31). Hadcroft’s identification with the moral and ethical life of family and church appears at odds with the embodied performances and markers of cultural credibility that were valued within the field of school. In

addition, performative aspects of his presented identity, such as his self-described 'pedantic' and 'aloof' manner of speech, led him to be accused of thinking himself 'better' than his co-workers (Hadcroft, 2005, 60). This again needs to be understood in terms of the pre-diagnostic phase of life, in which Hadcroft was not only baffled at times by the practical 'logic' of social life, but was also unable to provide a counter-narrative sufficient to overcome or renegotiate the practical and cultural regularities of the field (i.e. which may have been available to a person with a formal diagnosis). What it indicates is that social position may provide vital clues to understanding particular forms of exclusion in differently situated AS people, which have implications for understanding and presenting the self in the pre-diagnostic phase of life.

It is not possible to ascertain from this extract the precise causes of the difficulties Hadcroft faced, for while he certainly appears to have suffered bullying and teasing at the hand of co-workers, he also acknowledges that his 'aloofness' and 'pedantic speech' may have played a role in distancing him from his colleagues (Hadcroft, 2005, 122). In addition, while the nature of the teasing aimed at Hadcroft appears to relate to transgression of norms associated with practical aptitude and gender, it is clear from the extract that he also operated with his own understandings of what constituted 'appropriate' behaviour, particularly for the young women in the superstore. What the extract does offer is an example of how in the pre-diagnostic

phase of life, Hadcroft came to understand and experience differences from others through a combination of dispositional and reflexive factors.

Hadcroft's disappointment with the cultural life of the superstore, compounded by experiences of bullying and isolation, reinforced a sense of self defined in opposition to the habitus of workplaces that were seen as both practically alien and morally objectionable. It is also important to consider the impact of Hadcroft's dispositional attachment to express communication and consistent behaviour in terms of how he understood appropriate or legitimate ways of being. For Hadcroft, clarity and consistency were not only conditions of meaningful connection with others, but of legitimacy in social relations. Differences in interests from those of his peer group, opposition to what he saw as the dishonesty of others, and the bullying co-workers were all persistent sources of stress for Hadcroft during his early working life:

It's exactly like school, but without the teachers. It's worse...They're false. They're all false. The world is one big lie. Two-faced. One thing in one set of circumstances, completely different in another. Everyone is acting. I hate it. I wish I were dead. For the first few weeks I was a subject of idle mockery, with various staff members commenting on my crippling shyness, the fact I

was still a virgin, the fact that I didn't share any of their interests (Hadcroft, 2005, 121 - emphasis added to denote internal monologue).

In the face of chronic isolation and teasing within the workplace, Hadcroft turned to a range of cultural resources which, in addition to his spirituality, provided both a means of escape and a narrative through which to make sense of his isolation. One such example was in his identification with the plight of the central character in the 1960s television series, *The Prisoner*:

It really did seem to be me versus the rest of the world. I confided in my pen pal Dominic, and in response he sent me a video to watch. It was of the 1968 television series *The Prisoner*, starring Patrick McGoochan. He thought I might identify with it, and boy was he right! *The Prisoner* tells the story of a government agent who turns his back on the world system and becomes resigned to maintaining his individuality. While at home, packing for a much-needed holiday, he is rendered unconscious and then imprisoned in a strange island community called the Village: a bizarre parody of the world he thinks he's left behind. There are a lot of colourful people in the Village, but no one is identified by name, only by number...Certainly I was feeling trapped, as though I was the poor subject of some sick joke and that the

whole world was in on it. The more they laughed at me, the more I resisted them. The more they tried to make me conform, the more I was determined not to crack.

“I will not be pushed, filed, stamped, indexed, briefed, debriefed or numbered.” I had found a new lifeline (Hadcroft, 2005, 151; 153)

The line quoted in the penultimate sentence comes from the central character’s statement at the beginning of every episode, a statement of resistance against the oppressive and conformist machinations of the island’s controllers. In addition to *The Prisoner*, Hadcroft also developed intense interests in the series’ *Dr. Who* and *The Tripods*, in the latter in which an alien race achieves a clandestine takeover of the earth, while the human population are kept from realising the true nature of their fate by an implant which prevents critical thought. This narrative device, known as ‘capping’, provided Hadcroft with another concept through which to make sense of his isolation (Hadcroft, 2005, 152). The use of fictional narratives as cultural resources for understanding reflexively his isolation, and for maintaining a personally justifiable sense of self, also appears to have been important in relation to his mental wellbeing, as indicated in a recollected exchange between Hadcroft and his psychologist in later life:

“Right”, said Stephanie...as I arrived for my second appointment...

“First of all, you’re not mentally ill.” Phew, that’s a relief.

“Second, your attachment to Doctor Who.” Oh no, here we go.

“If you hadn’t have used Doctor Who and the other sci-fi stuff as a means of escape, you almost certainly would have been mentally ill.” This was quite a revelation for me, as I’d been struggling with guilt feelings over the way my obsessiveness had intruded on the lives of my brothers, and in particular my mother. I told that one to Mum, and she accepted it (Hadcroft, 2005, 188).

These ‘obsessions’ were, for Hadcroft, both an expression of his dispositions toward focused attention on a particular subject, and at the same time a set of resources for maintaining a reflexive narrative of self in problematic conditions (Hadcroft, 2005, 226-228). Special interests and detail focused attention are known to be common in AS people, and are often important both as a source of practical involvement and a valued aspect of self (Baron-Cohen et al., 2009). What Hadcroft’s example illustrates is how these interests can also provide resources for understanding the dispositional self, particularly in conditions of isolation. This may be of particular importance for those who have grown up without a diagnosis, in terms of providing a way of understanding their differences from others.

While his special interests were important in circumstances where the author had little else to turn to, these were not unproblematic, as indicated in the previous quote. Cultural resources provided a means of 'escape' and narrative justification of isolation; however, they did not provide the author with a sense of belonging, acceptance or the resources to maintain a liveable sense of self. What allowed this to emerge was the progressive experience of three life events, the first of which was meeting his wife, Carol:

This was completely new for me. I was wanted and loved, not for any other reason than for simply being me. Carol had a sense of being whole too. She loved my candid honesty, a quality that some had interpreted as bombastic and arrogant, but that she viewed as pure. There was no hidden agenda, no secrets, no other life going on behind her back. I said what I meant and I meant what I said...My girlfriend had filled a massive chasm of loneliness and despair. While I still loved those interests, I no longer needed them to survive...The stark loneliness which I had experienced since puberty had been unbearable, to the point where I had been trying to think of ways to commit suicide. Companionship was what I needed more than anything else – to be loved for who I was, warts and all, and to give love (Hadcroft, 2005, 171-172).

Hadcroft and Carol were married in August of 1993, when the author was twenty three. While the companionship and love experienced in his relationship with Carol appears to have significantly improved the author's wellbeing, it did not erase the difficulties which Hadcroft faced in everyday life. Social issues at work, exacerbated by continuing mental distress in the form of depression and anxiety meant that the author continued to experience periods of chronic mental distress (Hadcroft, 2005, 202). After being made redundant from his position at a soft drinks factory, an event which he greeted with ambivalence (not knowing 'whether to burst into tears or jump for joy'), Hadcroft turned to creative writing with the intention of becoming an author (his first novel, *Anna Droyd and Century Lodge*, was published several years later in 2002) (Hadcroft, 2005, 210). In addition to achieving one of his 'dreams', publication of his novel also appears to have been important in making sense of the dispositional self. Writing provided him with a sense of fulfilment, a positive aspect of his identity and a practical means through which to explore his experiences of difference. Becoming a published author and marriage to Carol were two of the key events which Hadcroft describes as the 'pieces falling into place'; the last of these being his AS diagnosis. Although the author does not discuss the event itself, he describes the implications of understanding himself as AS as follows:

It all made perfect sense and I had an overwhelming feeling of completeness and, in a way, a new-found confidence... I set off to see my GP, Dr Tauk [Hadcroft's GP] once again, to set the ball rolling in my quest for an official diagnosis. It all made perfect sense and I had an overwhelming feeling of completeness and, in a way, a new-found confidence. Stephanie and Suzanne had defined the individual traits and had taught me how to combat them, but no one had ever come up with a satisfactory explanation as to why these problems had existed. But now it was crystal clear. I regressed myself back through key moments of my life and suddenly all the pieces fell into place. I considered the themes I had explored in my novel *Anne Droyd and Century Lodge*: being different in a world that demands conformity, and Anne Droyd's difficulties in understanding and accepting the things we all take for granted. She is the epitome of the Asperger child. It slowly dawned on me that I had been writing about Asperger Syndrome without knowing it. Today I am feeling better than ever. Still at odds with what I see going on around me, still at odds with myself, but better at dealing with it, better at understanding it. The chip has well and truly been knocked off my shoulder (he says humbly!), I have learned to respect people and I always try to see why they think what they think, even if I can't agree with it. I'm getting on with my life. The job, the people skills, they're getting easier by the day. I have friends. I have my best friend. I have my soul mate. I'm looking to the

future. I haven't had a genuinely suicidal thought for well over a decade.

You know, I think I'm going to be all right (Hadcroft, 2005, 230-231).

It is difficult to isolate the specific impact of the diagnosis in terms of Hadcroft's development of a liveable sense of self; however, what is apparent from the quote above is that it was one among a number of important life events through which he was able to overcome the isolation and unhappiness of earlier years. The difference is illustrated by comparison with an event in his later school years, where a girl in the playground had asked him the question 'why are you weird?', to which he replied, 'I don't know' (Hadcroft, 2005, 92). This exchange indicates that, although the author understood himself to be in some way different from others in dispositional terms in the pre-diagnostic phase, the reasons for these apparent differences eluded him. However, following his marriage, publication, and eventual diagnosis Hadcroft's sense of dispositional self was one in which the difficulties associated with AS were manageable. The statement that 'the chip had been well and truly knocked off' his shoulder, and that he had 'learned to respect' people, also points to a reflexive realisation of the potential impact of his dispositions and cultural values on how he framed others. In this way, Hadcroft's narrative provides a contrast to the other narratives discussed in terms of his understanding of dispositional self in relation to others. For Gerland, Lawson and Willey, their dispositional ways of understanding and acting in the social world came up against a

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range of different practical 'logics' in the dominant (non-autistic) habitus of everyday settings, leading them (in various ways) to experience their ways of being as illegitimate. While Hadcroft's dispositional ways of being also came up against the norms of dominant habitus (in school and the workplace), these encounters were experienced in the context of himself as a legitimate 'outsider', amidst a world of illegitimate 'insiders'. In Hadcroft's narrative, his differences and difficulties were interpreted through various lenses (such as the biblical account of the life of Jesus, and the narratives of science fiction) as a way of justifying and making sense of his isolation.

This is important because it points to the potential heterogeneity of pre-diagnostic experiences, in terms of how the dispositional self may come to be understood by different people in different circumstances. Hadcroft's narrative points to several factors in which this variation may manifest. One of these is the importance of social position, specifically the habitus of school and the workplace with their interplay of gender and class-based regularities. Throughout school and working life, Hadcroft's dispositional differences were interpreted by others as markers of 'aloof[ness]' and he was a regular target of bullying. For his part, Hadcroft's response to this was to reinforce his embodied and cultural dispositions, opposing them to what he saw as the 'vulgar' activities of other children and colleagues. Opposition to the habitus of school and the workplace thus involved a combination

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of different dispositional aspects of self (i.e. AS ways of being with those conditioned by family and church) in reflexive negotiation of self-other relations.

Another important theme is the role of Hadcroft's special interests (both spiritual and cultural) not only as forms of personal involvement but as resources for making sense of his isolation. The author's reflexive identification with the figure of Jesus Christ, and later encounters with the narratives of *The Prisoner* and *The Tripods*, provided him with resources for framing and legitimating his isolation from others. Finally, Hadcroft's experience of the diagnosis was one that, while largely positive also illustrates the need to understand its impact in biographical terms. While having a diagnosis provided him with both a narrative for understanding his dispositional differences, as well as a resource for re-evaluating previous life events, these developments need to be understood in the context of both his marriage and becoming a published author. They are events that had already provided Hadcroft with experiences of companionship and fulfilment which had helped mediate feelings of isolation and inadequacy, and improve his mental wellbeing.

5.2 –Discussion.

Growing up as an AS person, and coming to understand the dispositional self in a world of others who often behave in ways that may be confusing, is often challenging for those who are diagnosed in early life; however, for those who live for long periods undiagnosed, understanding one's differences from others and the events of life, can be especially difficult without the resources for developing self-acceptance and biographical coherence that a diagnosis can provide (Molloy and Vasil, 2004; Bagatell, 2007). The discussion of the four cases shows that even within what is a small group, there is considerable variation in pre-diagnostic experiences, and their implications for how one comes to understand their dispositional self. However, there are some general themes that emerge; one of which is how early understandings of dispositional self, that emerge in terms of strengths and weaknesses, are configured as differences, with associated feelings of distance and illegitimacy, as the person meets with different forms of habitus and field in everyday life.

In each of the monographs, disconnection and distance between the self and the worlds of others is a strong theme, as reflected in their respective titles (*A Real Person, Life Behind Glass, The Feeling's Unmutual, Pretending To Be Normal*,). In early years, dispositions may come to be understood in terms of strengths and

limitations in dealing with everyday environments and social encounters, for example, Gerland's 'sharp vision' and difficulties with making gestalt connections (Gerland, 1997, 249, 50), Lawson's perceptual and affective connection to the natural world and difficulties with 'apprehension, interpretation, communication and comprehension' (Lawson, 1998, 28, 1), and Willey's ability to 'captur[e] the essence and persona of people' matched against feelings of 'remova[al] from [the] domain of others' (Willey, 1999, 22, 27). As the authors grew older, particularly as they moved into wider fields of school and the workplace, and often as a result of difficulties in connecting with the demands of the dominant habitus, aspects of their dispositional selves became associated with feelings of difference and separation from others. One example in Gerland's narrative is her move into the 'world of school' as a young child (Gerland, 1997, 146); in Lawson's writing, this emerges in her later school years and early working life (Lawson, 1998, 16, 40). Willey experienced this as she moved from the high school and the accepting field of the drama group, to college where the regularities of social life were not as accommodating (Willey, 1999, 35, 51). For Hadcroft, 'being eccentric' at an early age was contrasted with later problems in school and the workplace, when his differences marked him out as 'weird', and a target for bullying (Hadcroft, 2005, 29, 91). The timing of these events, and the quality of the experiences associated with them, appear variable; however, what appears consistent is the role of encounters with habitus and field in the development of the dispositional self.

This is of course not something unique to AS people who were diagnosed in later life, as the importance of these factors has been noted elsewhere in work relating to those diagnosed in earlier years (see 2.1.2). The precise impact of the diagnosis (and its absence) is often difficult to isolate in these narratives, due both to the variability in the degree of reflection provided on the diagnosis specifically, and also how it intersects different life events. However, if we compare the narratives here considered with existing literature on the impact of the diagnosis in those diagnosed earlier in life (as discussed in 2.1.2), one can see that issues of self acceptance and biographical coherence upon which the diagnosis is indicated to have a positive affect are especially challenging for those living without a diagnosis.

Beyond the practical difficulties in dealing with everyday environments and social situations, the authors' pre-diagnostic experiences are marked by feelings of difference and confusion from the worlds of others, and these have implications for understanding the dispositional self. One way in which this operates is in restricting opportunities for dispositionally appropriate practices and experiences to emerge, for example, Lawson's feelings of 'fascination' with the physical world and the problems this created in relations with other school girls (Lawson, 1998, 40). Lawson's terms of engagement with this situation appear different from those of

the other girls, and as such renegotiation by both parties appears to have been necessary in order to overcome the breach in the interaction that arose. There are indications, for example, in Lawson's exchange with Sheila (Lawson, 1998, 10-11), that the post-diagnostic phase is one in which an understanding of dispositional differences from others, in tandem with greater self acceptance, can create space for renegotiation of the practical conduct of potentially problematic interactions. While the potential for renegotiating habitus cannot be reduced to greater self understanding on the part of the AS person (i.e. it would still require both the actors and cultural horizons of an interaction to be amenable to this renegotiation), it does appear significant in mediating opportunities for avoiding the kinds of exchange associated with social exclusion in the narratives. One way in which this process relates to the dispositional self is in terms of how encounters with habitus and field shape understandings in relation to legitimacy. Here, habitus appears to play a vital role through the accountability relationship, where personal feelings of validity are mediated by the congruence of dispositional ways of being with accepted norms, and the cultural horizons of 'what one can get away with' in a given field.

In Gerland, Lawson and Willey's narratives, pre-diagnostic understandings of dispositional self are associated with feelings that can be characterised in terms of illegitimacy, in the face of problematic encounters with others. In each case, this

led to feelings of wanting to be more like others (in opposition to dispositional ways of being), but not knowing how to comply with the expectations that would allow this to happen, or being able to renegotiate the conditions of interactions in order to accommodate their differences. Hadcroft's narrative does provide an exception to this, pointing to the possibility of seeing the dispositional self as 'legitimate' amidst a world of 'illegitimate' others. However, it should be noted that Hadcroft's sense of self was not without tensions, as indicated in his response to the question, 'why are you weird?' ('I don't know') (Hadcroft, 2005, 91). He acknowledges a sense of difference, but at the same time maintains a sense of self rooted in his own expectations of appropriate behaviour, through which he frames both his own ways of understanding and acting, and those of others. In the wake of his marriage, publication of his novel, and AS diagnosis, Hadcroft's understanding and acceptance of others also appears to have increased. This points to the possibility that for some AS people, diagnosis may be important in understanding the ways of being of others, in addition to their own.

It is important to bear in mind the historical context of these narratives, and the implications of this for the authors' experiences of coming to understand the dispositional self. In addition to the absence of formal diagnosis, all three authors also grew up at a period in history when AS was not widely understood, and so

opportunities for making claims of difference may have been restricted. Common understandings of autism were focused on children with cognitive impairment, and few would have made links between the authors' behaviour and AS (Attwood, 2007; Baron-Cohen, 2008a). In addition, most of the experiences described take place prior to the emergence of autistic communities, particularly those online, which (as discussed in chapters one and two) have been significant for AS people in developing a sense of self-acceptance and legitimacy in relation to their own experience.

Notwithstanding these qualifications, the themes here discussed do point to some wider considerations that may be useful for framing and exploring pre-diagnostic understandings of dispositional self for AS people more generally. The concept of the 'double-burden' points to two aspects of experience (practical issues and biographical coherence) that may arise as a result of living with an undiagnosed condition (however, as discussed in 2.1.3 this term should be used with caution, due to its origins in relation to conditions more appropriately described as pathological). I suggest that the themes emerging from this section can usefully be theorised in terms of the relationship between authenticity, accountability and legitimacy:

- **Authenticity** - Particularly in early years, an AS person may develop a sense of the dispositional self in terms of particular strengths and limitations. This is not simply a practical issue, but one that can involve affective experiences and forms of connection or 'autistic emotion'. Often, these are not 'visible' to non-autistic others, but are important and valued aspects of the AS person's experience. In the pre-diagnostic phase of life, potential resources of self-acceptance and the biographical coherence that this may provide, are limited not only for the AS person but for others. This can constrain opportunities for mutual understanding, and for 'making space' for these ways of being within the practical life of everyday exchanges. Thus in the pre-diagnostic phase, a person's ability to experience and express ways of being that feel 'authentic', and not simply a copying of another person or 'pretending to be normal', may be restricted.

- **Accountability** - Later experiences of coming up against differences in the habitus and cultural horizons of fields (e.g. what Hadcroft calls 'rowing against the other boats') can involve difficulties in being able to enter relations of accountability with others. Here the 'logic' of what goes on in problematic interactions may be vague and confusing. The ability of the AS person to understand and respond to 'calls to order' can be restricted, in

terms of their ability to provide the necessary 'commentary' on their experience, and to grasp the 'logic' of the how and why they are being held to account by others.

- **Legitimacy** – Problems with the accountability relationship have implications for legitimacy. For some AS people, in the absence of a narrative such as formal diagnosis by which one can make sense of and account for their differences in everyday exchanges, feelings of difference and distance, compounded by social isolation, can cause a person to internalise these experiences as evidence of the illegitimacy of their dispositional self. This may lead to attempts to erase their differences, and conform to the ways of being of others through imitation. The success of these strategies may be limited, and can have further negative consequences for understandings of dispositional self. In other cases, a person may come to understand themselves as a legitimate actor amidst a world of illegitimate others. This may further compound existing experiences of isolation, with implications for social and mental wellbeing. In the narratives here considered, the impact of diagnosis on understandings of the dispositional self is variable and often difficult to isolate, and so it should not be thought of as something

that will suddenly resolve all issues relating to legitimacy. However, it may help the person to develop understanding, both of their dispositional selves and self in relation to others, such that they are better able to negotiate relations of accountability, and thereby carve a space of legitimacy for experiencing authentic ways of being.

As indicated in the introduction, the discussion in this chapter and the next overlap in understanding the development of pre-diagnostic selves. In this chapter, I have focused on how four of the authors came to understand their dispositional selves in the pre-diagnostic phase of life. In the next chapter, I will explore on how the identities of three other authors were affected by relations with others, where I will move from focusing on the dispositional self to explore its interrelation with others (reflexive and collective) aspects.

6 – How do self-other relations affect pre-diagnostic understandings of self?

Having discussed pre-diagnostic formations of dispositional self, in this chapter I move to explore how these relate to other aspects of self (reflexive and collective) in negotiation of self-other relations. Firstly, I will explore Jeanette Purkis' experience of moving through a range of different 'selves' in different fields of her lifeworld. Her writing calls attention to how dispositional aspects of self may combine with others, such as collective identities, in an overall sense of self, and also the importance of cultural resources in framing opportunities for social participation. Secondly, I will discuss Jen Birch's experience of moving through different iterations of gender and sexual identity, and the significance of finding a term (androgeny) to describe her sense of difference from others. This discussion will show how in addition to dispositional aspects of self mediating opportunities for connecting with different social groups, understandings of dispositions may themselves be configured by social participation within the 'cultural horizon' of different fields. Thirdly, I will explore John Elder Robison's understanding of 'logical empathy' and how this operated as a form of distinction between his way of relating to others with those of differently disposed others. This will serve as a contrast to the discussions of positive identification in the narratives of Purkis and Birch, by showing an example of how pre-diagnostic understandings of the self in relation to others can be shaped by reflexive understandings of dispositional

differences. Following on from this, I will discuss some more general themes arising from the autobiographies in terms of how dispositional aspects of self may combine with reflexive and collective elements in formations of pre-diagnostic identities. Finally, I will explore the implications of the discussion in this chapter for the concepts of authenticity, accountability and legitimacy introduced in the previous chapter.

6.1 – Formations of pre-diagnostic self and self-other relations (Analysis).

6.1.1 - Rules, 'selves' and fields (Jeanette Purkis)

Jeanette Purkis' autobiography provides a point of connection between the discussion of the dispositional self in the previous chapter, and its relationship to reflexive and collective aspects of identity in the context of self-other relations. It illustrates how dispositional aspects of self can mediate participation in different collectives, in terms of their compatibility with the practical life of the group. However, it also shows how the conditions of habitus and field, and the cultural resources available in different settings, are also important in this process, and how dispositions may not necessarily override other aspects of identity. In addition, Purkis' narrative indicates that forms of reflexive and collective identification can play a vital role in shaping how the dispositional self is understood and presented to

others in pre-diagnostic life, and in particular whether or not these are seen as legitimate by others in different fields.

One of the central themes in Purkis' narrative is what she refers to as a 'search for the rules' for how one should act in the social world (Purkis, 2006, 25). This involved a series of different 'identities' (her terms) each of which 'belong[ed] to a particular group with its own set of rules' (Purkis, 2006, 186), framed in terms of practical dispositions towards 'reason and logic' (Purkis, 2006, 191-2). These dispositional tendencies were configured in different ways during her life, often with radically different outcomes in terms of her reflexive and collective identity, and presentation of self to others. Writing of her early childhood, Purkis describes her life as being split between the 'world of family and home', and other fields such as school. The contrasting nature of these fields involved oppositions of safety and clear 'rules' (family and home), with vulnerability and vague social regularities (school). In childhood, her sense of collective identity was rooted in the 'world of family and home', which included the Christadelphian church, wherein the rules of social life were clear and provided her with a sense of security (Purkis, 2006, 41):

Although some of the expectations of my church seemed a little onerous and even illogical, I liked the structure that being a Christadelphian imposed

on all walks of life. I liked to know that what I believed was right, to not have to debate morals, as that had apparently already been done. My absolute belief that if I followed the specific set of rules laid down by the church I would be guaranteed a better life in the next world was very comforting for someone as bound by rules as I. To me, God was the ultimate authority figure and I had a direct link to him. I would pray for at least 40 minutes each night before going to bed. God became my friend and confidant. I told him things no one else knew, knowing that he would understand. As my teachers were authority figures I could befriend, to me, so was God. I decided to be baptised into the Christadelphian church. After baptism I would be called 'sister', I would be allowed to take communion with the other adults, I would no longer be a child in the eyes of God even if I was in the eyes of everybody else. I learned all the correct responses to the questions the older 'brothers' of the church asked me. While I knew the rule book backwards, I had little knowledge of the concepts the church elders spoke of: commitment, love, forgiveness, mercy. I tried as hard as I could to feel something about what I was doing, but the closest I came to understanding was to think of myself as a white-board covered in red marks left by my sins and then imagine God wiping the board clean the moment I was baptised (Purkis, 2006, 40-41).

Here, Purkis writes of a dispositional 'rule-oriented' self is implicated in a reflexive project in which she draws on the cultural resources of the field, and aspects of collective identity. She also highlights some limits in the collective aspect of Purkis' involvement in the church, which appears to have been motivated more by her dispositions towards 'rules' and the comfort provided by her experience of connection to God, than by any shared sense of the meaning in relation to the cultural life of the church. This provides an example of how for some AS people, collective aspects of identity may be configured by dispositional aspects of self which shape the quality of practical connection to the group. The passage is indicative of what would, for much of her life until her eventual acceptance of her diagnosis, be a constant tension between compliance with the 'rules of the game' in different fields, and meaningful connection with the life of the group. Further evidence of this appeared during a period of internal conflict over church doctrine, an event which precipitated the first of her major shifts in identity:

My world seemed to have broken in two. I had always known what the rules were and that the church I had been raised in, and to which I belonged, knew all the answers. Now there seemed to be no certainties and people who had once respected each other and seemingly agreed on fundamental truths were now arguing with each other. I attended many tense church meetings and began to realise that the Christadelphians, who I had once

thought had the answers to everything, were disappointingly as human as everyone else (Purkis, 2006, 42).

The disruption of 'truths' which underpinned the rules of the church also undermined the reflexive and collective aspects of her Christadelphian identity; by destabilising what were previously clear regularities and cultural horizons. This sense of disconnection can also be framed in terms of a connection between accountability and legitimacy. Where the 'rules' were clear to Purkis, she was able to participate in relations of accountability with others and thereby engage with the habitus of the church on the practical level. In so doing, she could experience a sense of legitimacy in relation to her acceptance within the cultural life of the field. However, with the breakdown of clear regularities within the church, Purkis sought other 'rules' within a different field:

My interest in the far left, fostered through my obsession with the Cold War from the previous few years, suddenly became urgent. I watched the news constantly and started seeing political answers to things I had previously explained with Christianity. At the time the Soviet Union collapsed and the Berlin Wall fell I found my calling. I left the church and decided to become a communist (Purkis, 2006, 42).

Purkis' transition from Christadelphian to communist (the first of her shifts in identity) also highlights the importance of cultural resources in the development of identities, in this case the objectified form of a 'rulebook' (as had been the case with religious texts in the field of the church). This took the form of the magazine of the Australian Communist Party, which she would join at the age of sixteen:

I started to read it and the more I read, the more I wanted to believe. This paper welcomed the end of Eastern European communism and described the former communist regimes as 'state capitalist'. This paper was exactly what I had wanted – a new rule book (Purkis, 2006, 46).

Part of what made both the Christadelphian and communist fields suitable arenas within which to develop a reflexive and collective sense of self was not only the express nature of habitus, but also the resources of the field. Purkis' dispositional attachment to express rules meant that, where these were objectified in the form of texts, she could better participate in the life of the group and thereby develop both a personal and collective identity through a reflexive project. The importance of 'rulebooks' therefore indicates that the availability of different resources for making sense of social interaction in different fields may be a significant factor in

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mediating opportunities for AS people to grasp and participate in relations of accountability. While clear regularities may be beneficial to AS people in general with respect to being able to engage with differently disposed others, for those living without a diagnosis this may be of particular significance with respect to the 'double burden' of having difficulties that have no obvious cause. Another important factor in Purkis' development of her communist identity was the acceptance of her dispositional differences within the field of the party:

The best thing about being with my comrades, though, was the fact that they all accepted me. No one minded that I was 'odd' or different. In a world where the only important thing was politics I was always among friends, providing I adhered to a few simple rules, and if there was one thing I was good at it was following rules. (Purkis, 2006, 48)

For Purkis, the practical conduct of accountability relations provided conditions in which her ways of being were accepted as legitimate. However, there also remained a degree of difference between her meaningful experience of party life and that of her 'comrades':

For my fellow leftists, being involved in political action was about stopping a school from being closed, or standing on a picket line alongside wrongfully dismissed workers. There was an emotional involvement for the average socialist; he or she felt bad when a perceived injustice was committed. Socialists and others on the left are often described as having a 'social conscience' and to most it's exactly that. Yet I had joined the left as a sort of substitute to the set of rules I had grown up with. I constantly tried to feel something for those I was defending, yet I couldn't... Feeling may have been beyond me, but fighting wasn't. When I first joined the Party the only kind of fights I had were verbal ones: arguments with my parents, or someone at school, or a church member. However, by 1992 I had been involved in some physical fights for political causes, too. I had engaged in fights with the police at protests or with right-wing protesters at a march organised against the neo-Nazi skinheads...My morals were based solely on following rules and, as far as I was concerned, I wasn't breaking any of them. I was following the socialist rule book and in that rule book there's nothing wrong with physically attacking the police – they constitute 'the enemy' (Purkis, 2006, 79).

Purkis' writing points to the possibility that for some AS people, identification with particular groups may be influenced by the practical conditions of exchange and the

cultural horizons of field, more so than any shared sense of meaningful attachment. This observation does not exclude the potential for shared meaningful attachment, but indicates that dispositional aspects of self may involve needs which find fulfilment in particular fields, thus mediating the collectives with which one becomes involved. For those living without a diagnosis, this may be especially important, as particular fields may provide a home for ways of being that are problematic in other areas of life. The extract also suggests that, in addition to the field of the party providing a compatible arena for her dispositions toward express rules and logic, it also provided outlets for different dispositional aspects of self (i.e. her enjoyment of the thrill of violent protest). This potential suggests that dispositional aspects of identity should not be seen as fixed, but may emerge across the life course as different sets of social conditions provide bases for contrasting patterns of practical activity to emerge.

During her time with the party, Purkis was charged with assaulting a police officer at a demonstration (Purkis, 2006, 80-81), and eventually sent to prison for her unwitting participation in an armed robbery with a man named Joe, whom she had befriended (Purkis, 2006, 87-88). In prison, Purkis was diagnosed with AS; however, while it was to be a vital part of her defence during her trial, she did not at the time accept this as a valid description of her differences.

My parents had thought me strange my whole life, but had never known why, and even the psychiatrists I had been sent to had been puzzled by my apparently inexplicable behaviour. My mum's work friend said her son had been diagnosed with something called Asperger's Syndrome...There were only two professionals in Melbourne at that time who could diagnose it and my parents contacted the psychologist who worked with adults with Asperger's Syndrome, Vicki Batista. She agreed to come to the prison and conduct the relevant tests. When I heard my parents speak of the possibility that I had this condition I was torn between wanting to know why I was strange and feeling that my parents were just trying to feel better about themselves by finding an explanation for my bad behaviour. I did the tests Vicki gave me...[and a] short while later my parents told me she had diagnosed me with Asperger's Syndrome and that it was the reason I felt no remorse for bad behaviour and didn't have any ability to empathise with people, including the victim of my crime. It was also why I could not recognise people's faces or facial expressions and why I found body language and non-verbal communication so hard to fathom. All of a sudden I had a reason for all the problems that had made my life so difficult and had left me wondering how other people 'work' and why I had trouble keeping friends. I was torn between a sense of relief and a stronger feeling, the

knowledge that I was fundamentally different from most people and that there was nothing I could do to be like others. I had been running from my difference all my life and trying to be like other people, something I now knew was impossible. Deep down I knew what Vicki had said was true and that I did have this thing everyone was telling me I did, but on the surface I wanted to be the same, to be included. I refused to accept that I had Asperger's Syndrome and went back to my 'normal' act. I was a good actress and even convinced myself that I was like other people (Purkis, 2006, 100-101).

Purkis' initial reaction to being diagnosed indicates that while a diagnosis may be important for many people in making sense of the self, there is no guarantee that this will be accepted by the person, even if it appears to 'fit' with their understandings of dispositional identity. It also shows that dispositional identities, while fundamental to one's sense of self, may not in all cases override those established through reflexive activity and/or those which arise through collective exchange. The links between dispositional, reflexive and collective aspects of identity may therefore involve fractious as well as complementary aspects. For AS adults who receive a very late diagnosis, their sense of self may be embedded in long-standing and/or complex relationships between different aspects of identity,

and the time it may take for the diagnosis to be integrated into a sense of self (if indeed at all) may therefore vary between individuals.

After rejecting the diagnosis at this stage of her life, Purkis experienced another shift in her identity while in prison, drawing on her rule-following dispositions in a process of compliance with the practical and cultural regimes of prison life:

I had worked out that I had to fit in or life was going to be very difficult for me. Surprisingly I found it very easy to play the role of a criminal. There was a strict set of rules that were very easy to learn and prisoners had no problem accepting someone who was a bit different if they followed the rules. Had I been my different self and not worked out what was expected of me, I imagine my life would have been hellish, but I'd had plenty of practice at doing what was expected of me and playing various roles and I had little trouble becoming Jeanette the criminal. I soon had more friends than I'd ever had before, although I was in a constant state of alert, knowing that most of my friends would think nothing of attacking me physically should I do something wrong. I became known as a weird but 'staunch' girl, particularly after a fight I started with the sole intention of being accepted...Everyone thought that, even though I had a university education

and came from a decidedly middle-class background, I was a decent sort, a 'toff' (Purkis, 2006, 93).

This example is one of several in the narrative where Purkis engaged in violent acts as a means of maintaining her presented self within a field where not to do so would have been highly risky (she would later do this in order to be sent back to prison from mental healthcare). Her disposition towards rule following, coupled with the explicit demands of the prison habitus, shaped a reflexive project in which her identity as 'Jeanette the criminal' was asserted through a number of strategies circumscribed by the cultural horizons of prison. There are also positional aspects to consider here, as Purkis points to her 'middle class, university educated' background as a marker of difference from her peers, one which required mediation through explicit compliance with the demands of habitus. Playing the role of 'Jeanette the criminal' was again something that cannot be explained by dispositionality or reflexivity alone, but may be better understood in terms of relationships between these domains and their interplay with the habitus and cultural horizons of the field. While the 'rules for living' within the prison were clear, in terms of how and why she would be held to account by others, this contrasted sharply with her experience upon release:

The outside world didn't seem as great as people seemed to think it was. I thought my life in prison was much more fun than life outside, where people betrayed me and stole from me and expected what seemed totally unreasonable things from me (Purkis, 2006, 105).

Adjustment to life after prison was difficult was difficult for Purkis. '[S]hunned' by her former friends in the communist party she entered a world where the regularities of daily life were vague and unstable (2006, 104). Purkis became a heavy user of recreational drugs (2006, 108-113) and suffered from chronic depression, as well as episodes of acute mental distress (Purkis, 2006, 120). Over the next few years, she experienced a number of stays in mental health institutions and, finding life in these fields extremely challenging, engaged in violent acts in order to be sent back to prison (Purkis, 2006, 138, 146, 153):

I had my mind set on going to prison...I returned to the hospital, my black mood returning the moment I stepped inside the door. Two days later I attacked another nurse and this time it meant the police arrived instantly and charged me with assault. I went to court and was refused bail. I was going back to prison. I thought that surely this had to mean I was going to be happy again (Purkis, 2006, 138).

After her final release from prison, Purkis was able to find a form of life within which she could develop a liveable sense of self that was practically compatible with her ways of being; however, unlike her previous 'selves', this also allowed her a more meaningful experience of self-other relations. She enrolled in the undergraduate arts programme at Monash University where she was both accepted socially and involved in creative activities:

A few weeks into my degree I got used to the dynamics of the class and found I had people to talk to most of the time. I was amazed at how popular I seemed to have become. Only one person in the Honours class reacted to me badly, everyone else talked to me and invited me to openings of exhibitions they were putting on or asked me to go to the pub with them for beers. My address book, which had three people's addresses in for about a year after I was given it, was now full of phone numbers and addresses of people I could call and talk to whenever I liked. I had an exhibition at a university gallery and loads of people turned up to the opening – not just family members but friends. I couldn't believe that so many people liked to spend their time with me. I'd never been popular before (Purkis, 2006, 138).

Here, we can see a difference between Purkis' experience of connection to and identification with the cultural life of the field in comparison to her earlier experiences in the church, the party and the prison. Whereas before her writing conveyed a tension between practical connection with habitus, and a sense of distance from meaningful involvement, here we can begin to see signs of personal connection and belonging in her descriptions of relations with others. However, while Purkis' acceptance of the AS diagnosis was a significant factor in her coming to terms with her dispositional differences, at this stage both her dispositional differences and AS diagnosis were still understood as potentially problematic in terms of self-other relations:

Just before I moved into my new flat [prior to studying at Monash], I accepted something about myself that had been threatening and challenging me for years – I now believed, for the first time in my life, that what I had been told in 1994 while a prisoner at Fairlea was indeed the case; I had Asperger Syndrome. I did not mind as much that I was 'different', that I moved in another world to most people. I started attending an employment service for people with autism and related conditions and felt more comfortable with myself for knowing there was a reason for the many difficult things I had experienced in my past. I was still quite embarrassed by my difference and would keep the fact of my Asperger Syndrome to myself,

so as to avoid having to 'confess' to those I knew... While still uncomfortable with the fact that I was a member of an apparently strange minority, I could at least accept it to myself. I knew why I liked being alone, why I'd had universally bad experiences in relationships and why I was incapable of truly knowing how my actions impacted on others (Purkis, 2006, 175).

While a diagnosis may be important in terms of understanding the dispositional self, it will not necessarily change the social conditions that shape self-other relations. What allowed Purkis to incorporate her AS identity into everyday presentations of self were shifts in the conditions of habitus and field, for example, as she describes in her developing friendship with Rana, a fellow student on a post-graduate art course she undertook after her diagnosis:

Rana put up with my literal interpretation of everything she said, letting me know she was 'only joking' every time I took offence to something she said that was meant in fun. While other friends had laughed at me for my perceived oddities, Rana laughed with me. I told her about my having Asperger Syndrome and, far from judging me or putting me down, she asked questions about my perception of the world and tried to involve me in her world (Purkis, 2006, 186).

Rana was also a source of support and encouragement as Purkis encountered other AS people through a specialist employment agency, an event which had caused her significant anxiety beforehand, but turned out to be a highly positive experience:

The first day I spent at the course run by the autism employment service, I was filled with emotion and wonder. There were 25 people in the room and it was like looking into a mirror; I saw elements of myself wherever I looked – a strange, fascinating, moving and wonderful thing (Purkis, 2006, 187).

Accepting the diagnosis helped Purkis to come to terms with her dispositional differences, although both they and her AS identity remained sources of anxiety in exchanges with others. The presence of accepting others, and fields within which acceptance of difference was possible, allowed Purkis to alter her reflexive management of the presented self, such that her AS status could be a legitimate part of her identity. Finally, encounters with similar others helped her to develop a sense of legitimacy in relation to her AS status through identification with the wider collective of AS people:

The actor I once was is now past. I am almost able to be myself in most situations and many of the people who know me now know as close to a version of my true self as there is. I can finally say I actually quite like myself. It seems strange to be in a position where things seem to work out most of the time. I have to consciously remind myself that I am no longer the criminal, the drug addict or the disturbed person I was in the past... I am, however, quite happy. I fit into the world to which I was born. I am comfortable to be a woman with Asperger's Syndrome who has had a somewhat dark and bizarre life. I see my understanding of logic and reason and my dedication to whatever I put my mind to as an enormous advantage. If I had the choice to see the world the way most people see it and to have the understanding and communication skills of the majority, I would not take it. I look forward to what lies ahead with great interest and enthusiasm (Purkis, 2006, 191-192).

Once again, it is difficult to isolate the precise impact of the diagnosis in terms of Purkis development of a liveable sense of self. What appears clear however, is that acceptance of her diagnosis was one of several events (as with Hadcroft) that allowed her to develop a liveable sense of self in relation to others. While acceptance of the diagnosis provided Purkis with a narrative with which to understand and present her dispositional self to others, the conditions of habitus

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and field in which these presentations were made were also significant. Purkis' ability to accept and assert her AS identity as a liveable experience of selfhood appears predicated on the practical conditions of life providing the potential for meaningful experiences of the social, as well as the conditions of participation within wider collectives being hospitable to her ways of being. In the final shift of her identity, we can see a move from conditions of practical compatibility (incorporating accountability and legitimacy), to a situation in which she could also experience authentic connection to the life of the field and a liveable sense of self in which her AS status could be presented to others. The combination of these conditions with the sense-making resources provided by the diagnosis appears to have helped Purkis develop reflexive understandings of self, within which both practical and meaningful aspects of life could be accommodated.

Purkis' narrative draws our attention to two important observations, in terms of how the conditions of self-other relations may affect the development of pre-diagnostic identities. Firstly, orientations to participation in, and identification with, the life of the group may have particular qualities for AS people due to dispositional differences. In each of the author's 'selves', we can see a general theme of being practically compatible with, and at the same time distant from the meaningful life of the groups in which each of her identities was embedded. This is not something that can be shown to result exclusively from not having a diagnosis; however, a

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person's ability to make sense of and overcome these differences in self-other relations may be constrained by the lack of a narrative for understanding their dispositional differences from others. In such situations, the conditions of participation in different social collectives may be predicated not only on dispositional compatibility with the habitus of the group, but also the resources available within the social fields which they inhabit. In both the Christadelphian church and the Communist party, Purkis found 'rule-books' in religious and political texts, which provided practical guidance on social regularities, the horizons of field and the economies of symbolic value at play within them. In the absence of a diagnosis, this may be especially important, as resources for understanding self-other differences may be restricted, an idea which is supported by her experiences in the post-diagnostic phase of life.

Secondly, dispositional aspects of self may not in all cases override elements which are constructed reflexively, as evident in Purkis' initial rejection of her formal diagnosis. While the author appears to have acknowledged the compatibility of the diagnostic label with her dispositional sense of self, this was nevertheless rejected at the time. Thus there exists the possibility that the diagnosis may not be accepted, even where it is understood in some way to 'fit' with one's understanding of self, and this suggests that social and biographical conditions may also play a significant role in this process. When Purkis did eventually accept her diagnosis, its

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importance related to her coming to terms with her dispositional differences, while both her AS status and her dispositional differences remained a source of concern in self-other relations. Encounters with accepting others in fields hospitable to her differences (i.e. the post-graduate art course), and the possibility of collective identification helped her reframe her AS as a legitimate aspect of her presented self.

6.1.2 - Gender, sexuality and pre-diagnostic identity (Jen Birch)

Jeanette Purkis' narrative indicates how the dispositions can interact with reflexive and collective aspects of identity, as well as the conditions of habitus and field, in shaping understandings and presentations of self. Her experiences highlight the role of differential social conditions and resources for negotiating the self in different settings, and in particular the idea that while the dispositional self plays a vital role in how one negotiates the self in social settings, it does not necessarily determine this. For Purkis, until her eventual acceptance of the diagnosis, her presented self was shaped by the congruence of her dispositions with the practical and cultural conditions of habitus and field, in terms of how far she was able to develop and present a 'legitimate' self. Jen Birch's autobiography offers another perspective on relations between dispositional, reflexive and collective aspects of self, in terms of how the author came to understand her differences in relation to gender and sexuality. In particular, it illustrates how, in the pre-diagnostic phase of

life differences later associated with AS may be understood and configured through other aspects of self.

In common with other authors here discussed, Birch describes a lifelong attachment to express rules as a way of understanding the world.

I lived by the rules; rarely disobedient, I liked and needed the security that rules provided...I found that each sphere of knowledge had its own set of facts, or rules...To find out the facts, the rules, was to achieve mastery over life. Alas, the older I became, the more the uneasy feeling grew, that the rules for living amongst people were elusive and liquid. This was the only set of rules that could not be nailed down and kept down (Birch, 2003, 27-28).

Social interaction was a lifelong challenge for the author, in particular where this involved tacit or implicit understandings, and this led to problems in her ability to 'keep up with the play' in exchanges with differently disposed others (Birch, 2003, 73). The author describes sensitivity to loud noises, as well as problems with 'surprising' images that entered her visual field unexpectedly, as examples of everyday sensory issues (Birch, 2003, 34-35). These dispositional differences were

also attended by lifelong feelings of difference in relation to gendered aspects of her identity:

From early childhood, I had noticed that I did not fit in with the little girls. Dolls, dressing up, playing mothers and fathers, playing house, interest in make-up and jewellery, pretty clothes, hair-dos, boyfriends – these things seemed to fascinate little girls, but not me. In spite of Mum’s considerable skills as a tailor, and her natural wish to dress me up in pretty clothes, I hated even trying on new attire, and would revert as soon as possible to my shirt, long trousers (“longs”) and gumboots. (Jeans had not yet been invented, or, at least, were not yet known to my rural family.) When “dressed up,” I felt so uncomfortable and unnatural that I would rather stay home in my old clothes than go anywhere; but then, also, there were so many interesting things to do at our farm home, and few outings could match this. The exception to this, which my family undertook once a year, was our trip to Auckland Zoo. Even though this was probably the highlight of my year, one year I announced: “If I can’t wear my ‘longs’, I don’t want to go!” Such was (and is) the intensity of my need to feel “comfortable” in my favourite clothing, rather than dressing up. “Image” based on one’s clothing, hairstyle and adornments is a concept which I find puzzling and distasteful. I assess others on their personality and behaviour, not on their clothing labels,

and I find it hard to understand why other people cannot do the same! At any rate, I found that this whole area of life was one of difference between myself and others, and particularly between myself and little girls. On the other hand, neither was I interested in the “macho” activities of the day, such as sports and boisterous adventures. I was aware of wondering where I fitted in to the scheme of things. Therefore, one of my identity issues was “Am I a boy or a girl, or something in between?” (Birch, 2003, 45-6).

Here, Birch contrasts her understanding of what were deemed to be acceptably ‘feminine’ childhood interests, with the dispositionally conditioned curiosities of her childhood (2003, 18-26). Her experience suggests that for some AS people, their terms of engagement with the world may condition interests and ways of being that conflict with social regularities within particular fields and/or periods of life (such as childhood). In this case, these regularities took the form of gender norms, negotiation of which would be a significant issue for Birch throughout her life. Absence of a formal diagnosis may be significant in the sense that no other narrative may be available to account for these differences, with implications for how the person is perceived by others. In Birch’s case, this is supported by her reflections on the impact of her diagnosis, where she indicates that experiences such as ‘not knowing how to play with the little girls, therefore mixing with an ‘inappropriate’ group (‘the little boys’ as a child) (2003, 204), and later in ‘dating’

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with both men and women (Birch, 2003, 206), may have been easier to deal with, if she had been diagnosed earlier.

Birch's sense of androgyny also relates to her her sensory sensitivities, indicating how dispositional aspects of self may intersect wider social conditions in the presentation of self; for example, her attachment to 'comfortable' clothing which served as a way of managing sensory issues (i.e. her need to feel "comfortable" in her favourite clothing, rather than 'dressing up' – a common issue for AS people – Attwood, 2007), resulted in a practical (though apparently unintentional) rejection of gender norms. This was not something recognised 'post-hoc' but identified as a constituent part of her experience of negotiating gender identity as a child. Gender and sexuality became increasingly important aspects of self as she moved into adulthood; at the age of twenty two, Birch met her first husband (Lindsay) whom she married a year later. Initially, the relationship appears to have been a happy one; however, later issues with physical intimacy and the desire for children led to their eventual separation.

[a]fter five years, Lindsay and I decided that we had had enough. Lindsay now wanted children, and I knew that I was not the right person to provide them. Still waiting to become "normal," I could see that the "instincts" I

needed and wanted were just as lacking as before. The only instinct I have about babies is with feathered and furry ones. Better to let Lindsay find someone else and have a new chance, I thought (Birch, 2003, 81).

Disagreements over the desire to have a family (as well as their consequences for marriage) are of course not unique to AS people or their partners; however, what is significant with respect to self-other relations is the role that understandings of her dispositional self appeared to play in mediating the author's desire to have children. Birch opposes her ways of understanding and acting in the world to those which she understands as being proper to motherhood (i.e. tacit, 'instinctive' ways of being). Thus her reflexive understanding of the relationship between the dispositional self and the wider category of motherhood is indicative of how this relationship can shape orientations to potential future selves.

Birch's divorce from Lindsay marked the beginning of a period in which she sought to explore her sexuality, and following the breakup of her marriage she went to live in a shared house with several lesbian friends. In this environment, she states that she was accepted for her differences and began to self-identify as 'gay' (Birch, 2003, 51); however, in spite of her newfound acceptance, Birch describes a lack of 'close friendships', while her participation in fields such as gay bars and clubs was often

motivated more by sensory pleasures at the lights and ‘crush of bodies on the dancefloor’ than by shared connection to the practical and cultural life of the field (echoing Purkis’ experiences in the Church and the party) (Birch, 2003, 51). The ‘hidden’ regularities of social relations remained bewildering, leading her eventually to question her ‘gay’ identity as a valid narrative of her differences. Reflecting on this period of life, she writes:

[L]ooking back on it, I can now see that there was an element of wish-fulfilment – and of trying to convince somebody – myself – that my gay orientation was the reason for my feeling different. This was no longer convincing to me, however, as I could perceive for myself that, having entered lesbian society, I was still on the outer! In fact, I was even more of an alien in my new milieu, because the “women-only” community prided itself on such things as “women’s intuition,” “the feminine mystique,” “women’s knowledge;” and these were things which I never understood in the first place. Therefore, without men around to balance up the equation, I was even more baffled than before as to how to live amongst people (Birch, 2003, 54).

Initially, Birch’s entrance into the field and identification with the collective

category 'lesbian' appears to have been motivated by the support and acceptance which she received. However, her dispositional ways of understanding the social world contrasted sharply with the dominant habitus, where 'feminine' intuition prevailed over express rules and explicit negotiation. This experience led Birch to reject both the label of 'gay' as well as the wider lesbian collective, and subsequently to explore bisexuality as an 'intellect[ually]' satisfying way of understanding her differences:

I came to the conclusion, at one point, that I was Gay. After six or seven years identifying this way, I then felt that this was no longer correct, and that I was, instead, Bisexual. This unleashed another set of issues, as, at that time at any rate, Lesbians had a policy of strong disapproval of Bisexual females. As I understood it, Lesbians would not have minded Bisexuals as long as the latter kept well away – but Lesbians became very upset if Bisexual women tried to attend Lesbian events. It may have been, however, a case of the more radical Lesbian elements having the loudest voice; in which case, perhaps the "rank and file" Lesbians did not necessarily feel the same way. So, I now entered my Bisexual phase (Birch, 2003, 81).

For Birch, bisexuality was something to be explored 'concept[ually]' (2003, 81)

through reflexive consideration and express discussion with interested others, an understanding that came up against quite different notions as she sought out similarly interested others:

I experienced quite a number of other unwanted sexual encounters along the way. I was no longer calling myself Bisexual, as it was by now apparent that this was getting me unwanted results. Even advertising for a flatmate to live in my spare bedroom was enough to get me a lot of unwanted attention from males who saw me as something more than a potential flatmate. One flatmate frequently harassed me for sex; another potential flatmate tried to pressure me to have sex on the spot; another, I realised just in time, intended to run a prostitution business from my spare bedroom; a fellow student at university suddenly and unexpectedly grabbed me and tried to kiss me, but I managed to pull away before our mouths met; and other men, who invited me to their places for “a cup of coffee,” proved sooner rather than later to have something more than refreshments on their minds. Other people have told me, at various times in my life, “Listen to your feelings about a situation; feel the vibes; trust your instincts – and thus be forewarned about dubious situations.” But! – I did not have any feelings, vibes, or instincts in the sphere of social relating, so I had nothing inside me for guidance. Therefore, I had no “alarm bells” available to warn me of

impending danger – where people were concerned, at any rate (Birch, 2003, 82).

This extract points to a practical issue in self-other relations with implications for identity, in terms of how aspects of ‘normative’ languages of identity negotiation within particular cultures – ‘listen to your feelings, vibes etc.’ – may reflect dominant dispositional ways of knowing, rooted in different experiences of lifeworld. Birch’s experience of social life and the practical ways in which she sought to make sense of interactions often appear in contrast to the ‘normative’ ways in which others did so. This affected the forms of group participation in which she could become involved, as seen within both the lesbian and bi-sexual fields. Not only was her way of connecting with others through habitus different, but her understanding of what was at stake in both fields appeared at odds with the implicit understandings of others. This exposed Birch to unwanted sexual attention, something that has been observed elsewhere to be a particular hazard for AS women (Faherty, 2006) due to difficulties in understanding the ‘tacit signals’ of such situations.

After rejecting the categories of ‘heterosexual’, ‘gay’ and ‘bisexual’, Birch settled on a more ambivalent label, after hearing a friend describe her own orientation to

sexuality.

By now I had discarded all my previous orientations of Heterosexual, Gay and Bisexual... So, when I heard a female friend call her own sexual orientation "Unlabelled," I adopted this with delight and relief. With this solution, one no longer has to waste time and rack one's brains trying to work out what one is! (Birch, 2003, 83)

While acceptance of ambivalence provided a relief from the stress of conformity with established categories, finding a language with which to discuss the gendered aspects of her identity remained important for Birch.

My preference...for male company...was also part of my life-long feeling of androgyny...I had never felt like a girl...so how, therefore, could I fit in with girl-only groups? Again, in hindsight, it seems to be a matter of the "secret language of indirect communication" which was at least one component of my deficits in all-female company – I could not decipher the code. Also, I have, for a lifetime thus far, lacked the "feminine" desires to dress prettily, use make-up, wear jewellery, follow fashion, style my hair, or have babies.

When, in adulthood, I learned the word “androgyny” – that is, neither male nor female, or having equal amounts of both – I was glad to have a word to describe how I felt (Birch, 2003, 119-120)

The concept of ‘androgyny’ opened up the potential for Birch to accept an ambivalent relationship with the categories of sexuality available to her, and communicate this understanding to others. When viewed in the context of her dispositional attachment to reflexive rule-based ways of knowing, this appears to have been an important step for Birch in understanding her differences. This indicates that understanding of dispositional differences may also be shaped by the language and cultural resources that AS people have ‘ready to hand’ within the fields which they inhabit. For AS people who receive a very late diagnosis, this may mean that in the pre-diagnostic phase of life their differences are understood through the conditions of individual encounters, and that links between different experiences of self in disparate fields and in different periods of life may not be ‘visible’ as such. For people in this category, experiences of difference across fields or social encounters may involve fractured understandings of dispositional identity in the absence of any unifying biographical narrative. For Birch, while this is something that the diagnosis helped to provide, other concepts and resources such as the idea of ‘androgyny’ remained important. This points to the wider idea that understanding the self in dispositional, reflexive and collective terms may involve

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other important sense-making resources beyond the diagnosis, and that these may then interact with the diagnosis in understanding and presenting the self.

Birch's narrative provides an example of how AS-related differences may be understood in the pre-diagnostic phase of life, and how understandings of self-other differences may be configured through other aspects of identity, such as gender and sexuality. It indicates that AS people who receive a very late diagnosis may come to understand dispositional aspects of self and their relationship to groups and collectives in different ways, shaped by social and cultural circumstances. In addition, understandings of dispositional differences can affect orientations to other aspects of identity or to potential future selves, for example, Birch's decision not to become a mother. Finally, understanding and negotiation of self-other relations in the pre-diagnostic phase of life may be particularly limited by the language and forms of expression through which the person is able to make sense of and present themselves to others. Dispositional aspects of self may shape possibilities for coordination in habitus, as well as reflexive orientations to participation within the cultural life of particular groups and resulting forms of collective identification.

6.1.3 – ‘Logical empathy’ as form of distinction (John Elder Robison)

The narratives of Purkis and Birch have drawn our attention to how social encounters, set within different conditions of habitus and field can shape different iterations of self. While discussion thus far has focused primarily on identification with different collectives, John Elder Robison’s narrative presents a contrast to these stories in terms of distinction from others as an aspect of pre(and post)-diagnostic identity. In the introduction to his autobiography, Robison states that an important reason for telling his story is to demonstrate to others that ‘however robotic...Aspergians might seem, we do have deep emotions’ (Robison, 2008, x). This is particularly apparent in relation to what he calls ‘logical empathy’ – a way of relating to others based upon formal understanding, that also served to frame differences between himself and non-AS others, with respect to affective responses. Robison describes a sense from a young age of differences in his understanding and negotiation of social situations. For example, as he writes of an experience in early childhood:

People with Asperger’s or autism often lack the feelings of empathy that naturally guide most people in their interactions with others. That’s why it never occurred to me that Chuckie [another child] might not respond to petting in the same way a dog would. The difference between a small

person and a medium-sized dog was not really clear to me. And it never occurred to me that there might be more than one way to play with a toy truck, so I could not understand why she objected to me showing her. The worst of it was, my teachers and most other people saw my behaviour as bad when I was actually trying to be kind. My good intentions made the rejection by Chuckie all the more painful. I'd watched my parents talk to other grown-ups and I figured I could talk to Chuckie. But I had overlooked one key thing: *Successful conversations require a give and take between both people.* Being Aspergian, I missed that. Totally (Robison, 2008, 11 - emphasis in the original).

Robison's description reveals the practical as well as emotional consequences of early difficulties, where the 'pain' of problematic encounters was attended by a lack of understanding as to the reasons for them. Once again, although not aware of AS at this stage of life, the sense of his dispositions as differences seems to have been apparent:

Even at five, I was beginning to understand the world of things better than the world of people (Robison, 2008, 18).

As he grew older, this difficulty in understanding the 'world of people' was framed in terms of dispositions towards 'logical' ways of relating to others, which also served to distinguish his experiences of affective connection and response from those of others. For example, he describes issues in terms of his reactions to pre-diagnostic events involving unknown people which elicited emotional reactions from others, but were seen as having little relevance to him personally:

I have what you might call 'logical empathy' for people I don't know. That is, I can understand that it's a shame that those people died in the plane crash. And I understand they have families and they are sad. But I don't have any physical reaction to the news. And there's no reason I should...I feel I must put things like this in perspective and save my worry for things that truly matter to me. As a logical thinker, I cannot help thinking, based on evidence, that many people who exhibit dramatic reactions to bad news involving strangers are hypocrites...Often these same people will turn to me and say things like, 'What's wrong with you? You're not saying anything. Don't you care that all those people got killed?'...As I got older, I found myself in trouble more and more for saying things that were true, but people didn't want to hear (Robison, 2008, 32-33).

This way of framing differences in empathising also applied to practical difficulties, such as making socially inappropriate expressions, which he states led to him being seen as a ‘weird, screwed-up kid’ by others (Robison, 2008, 29). One example of this involved being chastised by another parent for grinning uncontrollably upon hearing of the death of a local (though unfamiliar) boy:

Betsy said, “Did you hear about Eleanor Parker’s son? Last Saturday he got hit by a train and killed. He was playing on the tracks.”

I smiled at her words. She turned to me with a shocked expression on her face. “What! Do you think that’s funny?”

I felt embarrassed and a little humiliated. “No, I guess not”, I said as I slunk away. I didn’t know what to say. I knew they thought it was bad for me to be smiling, but I didn’t know why I was grinning, and I couldn’t help it. I didn’t really know Eleanor. And I had never met her kid. So there was no reason to feel joy or sorrow on account of anything that might happen to them. Here is what went through my mind that summer day:

Someone got killed.

Damn! I’m glad I didn’t get killed.

I'm glad Varmint [Robison's younger brother] or my parents didn't get killed.

I'm glad all my friends are ok.

He must have been a pretty dumb kid, playing on the train tracks.

I would never get run over by a train like that.

I'm glad I'm OK.

And at the end, I smiled with relief. Whatever killed that kid was not going to get me. I didn't even know him. It was all going to be ok, at least for me. Today, my feelings would be exactly the same in that situation. The only difference is, now I have better control over my facial expressions... The fact is, from an evolutionary standpoint, people have an inbred tendency to care about and protect themselves and their immediate family. We do not naturally care about people we do not know...But then I see people making a big deal over it and it puzzles and troubles me because I don't seem to be acting in the same way. For much of my life, being different equated to being bad, even though I never thought of myself that way...Some people will cry and carry on, and I wonder...*Do they really feel that? Or is it just a play for attention?* As I've gotten older, I have taught myself to act "normal". I can do it well enough to fool the average person for a whole evening, maybe longer. But it all falls apart if I hear something that elicits a strong

emotional reaction from me that is different from what people expect (Robison, 2008, 31 - emphasis in the original).

Despite his apparent disconnection from the accountability relationship (i.e. not being able to describe the practical 'logic' of how he would be held to account), Robison's form of empathic connection was framed in terms that suggest a sense of both authenticity (in the sense of being dispositionally agreeable to him) *and* legitimacy (as opposed to the 'hypocritical' reactions of some others upon hearing of remote tragedies). This indicates that internalisation of the feelings of illegitimacy stemming from problematic encounters with others is by no means inevitable in pre-diagnostic life.

For Robison, the fact that his reactions appear to have come up against expected norms was not a concern in relation to legitimacy. Rather, this was framed as a challenge of maintaining practical contact with the dominant habitus through, for example, being able to control his facial expressions in conformity with the norms of others. His concern was with being able to 'pass' in accountability relations with differently disposed others, but this does not mean that he necessarily accepted the 'logic' or legitimacy of their reactions. Robison's characterisation of empathy does not concern me here; what is of interest in terms of self-other relations is that he

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does not appear to have internalised the negative responses of others in the same way as, for example, Gerland and Lawson, nor depended on accountability relations as a way of experiencing an authentic or legitimate sense of dispositional self. Rather, the 'puzzling and troubling' reactions of others are here framed as practical issues with affective consequences (i.e. the 'embarrass[ment]' and 'humiliation' he felt after being chastised by his mother's friend). In pre-diagnostic life, while being seen as 'weird' and 'messed up' was associated with negative feelings, Robison (in a similar way to Hadcroft) nevertheless framed himself as the 'logical' actor, in a world of less logical others.

This continued into the post-diagnostic phase of life, where his diagnosis served to validate 'logical empathy' and connect it with a wider sense of collective identity in terms of being 'Aspergian'. Reflecting on his reaction to encountering AS for the first time (just prior his formal diagnosis), Robison writes:

It was like a revelation...As a child, I had been told I was smart but I was lazy. Reading the pages, I realized I wasn't lazy, just different. I knew that I did not look up at people when I talked to them. Hell, I had been beaten up and criticized for that all through my childhood. But until I read that book I had never understood why people treated me the way they did. It had always

seemed so mean, so unfair. It had never occurred to me that other people might find what I did (or did not do) naturally disconcerting...The realization was staggering. *There are other people like me. So many, in fact, that they have a name for us...*I had spent most of my life listening to people tell me how I was arrogant, aloof, or unfriendly. Now I read that people with *Asperger's display inappropriate facial expressions*. Well, I certainly knew about that. When I was a child, I was told my aunt had died, and I grinned even though I was sad. And I got smacked. Just reading those pages was a tremendous relief. All my life, I had felt like a sociopath waiting to be found out. But the book told a very different story...I was normal, for what I am (Robison, 2008, 238 - emphasis in the original).

For Robison, the 'revelation' of the diagnosis was not to dispel internalised feelings of illegitimacy, but rather to validate his dispositional and reflexive aversion to the reactions of others which he had found 'puzzling'. In addition, knowledge of AS helped him to situate both his dispositional traits and difficulties in relations with others within the framework of a wider collective identity ('there are people like me'). The relief felt by Robison can be framed in terms of providing the biographical coherence it provided for his experiences of difficulty; however, while the diagnosis helped him to develop a more coherent understanding of self-other differences, there remained limits in terms of how far he was able to manage

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practical difficulties in exchanges with others. As he makes clear, through both his practical efforts and reflections on the desire to be 'liked', connection with differently disposed others remained important despite their (at times) 'troubling' behaviour:

I'm a very logical guy. Psychologists say that's an Aspergian trait. This can lead to trouble in common social situations because ordinary conversation doesn't always proceed logically. In an effort to improve my own interpersonal skills, I have studied computer programs that engage in conversation with people. The best programs follow logical pathways to arrive at suitable responses. The results, however, don't always sound natural, and I am not sure that I do much better than the machines (Robison, 2008, 189).

Here, Robison indicates a reflexive understanding of differences between his (logical) dispositional orientation to conversational exchange, and contrasts this with the less formal ways in which non-AS interactions may develop. While at no point does he frame his difficulties in terms that might be described as illegitimate, in post-diagnostic life he does identify 'interpersonal skills' as an area for potential improvement. His reflection on the 'results' of his 'logical' approach to

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communicative exchange also point to an implicit acknowledgement of the limits of this dispositional way of seeing the world, in terms of how it frames self-other relations. Robison gives a detailed example of how this played out in practice, through a recollected exchange with a co-worker at around the time the book was written:

[L]ast week my friend Laurie said, "One of my girlfriends is having an affair. And the guy rides a motorcycle just like yours!". Laurie's statement posed a problem. Unlike most interactions, ours had not started with a question. Should I respond with an opinion about the statement? Or should I ask a question myself? I considered what I had just heard: Laurie has a girlfriend. *Yes, Laurie has lots of girlfriends. Which one is she talking about?* The girlfriend's having an affair. *Why tell me? Do I know her? Do I know the guy? Is this a convoluted way of suggesting I should have an affair, since I have a motorcycle?* The boyfriend has a motorcycle. *Well, that narrows it down. Most potential boyfriends had cars, not bikes. So this boyfriend is one of 5 percent, as opposed to 95 per cent of the motoring public. Do I know him?...*I was not able to deduce a suitable response to her statements. What did she mean by them? There was no logical connection between Laurie's sentences. I stared at the floor and pondered my next move. I knew I had to think fast. If I think too long, people say, "Did you hear me?" or "Are you

paying attention?”. I knew she wanted a relevant response – something connected to what she had just said, more than just “Oh.” I also knew from experience and observation that a statement like “I went to Newport to see the Jazz festival last weekend” would not be an appropriate answer. It occurred to me that what I needed to do was to keep gathering information until I could frame an intelligent conversation. The successful conversational computer programs did that. So I asked a question.

“Which girlfriend is that?”. Laurie looked surprised.

“Why would you want to know that?” she said. I hadn’t expected a challenge. She sounded suspicious. I wiggled my ears and wondered a little at that. The fact that she had responded that way told me she had been expecting some other response. *What did she expect me to say?...*When I asked Laurie why she was suspicious, she had a couple of questions for me:

“Why do you need to know? Nothing good will come of me telling you. What if it got back to her husband?” I figured out what I should have said by chance, observing two women talking at a restaurant a short while later:

“Jenny in accounting is having an affair, and the guy drives a Corvette”. The opening line is strikingly similar, so I paid attention.

“How cool is that! Is he married?”

Listening to that exchange, it was obvious that this was the correct response. When I heard them talk, I suddenly understood that Laurie's statement had been meant to entertain or impress me, and that my response should have been an expression of admiration or excitement. However, that never occurred to me at the time...I suspect normal people are hardwired to develop the ability to read social cues in a way that I am not (Robison, 2008, 189-191).

Robison's is aware that the other speaker is making an implicit 'call to order' not covered by his express understanding of the parameters of the conversation (Bottero, 2010); however, what eludes him is the ability to make sense of it in an intuitive manner such that he is able to produce a timely response. What is significant here is that (as Bourdieusian theory suggests) the social 'breach' arises as a result of disruption to the rhythm and tempo of the interaction *as well as* issues in meaningful understanding. This exchange also provoked a reflection (that 'normal people are hardwired to develop the ability to read social cues in a way that [he is] not') on both his dispositional aptitudes and the ability of his reflexive (logical) strategy for coordinating with others.

It is worth noting that in contrast to, for example, Lawson's exchange with Sheila (6.1.2), Robison's interaction with Laurie involves him attempting to comply with the problematic demands of non-AS habitus rather than seeking to renegotiate them, despite this occurring in the post-diagnostic phase of life. From what is given in the text, we cannot be sure of the reasons for this; it may be that Robison felt uncomfortable disclosing his AS identity to this particular person (given previous work on disclosure discussed in 2.1.2), or perhaps he wished to 'fit in' with others without being seen as 'different' (as was the case for Ryan and Raisanen's (2008) participants). Whatever the reason, it illustrates that while his 'logical' ways of being were framed as legitimate, Robison's sense of self in relation to others incorporated understandings of his limitations. It is notable that when one compares statements from before and after the diagnosis, his sense of dispositional limitations is defined more clearly post-diagnosis. What this indicates is that one effect of the diagnosis on self-other relations in the post-diagnostic phase may be that problems that were previously ill-defined (i.e. 'puzzling' experiences) in everyday exchanges with differently disposed others may be interpreted in more precise terms as limitations, and these limitations then become integral to the person's identity.

Robison's narrative presents another perspective on how self-other relations shape pre-diagnostic formations of identity. In contrast to Purkis and Birch, his sense of

dispositional self remained relatively stable in terms of authenticity and legitimacy through his life. When the diagnosis came, its effect was to validate his existing understandings of self, and connect them with the wider category of being Aspergian. For Purkis and Birch, the 'revelation' of the diagnosis offered new resources for understanding and presenting the self to others; however, while it was undoubtedly a positive experience for Robison, knowledge of his diagnosis meant that subsequent encounters with others also served to sharpen his perception of his limitations (echoing the sentiments of Singh's (2011) participant 'Helen', discussed in 2.1.2). As the encounter with Laurie shows, relations with others remained difficult in post-diagnostic life, and despite the confusion and scepticism he associated with the behaviour of differently disposed others (for example, in empathic connections), he nevertheless retained the desire for contact with them.

Robison's account of 'logical empathy' provides an example of how distinction (in addition to positive identification) may function as an important process in the formation of both pre-and-post-diagnostic identities. In pre-diagnostic life, while he appears to have experienced his way of empathising as both authentic and legitimate, he did experience negative emotions in response to problematic interactions with others, which shaped a desire to maintain contact with them through the accountability relationship. The significance of the diagnosis in terms

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of how 'logical empathy' figured in his overall sense of identity appears to have been two slightly contradictory ways. On the one hand it, validated his existing feelings of authenticity and legitimacy in terms of how he related to others empathetically. This is suggestive of different types of legitimacy in relation to identity, in this case what one might call a personal sense of legitimacy (beginning in pre-diagnostic life) which was then reinforced by a collective sense of legitimacy stemming from identification with the category 'Aspergian'. On the other hand, understanding his dispositional differences in light of the diagnosis also opened another aspect of identity in terms of self other encounters, where he began to see his dispositional differences in terms of limitations associated with being Aspergian. This extract therefore also supports provides further support for the idea (discussed in 2.1.2) of the diagnosis having multiple effects on a sense of self.

6.2 - Discussion.

The focus of the previous chapter was on understanding of the dispositional self in the pre-diagnostic phase of life. In this chapter, the focus has been on how self-other relations affect the pre-diagnostic self, with particular attention to the reflexive and collective aspects of identity. Once again, while the three narratives here considered show considerable variation, there are several themes that arise. In the previous chapter, it was observed that dispositions can shape orientations to

the life of the group in terms of their congruence with the dominant habitus. In this chapter, we have seen that reflexive and collective aspects of self can also shape understandings of dispositions, by contextualising dispositional differences through particular cultural lenses. In Purkis' narrative, we saw how her rule-oriented dispositions were filtered through the cultural context of practically hospitable fields, such as the church, the party, and the prison. Her initial rejection of the diagnosis also shows that even where this is believed to 'fit' with a dispositional sense of self it may not override reflexive or collective aspects of identity. Elsewhere, Birch's sense of dispositional difference was shaped by regularities of gender and sexuality, for example, in her coming up against gender norms in childhood, and negotiating the practical conduct of relations within the majority-lesbian household. Her discovery of androgyny also indicates the importance of other sense-making resources in the formation of a liveable sense of self.

The narratives also show how the meeting of dispositions and habitus can result in different degrees of identification with different collectives. Purkis' sense of security in knowing the 'rules' of church and the party, was contrasted with her sense of distance from meaningful involvement in the cultural life of either field. For Birch, acceptance of her differences was juxtaposed with her feelings of exclusion from the intuitive habitus ('the feminine mystique') of the lesbian household. Both narratives show that involvement in and identification with

different collectives may involve degrees of contact in both practical and meaningful contexts. Robison's story meanwhile offers a contrast to these experiences, by showing how pre-diagnostic identities may also involve processes of distinction, in terms of how a person comes to understand reflexively their differences from others. In a similar way to Hadcroft, discussed in the previous chapter, Robison came to define his 'logical empathy' against the dispositional ways of empathising exhibited by others. While in pre-diagnostic life this sense of difference was often ill-defined, in post-diagnostic life familiarity with the idea of being 'Aspergian' served to validate this sense of self by connecting it with a collective identity. Taken together, the narratives here discussed indicates how variations in the social and cultural conditions of life can shape different formations of pre-diagnostic self.

Finally, the three narratives also show how different kinds of social and cultural resource can mediate opportunities for identification with different collectives, and thus the formation of pre-diagnostic identities. In the church and party, the presence of 'rulebooks' was an important factor in Purkis' ability to enter the accountability relationship, and thus to participate in the cultural life of these groups. For Birch, encountering the notion of 'androgeny' helped her to understand those aspects of her gendered self that had hitherto been filtered through available categories of gender and sexual identity. Again, Robison provides

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a contrast to this by showing that available resources can also constrain opportunities for social coordination, even where the person understands their differences through the diagnosis. His description of the limited success provided by imitation of computer speech software also shows how a lack of opportunities for renegotiation of habitus may also limit the ability of the person to connect with differently disposed others. Thus both how far one is able to coordinate with others in practical terms, and to experience similar forms of cultural attachment within a given setting, can also be mediated by the resources that the person has to make sense of particular situations.

Building on the discussion at the end of the previous chapter, we can see from the analysis undertaken here that the interrelated concepts of authenticity, accountability and legitimacy are also useful for theorising the relationship between self-other relations and formations of pre-diagnostic identity.

- **Authenticity** – In the previous chapter, authenticity was framed in terms of a person's ability to engage in activities and ways of being that were dispositionally appropriate, and to avoid feelings of inauthenticity associated with copying others or 'pretending to be normal'(Willey, 1999). In this chapter, we can see how authenticity is involved in the relationship between

self-other relations and identity, in terms of the degree to which practical and meaningful participation with the cultural life of different groups is possible. Purkis and Birch both point to a degree of meaningful distance in fields where they appear to have been accepted and able to participate practically; in Purkis narrative this is also contrasted with her later experiences in the field of post-graduate study, where she felt a sense of belonging and connection to the life of the group. Birch's difficulties in finding a language to describe her sense of difference in terms of gender and sexuality also points to the fact that opportunities for presenting a sense of self that feels authentic may be mediated by the availability of social resources.

- **Accountability** – In the previous chapter, the ability to understand and participate in relations of accountability were discussed in terms of how they were mediated by the compatibility of a person's dispositions with the regularities of habitus. In this chapter, we have seen how accountability relations can involve degrees of connection in both practical and meaningful contexts, and how this shapes identification with different collectives. The degree to which one can be accountable, and hold others to account, in different fields, may therefore involve inequality in terms of an AS person's

ability to participate in a given field. For Purkis and Birch, conformity with the practical life of fields that were hospitable to their differences was central to their identification with the church/party and lesbian household respectively. However, in both cases, this was primarily about rule-following, with no indication that either party was in a position to renegotiate the conduct of interactions in such a way that would allow them a more meaningful (and equitable) experience of participation.

- **Legitimacy** – In the previous chapter, I discussed legitimacy in relation to the dispositional self, and how the pressure of conformity with the wider cultural horizons of habitus can mediate opportunities for experiencing authentic ways of being, and for experiencing the dispositional self. The discussion here suggests two different but related senses in which legitimacy relates to pre-diagnostic identity formation:
 - *Social legitimacy* – This refers to forms of legitimacy that arise from relations of accountability with others, through exchanges signalling that a person's ways of being are accepted by the wider collective. However, this does not automatically imply that those ways of being are experienced as authentic by the person. Social legitimacy can

therefore be conferred on ways of being that the person may be able to enact on the practical level, but of which their meaningful experience may be different (e.g. Purkis' participation in the Christadelphian church). Conversely (as Robison's narrative indicates), ways of being that are experienced as authentic and legitimate at the personal level may be seen as illegitimate in different fields. Thus while social legitimacy may constrain or facilitate a person's ability to experience and enact authentic and personally legitimate ways of being, this is not necessarily a requirement.

- *Personal legitimacy* – This form of legitimacy describes feelings that particular ways of being are justifiable and defensible. While authenticity refers to those ways of being that are dispositionally appropriate (i.e. what 'feels right' to the person), personal legitimacy speaks to a reflexive understanding or narrative of one's ways of being in relation to others. This may operate in a number of ways, for example, Robison's account of 'logical empathy' provides an example of maintaining a sense of personal legitimacy in the face of problematic encounters with others (and a lack of social legitimacy). Elsewhere, Purkis initial rejection of the diagnosis contrasts an understanding of self that appeared authentic in terms of fitting with

her dispositional sense of self, but was nevertheless rejected as illegitimate (in spite of the 'social legitimacy' this provided in terms of it accounting for her actions to the court). Both types of legitimacy may interact with the other (e.g. as seen in Birch's negotiation of gender identity within the majority lesbian household), however they are not synonymous.

I now turn to the final question addressed in this thesis. As indicated in chapter two (2.2.3), the combination of dispositional differences with problematic environments and social situations can mean that AS people face a range of everyday insecurities. My task in the next section will therefore be to explore, in light of the discussion here and in the previous chapter, how management of these insecurities relates to formations of pre-diagnostic identities.

7 - How does management of everyday insecurities relate to formations of the pre-diagnostic self?

In this chapter, I will explore how management of everyday insecurities is implicated in pre-diagnostic formations of self. The structure of discussion in this chapter will differ from the two previous chapters, as I will explore five of the autobiographies in relation to two themes (i.e. parenthood and the workplace). Parenthood emerged as a significant theme through engagement with the narratives discussed in this thesis, while as indicated in chapter two (2.1.1) gaining and maintaining employment is often highly challenging for AS adults. Both of themes were selected are examples through which to discuss comparatively, different experiences of negotiating everyday insecurities. In 7.1.1, I will explore insecurities relating to parenthood, firstly by comparing how Will Hadcroft and John Elder Robison's dispositional identities shaped their orientations to fatherhood, and secondly by exploring Wendy Lawson's experience of being a new mother labelled as schizophrenic. In 7.1.2 I will discuss management of social and sensory insecurities in the workplace, and their relationship to pre-diagnostic identities. Here, the importance of social resources in the form of supportive collegial relationships will be explored through Jen Birch's writing, before I turn to Gunilla Gerland's account of dealing with sensorily challenging environments as a day nursery worker. Gerland's narrative will serve as an illustration of how the stress of dealing with everyday insecurities, as well as not understanding the reasons for

them, can leave AS people particularly vulnerable to destabilisation by unforeseen events (in this case, her mother's mental health crisis). In conclusion, I will discuss how findings of this chapter can relate to the conceptual framework of authenticity, accountability and legitimacy developed in previous chapters, as a way of understanding pre-diagnostic formations of identity.

7.1 – Insecurity and parenthood (Will Hadcroft, John Elder Robison, Wendy Lawson)

7.1.1 – Negotiating dispositionality and fatherhood (Will Hadcroft and John Elder Robison)

In the previous chapter I noted Jen Birch's opposition of her dispositional self to what she understood as the personal qualities proper to the role of motherhood. Similar sentiments appear in Will Hadcroft's narrative, where he discusses his aversion to fatherhood, after learning that his wife could no longer bear children:

This was fine by me, in fact it was more than fine. I'd observed the stress experienced by new parents at the Kingdom Hall and did not fancy it one bit. Because of my personality, I knew I would find fathering a child emotionally

challenging. I would expect my child to have the same values as me, which would either bring a life of persecution and bullying or would make him or her want to live a double life, compromising at school. Either way, I would be severely troubled. Then there was the issue of my anxiety attacks and my depressions – and my anger – I still battled deep-seated negative feelings. While they were always internalized, I believed no child should grow up in that environment (Hadcroft, 2005, 172).

Hadcroft frames his suitability as a parent in terms of the traits and expectations that he imagined would be conferred upon his children, and also the ‘persecution and bullying’ that they might encounter. Here, dispositional understandings of self were brought to bear in reflexive consideration of potential fatherhood, in terms of potential hazards for both himself and the child. Hadcroft believed that, as a parent, he would demand compliance with his own values and dispositional ways of being, and that this could cause difficulties both for himself (in terms of relating to his offspring) and the child (i.e. either suffering the exclusion that Hadcroft himself has endured, or having to live a ‘double life’ split between the worlds of school and the home). In this way, Hadcroft’s rejection of parenthood was framed by a sense of dispositional self rooted in imaginations stemming from biographical experiences.

In contrast, John Elder Robison did choose to become a father (in pre-diagnostic life), and his narrative contains no indication that negative understandings of dispositional self were associated with this decision. Rather, it was in the post-diagnostic phase that his dispositions became a concern:

There's quite a bit of evidence that suggests Asperger's can be inherited. When I learned about my own Asperger's, Cubby [Robison's son] was six, and I was immediately concerned that Cubby might be that way too. And he is, but to a much lesser extent than me. As he grew, I watched him carefully and remembered the times that I had struggled as a child. Sometimes I'd watch him make the same mistakes I did, and I would cringe. I tried explaining what was happening to him, and it seemed to work. Cubby began making friends, and he grew up without the worst of my Aspergian traits. Now he's a teenager, the difference between Cubby and me is staggering. He's the life of the party – something I dreamed about but never attained. In other ways, we are very much alike. He's blessed with my gift for mathematics and imagination...I am quite sure that he will accomplish another of my childhood dreams: to graduate from high school and go on to finish college (Robison, 2008, 232).

In the previous chapter (6.1.3), I noted that for Robison, diagnosis served to not only legitimate aspects of his dispositional self (i.e. his 'logical empathy') by connecting them with a wider 'Aspergian' identity, but also to sharpen his sense of limitations. In the above quote, we can also see how these relate to his understanding of hazards pertaining to both his son and himself as a parent. Here, Robison's post-diagnostic reflections served to reframe both his sense of connection to 'Cubby', and how he framed his son's dispositional strengths and exposure to potential hazards. Understanding his dispositional self through the diagnosis also appears to have functioned as a resource for Robison to develop practical strategies for supporting his son (i.e. 'explaining' the mistakes to 'Cubby' and helping him to overcome them in future).

These contrasting examples indicate that differences in life experiences and understandings of self can shape a range of orientations to framing insecurities relating to parenthood. For Hadcroft, the personal and social hazards experienced in his own life shaped his aversion to becoming a father, both in relation to the potential hazards to the child and his own wellbeing. By contrast, Robison's understanding of how his son might grow up involved not only difficulties but also dispositional strengths. What is particularly interesting is that Hadcroft's decision not to become a father was taken in the pre-diagnostic phase of life, and the experiences which shaped this decision do not appear to have been affected by his

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diagnosis (i.e. there are no indications that his attitude to parenthood changed in his account of post-diagnostic life). By contrast, for Robison, hazards associated with his dispositional differences only appeared after his own diagnosis. Whether these would have been recognised in a different way had he not been diagnosed is open to speculation; however, what is clear is that it was significant in how Robison framed being a father. This suggests that while the diagnosis may play a role in shaping a person's understandings insecurities in relation to parenthood, its significance again appears variable and difficult to isolate from other aspects of self and life events. Understandings of dispositional self may therefore shape orientations towards possible futures, such as parenting, in terms of the potential hazards involved, and this can vary in relation to how biographical experiences shape pre-diagnostic identity.

7.1.2 - Labelling, insecurity and new motherhood (Wendy Lawson)

Hadcroft and Robison present contrasting examples of how understandings of dispositional self can affect orientations to parenthood. In Wendy Lawson's writing, we can see how aspects of identity conferred by others, in this case psychiatric labels, can interact with understandings of the dispositional self in framing insecurities relating to new motherhood. Some AS people, in particular those who grew up prior to the entrance of AS into the DSM and the ICD, may have been

misdiagnosed or had their differences attributed to other conditions (Beardon and Worton, 2011). People in this category may therefore have been forced to contend with the consequences of mis-diagnosis, as was the case for Lawson. She became pregnant at a very difficult time having recently left her job as a nurse, and then experienced a period of mental distress for which she was twice hospitalised at the age of twenty two (Lawson, 1998, 74). During her second stay, Lawson learned of her pregnancy, and her son James was born six months later, after she had left the hospital (Lawson, 1998, 76). She writes of her fear immediately after James' birth that she might 'misread' her son and not be able to attend to his needs, framed through her sense of dispositional self as someone who had difficulties with social interaction. However, Lawson's fears diminished after the birth, as she found that her ways of relating were compatible with his own (James would later be diagnosed with an ASC) (Lawson, 2012):

In spite of my fears, we made a very good team and I soon learned what he needed and how to respond to him (Lawson, 1998).

Anxiety over the ability to care for children may be thought of as a common experience for new mothers (Priel and Besser, 2000; Wilkins, 2006); however, what is significant here is how these concerns were shaped by her sense of dispositional

self, as well as reflexive understanding of her schizophrenia label. Despite her growing confidence in being able to care for 'James', what remained were concerns around how her activities in the role of mother would be interpreted by others within the fields of medical and social care:

After the delivery, I withdrew. I curled up into a ball and tried to comfort myself by sucking the roof of my mouth. The nursing staff left me alone and I slept on until the early hours of the next morning. When I awoke, I remembered I had a baby and I knew I needed to act like a mother or else I might lose him. I wanted to be able to for my son and I felt determined that I would do so. I went onto automatic pilot, trying to copy other mums (Lawson, 1998, 80).

For Lawson, being a new mother with a label of schizophrenia involved the potential hazard that her son might be taken away by those in authority. Her response involved careful compliance with what were often dispositionally challenging demands, an example of which was her attendance at weekly 'therapy' sessions prescribed by doctors for her perceived 'emotional disturbance' (Lawson, 1998, 81-83). Though intended as a forum in which she could 'explore' her

'feelings' in a 'therapeutic' context, Lawson's (hitherto unrecognised) AS-related differences meant that participation was in fact a highly distressing experience:

The idea was that we should get in touch with our emotions, but the whole idea terrified me and I could feel a big black nothingness coming up from the pit of my stomach. The thought of not being able to be normal, of having my baby taken away from me and losing all that I had fought to find, motivated me to keep attending therapy. We were told to join hands with the person next to us and walk around in a circle. The emotions I experienced made me feel sick, not connected and secure, as intended (Lawson, 1998, 82-83).

For Lawson, being a new mother involved coping with the insecurities of the schizophrenia label in combination with the practical and emotional challenges she faced as an undiagnosed AS person forced into dispositionally inappropriate performances and settings. Exposure to additional sensory hazards thus became a necessary condition of negotiating those associated with parenting. It is important to note the historical dimension to this experience, as her schizophrenia label would be overturned twenty-five years later following her AS diagnosis, something that was not available at the time. Lawson's writing is thus indicative of a particular

generation of AS people whose differences may not only have gone unrecognised but been understood through other labels such as schizophrenia (it is worth noting, however, that misdiagnosis and negotiation of psychiatric labels remains an issue for AS adults) (Beardon and Worton, 2011). Her narrative stands as an example of how risks associated with parenting can be exacerbated by mis-labelling, the demands that may accompany such labels, and their implications for configuring everyday insecurities.

7.1.3 - Discussion

The narratives discussed in this section show different ways in which understandings and presentations of self may relate to the negotiation of insecurities relating to parenthood. For Hadcroft, although his pre-diagnostic sense of dispositional self was understood as legitimate, he had clear concerns about the compatibility of his dispositions with what he understood to be the demands of being a father. In framing his insecurities around parenthood, Hadcroft draws on his own life experiences in imagining the hazards faced by himself as a parent and also by potential children. In contrast, Robison's account of becoming a parent is not linked to any sense of dispositional self until after his diagnosis. While Hadcroft used his biography exclusively as a reference for potential problems, Robison draws on his experience as a way of understanding both advantages and

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potential problems that might relate to his son, and also to himself as a care-giver. Robison's account thus also shows how connection with a collective category, such as being 'Aspergian' interacts with his parental identity, and how this shapes understandings of and practical responses to, insecurities associated with care-giving.

Whereas Hadcroft and Robison speak mainly to the dispositional self in terms of its relevance in negotiating everyday insecurities, Wendy Lawson's experience illustrates the role that reflexive understanding of self as seen by others can have on this process. For Lawson, despite the growing sense of dispositional compatibility which she describes in becoming a new mother, negotiation of the schizophrenia label compelled her to act in ways that went against 'authentic' ways of being. Here, her understanding of self in relation to others within the medical field conditioned a sense of insecurity that came not from her ability to care for her son, but to do so in ways that were seen as 'legitimate' by those in authority. The conditions of accountability here involved unequal relations of power, where Lawson was accountable to medical professionals, but was unable to hold them to account or challenge the practical 'logic' of their demands. Thus what Lawson's account indicates is that understandings of and responses to insecurities around parenthood can involve a conflict between dispositionally appropriate ways of

presenting the self, and those shaped by the demands of those who hold greater power within the accountability relationship.

7.2 - Insecurity and the workplace (Jen Birch and Gunilla Gerland)

As noted in chapters one and two, gaining and maintaining employment is a significant issue for AS people, and insecurities associated with everyday experiences of the workplace were also a prominent theme within the autobiographies. In this section, I will discuss two related examples; firstly, Jen Birch's experience of managing insecurities in the workplace, and how having (and then not having) supportive relationships affected both her ability to cope and her sense of identity; secondly, I will explore Gunilla Gerland's account of how the daily challenge of negotiating problematic sensory environments left her vulnerable to destabilisation, both emotionally and in relation to her sense of self.

7.2.1 - The importance of supportive relations for negotiating everyday insecurities in workplace fields (Jen Birch)

As discussed in chapter five (6.1.2) Jen Birch's dispositional sense of self involved a preference for reflexive ways of knowing over intuitive, and in particular an aversion to sudden changes in social interactions:

Thinking on the spot was difficult for me – hence, I can see now, my dependence on knowing the rules. Knowing what to do beforehand was, and still is, very important for me. I have been told, and in fact reprimanded and ridiculed at times, for not being able to act spontaneously. My lack in this area is, I know now, at least partly due to my mental processing speed being too slow for fast moving situations...On the other hand, if given sufficient data and time with which to think matters through, I can reason things out as well as, if not better than, other people (Birch, 2003, 27).

Problems with 'keep[ing] up with the play' in 'fast moving' (2003, 73) social situations were a factor in shaping the hazards faced by the author, in relation to the regularities and cultural horizons of her workplace (the admissions department of a local hospital) (Birch, 2003, 136, 141). Initially, the hospital provided Birch with a 'meaningful' (2003, 145) and practically suitable experience of work, with supportive others (Birch, 2003, 137) who helped her negotiate hazards relating to overwhelming social or sensory experiences (what she describes as 'losing the plot') (Birch, 2003, 138-139). Birch was aware that working in the admissions department environment involved the risk of becoming overwhelmed during busy periods;

however, support from colleagues meant that these were for the most part manageable, if not entirely unproblematic.

The importance of supportive relationships as resources for negotiating workplace risks was illustrated in her later experience of working the hospital, as her familiar colleagues moved on and were replaced with less sympathetic others. The author states that up until this point she had been able to manage risks relating to her dispositional differences; however, changes in the 'hidden' regularities of the office meant that she was now more vulnerable to difficulties in interactions with colleagues. One example of this was a situation that arose shortly after the arrival of new staff, where the misuse of a metaphorical phrase created problems with her new manager and another colleague:

Back in the booking office, without Nell [a supportive colleague], the clerk on the other side underwent a personality change. When I continued to talk to her in the same way as before, she responded grumpily and critically. At a time when this co-worker was out of the room, the new manager came in and told the rest of us something about how we should and shouldn't do our work...Reporting this information back to my colleague on her return, I made the bad judgement call of using a phrase which I did not fully understand: I

said that we (in the Booking Office) had been “hailed over the coals.” Little did I expect, however, that my colleague would go immediately to the new Manager and tell her exactly this! About five seconds later, the Manager was standing in front of me, demanding to know whether I had said these words. I replied “Yes.” My boss was furious, and I was in trouble with her already...I was usually a careful person in what I said and did, but this slip-up made me even more cautious about anything which came out of my mouth from then on. My “new-style” colleague also made a fascinating study in something I had previously heard of only in my sixth-form history lessons: the Balance of Power. Mr Fletcher had spoken of it with regard to the countries in Europe before the First World War. Now I could see it operating for myself: with Nell gone, the whole balance of the Booking Office had been upset; for example, my previously cheery co-worker was now unpleasant to work with...From that moment on, I had a new tool with which to study group dynamics (Birch, 2003, 139-140).

This extract highlights a tension between Birch’s reflexive understanding of the situation and her ability to respond to it in situ, meaning that some of her actions within the field were undertaken without her being able to get a timely grasp of their potential consequences. This would be an increasing problem in the ‘new style’ office, as Birch writes of a later situation in which a colleague reported

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experiencing racial discrimination, leading her to intervene by writing to her local trades union:

I felt very friendly towards some of my Admitting Office workmates, and our Samoan colleague sometimes brought us taro with coconut cream to share...One day she told me that she was being subjected to racism in the workplace, and from our superiors at that...I didn't hesitate in writing to our workers' union, asking for help with this matter. I had never contacted a union before, so I did not know the procedure. I thought that the issue of racism was the important part, and did not give my name, just "a concerned colleague."...When the management brought the matter to everyone's attention, the only important point was "Who wrote the letter?" The existence or absence of racism in the workplace was never mentioned – the hot topic was now the letter-writer's identity. As usual, the new situation took me by surprise. Always needing to assess a situation slowly and thoroughly in order to come to a decision, I waited whilst I thought what I should do...I asked a colleague for her opinion; she replied "You could always apologise!" This told me that no one, not even my equals, supported the letter-writing action, so I was on my own...I ended up going to the Deputy Manager and "owning up," in a flood of tears...My reputation now in tatters, I struggled on in my job for a while longer. I did not want to have to admit

“defeat” and “failure.” I now feel that this was rather misplaced heroics, but, at the time, I had no way of knowing what to do (Birch, 2003, 144).

What is significant in terms of the discussion here is not that Birch undertook this action in defence of her friend, but how her prior understanding of the situation informed her actions (Birch, 2003, 143). Birch’s reflexive understanding of what needed to be done was not connected to an understanding of how this might play out in relation to the habitus and cultural horizons of the office. Had she been in possession of this knowledge, she may well have reported the discriminatory behaviour, but chosen to do so in a different way. This interpretation is supported by the characterisation of her involvement in this episode as ‘mis-placed heroics’, undertaken in conditions where she had ‘no way of knowing what to do’ (Birch, 2003, 162). Whether or not understanding her differences through the lens of a diagnosis would have helped prevent such difficulties is open to speculation; however, given Birch’s reflections elsewhere on the impact of being diagnosed, it may have been relevant in shaping how she came to understand such difficulties in relation to her sense of self:

To say that this discovery was a bombshell would not be an exaggeration: it was a life-changing event. It reinterpreted most of my life in a new,

understandable, and logical way. As with everything else in life, I would rather know the truth about things, the reason why something is happening in a certain way: and now, for the first time, I could understand why things had happened in certain ways. Even though I still have some of the difficulties associated with Asperger Syndrome, it helps 100 per cent to know why I am different – instead of having to think... that I was “crazy,” “stupid,” “not able to get it all together.” (Birch, 2003, 199).

It cannot be expected that having a diagnosis would have given Birch the intuitive understanding of the potential consequences of her actions within the ‘new style’ office, nor made her co-workers more supportive. However, given her comments about the significance of ‘not ‘having to think...that I was “crazy,” “stupid,” “not able to get it all together.”’ when encountering difficulties in post-diagnostic phase, it may have played a role in mediating the feelings of ‘failure’ and ‘defeat’ that she associated with the last months of her job.

Birch’s experience in the office provides an example of how changes in habitus and access to supportive relationships can shape understandings of self in relation to the workplace fields, as well as associated insecurities. Initially, when surrounded by supportive colleagues such as Nell, Birch frames herself as one who faced

difficulties but was often able to cope with the help of others. However, changes in the cultural horizon of the office, and the 'new style' colleagues she encountered meant that she then had to face everyday insecurities without this support network. This meant that difficult situations became harder to manage, and were attended by increasing feelings of 'defeat' and 'failure' which ultimately led her to quit a job that had been 'so meaningful' to her (Birch, 2003, 145). These feelings speak to an internalisation and configuration of these difficulties not only as confusing, but also as illegitimate – the feeling that she should be able to cope in the same way as others around her. Birch's experiences in the old and 'new style' offices point to the idea that in addition to providing practical assistance, support from others can also provide a sense of social legitimacy that may help guard against the internalisation of everyday insecurities as personal failings.

7.2.2 - Sensory issues, stress and vulnerability (Gunilla Gerland)

Birch's narrative illustrates the impact that having/not having supportive relationships in the workplace can have on a person's ability to negotiate everyday insecurities, and the implications of this for pre-diagnostic understandings of self. Gunilla Gerland's experience of working in a busy nursery presents another perspective on this theme, by indicating how coping with everyday insecurities linked to sensory sensitivities over long periods can leave AS people particularly

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vulnerable to destabilisation by unforeseen events. In chapter six (6.1.1), I noted Gerland's experience having to consciously sort her sensory impressions in order to understand the world around her. Elsewhere in the narrative, she describes how this affected her experience of working in a day nursery, and in particular the challenges of sensory overload and physical exhaustion to which she was exposed. Initially, she found herself practically suited to working within this environment:

I hadn't chosen the job for any special reason. Anyone could get work in day nurseries. But I found out that I worked well with children and that I had an innate talent with them. I was concrete, clear and calm. I had endless patience. I never felt personally attacked by any child and I never got cross. I found it easy to set clear limits and be the same person without changing from one day to the next. I had no shifts of mood or days when I was easily irritated. On the whole, I was evenly the same. I was as if made for insecure children, so it turned out that I mostly worked with them (Gerland, 1997, 144).

Gerland frames her attachment to the field of the nursery in terms of its congruence with her dispositional ways of being with the children (i.e. 'concrete, clear and calm'), particularly the 'insecure' children. Working in the nursery also

gave Gerland the kind of activity that was both meaningful (1997, 144) and consistent (i.e. 'I...found it easy to be the same person without changing one day to the next'). However, these favourable conditions were attended by what were often demanding sensory experiences, compounded by a lack of understanding as to their cause:

[T]he environment was terribly demanding. I had no good explanation to offer for why it exhausted me so, but there was always noise and movement, a mass of people, and I found it muddling and tiring. Being there sucked all the strength out of me, although I liked being with the children so much...I just tried to arrange life in such a way that I wouldn't have to face things I couldn't bear. I felt peculiar in an obscure way – all my evasions took up so much of my energy. Why couldn't I have an ordinary job, an ordinary apartment, an ordinary life? (Gerland, 1997, 144-145).

While working in a nursery was in many ways dispositionally agreeable to Gerland, it also involved insecurities around the need to manage sensory issues. The 'double-burden' of having to deal with these challenges, combined with bewilderment as to their cause, left Gerland vulnerable to destabilisation by unforeseen events, specifically her mother's mental health crisis.

While walking to work one day, Gerland found her mother in a dishevelled and distressed state in the street, shouting and 'hallucinating' (Gerland, 1997, 190). After trying (and failing) to have her admitted to a local psychiatric clinic, Gerland took her back to the family home which she had left two years before. At this stage, everyday life was already highly stressful, and the re-emergence of her mother eroded further Gerland's ability to cope:

Before this incident, I had had no contact with my mother for a long time. But now she started telephoning me saying she was going to kill herself, or she would pour out a whole stream of invective about how awful I was. Those phone calls took up all my remaining energies...Life was not for me. I had no strength left, not for anything. I could hardly cope with work any longer – I hadn't the energy to sort my sensory impressions in those surroundings. It became too much for me to attempt to keep all those people apart and concentrate on whatever I was doing in a room full of children running about, jumping and yelling. Everyday day I'd finished work, I went home, closed the door behind me, and slept. I was totally finished. I did the best I could at work, then there was nothing left (Gerland, 1997, 193).

Having to deal with chronic conditions of chronic environmental stress, compounded by the feelings of confusion and frustration led to a gradual decline in both her physical and mental wellbeing, as well as her resignation from the nursery (Gerland, 1997, 193):

I was often ill and had minor accidents. I cut myself. I twisted my ankles and cracked a bone in one of them. My body kept saying it couldn't cope, but I didn't understand why it couldn't. I was young. I ought to be able to work, like anyone else. It had to be because I was lazy, just as everyone had always said. It had to be my own fault that I failed at everything, that I had no life. The will to live withered in me. I hadn't the strength to wish for anything any longer, except possibly to be away from everything (Gerland, 1997, 193).

For Gerland, negotiating the sensory environments of the workplace not only risked exhaustion and overload, but also left her vulnerable to destabilisation by unforeseen events. This was attended by feelings of inadequacy and inferiority when compared to others, and guilt at her difficulties in coping with daily life. The erosion of her coping resources also led to an internalisation of her difficulties as personal failings, and the feeling (compounded by comments received from others

in the past) that her struggles were illegitimate in both personal (e.g. 'I ought to be able to work, like anyone else) and social contexts (e.g. 'It had to be because I was lazy, just as everyone had always said'). Gerland's writing thus illustrates the consequences of having to deal with problematic environments and unforeseen events, in conditions where understanding of and support for negotiation of these insecurities may not be available.

7.2.3 - Discussion

As indicated in chapter two (2.1.1), gaining and maintaining employment can be difficult for many AS people due to social and sensory issues, as well as inadequate support and understanding of their needs as employees. The two narratives discussed in this section are indicative of the additional challenges that may be faced by those living without a diagnosis, and how these everyday insecurities can impact on pre-diagnostic formations of identity. Access to social resources in the form of supportive relationships may be especially important in the pre-diagnostic phase of life, given the confusion that accompanies such difficulties.

The discussion in this section is illustrative of the significance of having/not having social support, as well as the confusion and vulnerability and internalisation of

difficulties as personal failings that this may entail. On a practical level, having supportive colleagues can help negotiate social regularities which may not be immediately 'given' to the person, or to cope with problems linked to sensory overload. In addition to practical resources, supportive relationships may shape relations between everyday insecurities and pre-diagnostic identity. For Birch, prior to the changes in the field of the office, her writing conveys the experience of someone who faced difficulties but could cope, and differs markedly from the internalised feelings of 'defeat' and 'failure' that she experienced in the latter part of her time there. Thus supportive relationships may also be important in helping guard against internalised feelings of illegitimacy, in particular where the person faces negative comments from others in relation to their difficulties (as was the case for Gerland, in whose narrative there is no evidence of support from nursery colleagues). For both authors, the stress associated with managing everyday insecurities eventually led them to withdraw from employment, within significant consequences for their wellbeing.

7.3 - Summary

In chapters five and six, I sought to explore how different aspects of self developed in the pre-diagnostic lives of the seven autobiographers here considered. In this chapter, my aim has been to explore how these aspects of identity formation relate

to understanding and negotiation of everyday insecurities. In so doing, I have sought to demonstrate further how the approach to identity that I have taken is useful for understanding aspects of pre-diagnostic life. For this reason, two themes (parenthood and employment) were chosen that, while often highly personal, can also be seen as having general relevance to the wider AS population (see discussion in 2.1.1 and at the beginning of this chapter).

Negotiation of everyday insecurities is bound up with understanding and presentation of self in dispositional, collective and reflexive contexts. For Hadcroft, his sense of dispositional self shaped an aversion to fatherhood, whereas for Robison his dispositional differences were not considered in this context until after his diagnosis (when they were also connected with the collective category of being 'Aspergian', as a way of framing strengths and difficulties that his son might face). Lawson's account of her reflexive self also points to the impact of externally conferred labels in terms of how they shaped her understanding of self in relation to others and behaviour. Finally, Birch and Gerland present different perspectives on how having/not having access to social support as well as understanding of one's difficulties, can leave AS people vulnerable to destabilisation and the harmful internalisation of difficulties as personal failings in pre-diagnostic life.

The concepts of authenticity, accountability and legitimacy have also been helpful in understanding aspects of the experiences. For example, Hadcroft's aversion to parenthood indicates concerns about the freedom of his children to experience authentic ways of being, given the demands that he felt he might impose on them as a father (this also links back to his view of actions that were 'legitimate' for the role of parenting). In Lawson's account of negotiating her schizophrenia label as a new mother, we see how unequal relations of power played out in the practical negotiation of accountability relations within the healthcare field. Finally, in the writings of Birch and Gerland, we see the importance of personal and social legitimacy in understanding everyday difficulties, both in terms of how support from others can help prevent internalisation of difficulties as personal failings, while isolation and the confusion of not understanding one's difficulties may have the opposite effect.

Even within a very small sample group, and despite common experiences in social and sensory contexts, considerable variation exists in terms of both the quality of everyday insecurities and their implications for pre-diagnostic understandings of self. The relationship between these two domains is reciprocal; how one understands and presents oneself shapes orientations to understanding and negotiating insecurity, and vice versa (this echoes theoretical arguments made elsewhere in the sociological literature linking identity formation and risk

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negotiation (Tulloch and Lupton, 2005). Once again, while it is difficult to isolate the impact of the diagnosis from other factors in life, the narratives indicate that the absence of the sense-making resources provided by a diagnosis are significant in this relationship.

8 – Understanding formations of pre-diagnostic identities (Conclusion).

This thesis project began with the general assumption that the diagnosis would be the most important event in the lives of the writers. The results of this investigation reveal that, while diagnosis is undoubtedly an important event, as an event it is one among many factors that influence how knowledge of one's differences through the lens of AS affect understandings and presentations of self. Discussion of the narratives has indicated that it is often very difficult to isolate the specific impact of diagnosis, outside of the wider social and biographical context into which it enters as a life event. Even within what is a small set of life stories, we see considerable variation in terms of experiences and circumstances, and thus significant differences in formations of pre-diagnostic identities. Exploring lives biographically has allowed us to see how different aspects of self interact with others in the formation of different pre-diagnostic 'selves'. Just as it is difficult to isolate the impact of the diagnosis, is it often not possible to understand how aspects of self later associated with AS are understood in pre-diagnostic life, without reference to other aspects of a person's identity. In this concluding chapter, I will summarise the main findings of the project, and discuss their implications for future research.

8.1 – Summary of findings

8.1.1 – Question summaries

8.1.1.1 - Understanding the dispositional self in the pre-diagnostic phase of life.

For those who grow up without a diagnosis, feelings of confusion and distance in terms of relating to dispositional ways of being appear common. Early understandings of dispositional self can involve strengths and limitations, that develop through encounters with everyday situations. For example, Gerland's 'sharp vision' and difficulties with making gestalt connections (Gerland, 1997, 249, 50), Lawson's perceptual and affective connection to the natural world and difficulties with 'apprehension, interpretation, communication and comprehension' (Lawson, 1998, 28, 1), and Willey's ability to 'captur[e] the essence and persona of people' matched against feelings of 'remova[al] from [the] domain of others' (Willey, 1999, 22, 27). As the person grows older and moves into wider fields outside the family home, and often as a result of difficulties in connecting with the demands of the dominant habitus, aspects of their dispositional selves may become associated with feelings of difference and separation from others. Feelings of difference and separation from others may lead the person to view their dispositions as illegitimate, they may therefore seek to minimise these behaviours and/or imitate the actions of others, which can have implications for wellbeing by restricting opportunities to enact and experience dispositionally appropriate ways

of being (e.g. Willey's 'fitting in trick' and Gerland's attempt to 'bleach out' her differences) (Gerland, 1997, 127; Willey, 1999, 57). However, for some (such as Will Hadcroft) feelings of difference may have the opposite effect, in that the person comes to see their ways of being as legitimate, and opposes them to the dominant habitus.

8.1.1.2 – Impact of self-other relations on formations of pre-diagnostic identities.

Reflexive and collective aspects of self can also shape understandings of dispositions, by contextualising dispositional differences through particular cultural lenses, for example, in 6.1.1, we saw how Purkis' rule-oriented dispositions were filtered through the cultural context of practically hospitable fields, such as the church, the party, and the prison. Her initial rejection of the diagnosis also indicates that even where this is believed to 'fit' with a dispositional sense of self, it may not override reflexive or collective aspects of identity. Elsewhere, in Birch's story (6.1.2), we see how her sense of dispositional difference was shaped by regularities of gender and sexuality, for example, in her coming up against gender norms in childhood, and negotiating the practical conduct of relations within the majority-lesbian household. Meeting of dispositions and habitus can result in different degrees of identification with different collectives, for example, Purkis' sense of

security in knowing the 'rules' of church and the party (discussed in 6.1.2) was contrasted with her sense of distance from meaningful involvement in the cultural life of either field. In contrast, Robison distinguished his 'logical empathy' from the dispositional ways of empathising exhibited by others (as we saw in 6.1.3).

Coming up against difficult aspects of habitus and the cultural horizons of field can mean that it is sometimes difficult to enter relations of accountability, grasp tacit calls to order, and to provide the commentary expected by others within a particular field. Participation in social life (and therefore its implications for formations of pre-diagnostic identity) can also be mediated by the social and cultural resources to which one has access. For example, the presence of 'rulebooks' was a significant factor in enabling Purkis' participation within the church and party, by helping her to grasp some of the regularities at play within these fields. In contrast, Robison's description of his limited success in social interactions by relying on models provided by computer speech software indicates that available resources can also constrain opportunities for social coordination. Given the feelings of confusion and distance that appear in the autobiographies, access to social and cultural resources may be especially important in providing opportunities for connection and identification with others.

8.1.1.3 - Everyday insecurities and pre-diagnostic identities.

Understanding and presenting the self is also bound up with how a person understands and negotiates everyday insecurities. This can relate to how a person understands their dispositional self relative to potential future events, for example, fatherhood. In 7.1.1, we saw how Hadcroft opposed his dispositional self to the attributes that he felt proper to fatherhood; in contrast, Robison chose to become a father and later framed insecurities around parenting in terms of both strengths and limitations associated with AS in the post-diagnostic phase of life. Lawson's narrative (discussed in 7.1.2) shows how the intersection of dispositions with labels conferred by powerful others (in this case her schizophrenia diagnosis and positioning as a new mother within institutional mental healthcare) can condition understandings of and responses to insecurity. As observed in chapter two, gaining and maintaining employment is a challenge faced by many AS people, and those living without a diagnosis may face a particular set of challenges stemming from confusion associated with differences from others and everyday difficulties. As Birch's narrative (discussed in 7.2.1) indicates, access to social resources in the form of supportive relationships can help mediate practical difficulties, but also mitigate internalisation of those difficulties as personal failings. Gerland's account of how her capacity to cope eroded in the face of everyday sensory challenges and confusion surrounding them, and the subsequent re-emergence of her mother

following her mental health crisis, provides an example of how in the absence of understanding and support, internalised feelings of failure can have significant implications for wellbeing.

8.1.2 – General findings

8.1.1.1 – Authenticity, accountability and legitimacy

In the work of Nettleton (2006 – see 2.1.3) accountability was introduced as an important aspect of the ‘double burden’ of living with an undiagnosed condition, where additional stress is caused to the person due to their inability to account for the difficulties created by their illness. While Nettleton’s work dealt with conditions that can be more readily described as illnesses, her concept of the ‘double burden’ is relevant to AS people in the pre-diagnostic phase of life to the extent that they face difficulties arising from the interaction of their dispositions with problematic environments and situations, and confusion as to why these may be the case. In this thesis, I have suggested that issues relating specifically to formations of pre-diagnostic identities in AS people can be framed as involving relations between authenticity, accountability and legitimacy. These ‘thinking tools’ (Bourdieu, 1990b) cut across the dispositional, intersubjective and wider cultural domains to help explore their intersection in the formations of pre-diagnostic identities. They are

not proposed as a predictive framework, but rather a way of getting a grip on issues that are neither separate from, nor reducible to, individuals or wider social factors.

Authenticity, as I have argued, relates to ways of being that are experienced as being dispositionally appropriate to the person – ways of being that ‘feel right’ and through which the person is able to feel at home in the world. The ability of an AS person to pursue these ways of being can be mediated by whether or not these are accepted as legitimate within the dominant habitus (social legitimacy), and whether the person themselves then comes to understand them as legitimate (personal legitimacy). These opportunities are mediated by the practical conditions of the accountability relationship, in particular how calls to order are enacted, the degree to which these are intelligible to the AS person, their ability to respond appropriately, and/or whether they are able to renegotiate the practical conduct of interactions if necessary. Making space for authentic ways of being can be highly significant in terms of wellbeing, while conversely not having to fit into dispositionally inappropriate performances can also not only reduce stress but develop a liveable sense of self. In the pre-diagnostic phase of life, when a person may come to understand their dispositions as differences, the impact of this on formations of identity appears linked to the social and biographical conditions in which the person is situated, and the resources to which they have access. Therefore, while diagnosis may help the person to develop a more coherent

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understanding of themselves and their life events, it is neither a necessary nor sufficient condition for the development of a liveable sense of self.

8.1.1.2 – The contingency of the diagnosis.

While the impact of the diagnosis has not been the main focus of this thesis, the investigation has indicated that this needs to be understood in relation to the specific social and biographical context into which it enters. As we have seen, from the material given in the autobiographies, it is often extremely difficult to isolate the impact of the diagnosis from other events and experiences. While there are clear indications that diagnosis is significant in terms of how the person comes to understand and present themselves, it often appears as one among a number of developments in the formation of a liveable sense of self (which is by no means inevitable in post-diagnostic life, as indicated in Gerland's post-diagnostic reflections discussed in 5.1.1). What this means is that understanding formations of pre-diagnostic identities, and engaging with the life stories of AS people who receive a late diagnosis, is crucial to understanding the impact of the diagnosis on particular people.

8.2 – Implications for further research.

8.2.1 - The value of textual communication

The monographs here discussed reflect the findings of existing sociological research in that, for many AS people, textual communication can be a particularly suitable medium for exploring and communicating life experiences. Dispositional issues with more ad-hoc, iterative forms of communication (for example, semi-structured interviews) can be avoided, and the person may have more time and space to consider and formulate responses, rather than feeling compelled to comply with the demands of the social/research situation. For AS adults who receive a very late diagnosis, autobiographical writing can be also be a practical tool for sense-making in the light of profound changes to aspects of self that arise in light of the diagnosis, something that is supported explicitly by several of the autobiographers (Lawson, 1998, 3; Birch, 2003, 9; Robison, 2008, ix-x; Hadcroft, 2005, 17-18). Thus, in exploring the experiences of those who receive a very late diagnosis, the use of textual communication over more conventional forms of co-present qualitative data collection may be of benefit. Those who have the time, resources and inclination to write and publish autobiographies may well be a select group, for example, four of the seven autobiographers discussed here had been educated to undergraduate level, with three having higher degrees (see table 1 in 4.3.2). Therefore, other

forms of textual communication, such as online forums, text based chat, private or public blogs, or handwritten diaries may also be helpful in allowing others to tell their story.

8.2.2 - Development of qualitative data collection methods as an iterative and participatory process.

While text-based communication appears a useful medium for exploring experiences for many AS people, we should also consider other possible ways in which to explore life experiences. Multiple perceptual and dispositional profiles are known to be present in the population of AS people (Bogdashina, 2003; Jones et al., 2003; Baron-Cohen et al., 2009), in addition to variations in social position and biographical situation, and therefore there may be a range of different orientations to engagement and communication with which qualitative researchers will need to engage. Given this range of possible sensory experiences, exploring different ways of engaging with life experiences could open up new avenues for representation of life experiences to research audiences, as well as uncovering aspects of experience hitherto unrecognised in research.

One potential avenue could be the use of video technology as a way of exploring experiences of sensory environments, an example of which was produced as an adjunct project during my time as a researcher on this PhD. David Howell (a colleague who has a diagnosis of Asperger's Syndrome) and I collaborated on a

short film in which we explored his use of mobile technologies for mediating sensory difficulties in work-based travel, the abstract for which appears below.



Image 9 – David waiting for a train on a busy concourse at Kings Cross Station (still from 'Commuting Under Pressure')

For many people on the Autism Spectrum, sensory sensitivities and perceptual differences can present issues in navigating everyday public spaces. Crowds, noise and sudden changes to environment or scheduling are just some of the potential hazards faced by travellers on the spectrum, and this can have significant implications for access to employment. However, mobile technologies increasingly provide tools for addressing many of these challenges. In this film, David (who has a diagnosis of Asperger's Syndrome)

retraces his journey from Southampton to Leeds (via London) in order to illustrate the use of mobile technology to assist with travel. This was a journey that he made for work while an employee of the National Audit Office Graduate Scheme (Howell and Bracher, 2012).

This film was produced using commonly available consumer electronic and home computers, involving an initial day of shooting and a further month of collaborative editing and voice-over work conducted through online exchange. This flexible and low-cost (c.£300) process allowed us not only to explore Howell's experience of commuting but to do so in a way that brings to the attention of audiences aspects of experience that may be neglected in text. For example, it was noted that the camera gives a reasonably faithful representation of Howell's issues with sensory gating and overload. This is because the device captures visual and auditory stimuli *en bloc*, without the context-specific and interest-relative processing that shapes many non-AS people's experiences of lifeworld. As Howell notes in the introduction to the video 'it is very hard to describe what sensory overload feels like, and much easier to show it through sound and vision' (Howell and Bracher, 2012).

This is only one way in which researchers may work with AS people and help enable them to tell their stories. The wider point is that whatever the medium, it appears

advisable for the process of data collection to be collaborative and evolve in response to the person's experience of participation. Beginning with a range of potential methods, a 'toolkit', rather than a fixed medium may be beneficial in engaging and maintaining the participation of AS people, as well as overcoming the limitations of particular methodologies.



Image 10 – David describes his reaction to the noise of a tube train beginning to move (still from 'Commuting Under Pressure').

8.2.3 – Future research directions.

While the focus of this thesis has been on formations of pre-diagnostic identity, the discussion here undertaken raises a number of questions in relation to peri-diagnostic experience more generally.

8.2.3.1 – What happens next? Exploring formations of post-diagnostic identity.

It has been necessary at certain points in this thesis to compare pre-diagnostic life with post-diagnostic in order to explore formations of identity in the latter phase. Although the precise impact of the diagnosis is often difficult to isolate, it appears significant and variable in terms of the qualitative experience of different people diagnosed. Given the variability in individual biographies, pre-diagnostic experiences and experiences of the diagnosis, one area for future research could therefore be to explore how a diagnosis relates to the longer term development of identity. One potential direction of this could be to explore how the diagnosis as a form of knowledge is operationalized in different circumstances and settings, in terms of its variable value as a form of cultural capital (i.e. one that gives access to, for example, affordances and accommodations, and/or allows the person to make claims for renegotiation of problematic social and environmental situations). During the latter stages of my PhD project, I was recruited (on the basis of an early draft) by the Autism Diagnostic Research Centre Southampton as a Research Fellow, to explore peri-diagnostic experiences. Part of this has involved examining items of

unsolicited feedback (e.g. emails, letters and cards) for the purposes of service evaluation, and to inform an on-going project exploring post-diagnostic experiences. In these materials, there are indications that the diagnosis plays a significant role not only in how the person comes to understand their dispositional selves, but also how they understand their relationship to the habitus and cultural horizons of everyday situations.

Diagnostic reports provided by the ADRC contain information for the person being diagnosed (such as data from neuropsychological assessments) as well as guidance for employers and others who may work with the person. Early indications from this material are that for some people, the diagnosis (and the resources objectified in the diagnostic report) can shape post-diagnostic understandings and presentations of the self in a variety of ways. The conditions of pre-diagnostic life and formations of identity in this phase may be significant in understanding how a diagnosis affects different people who go through this process in adulthood.

8.2.3.2 – Aging and AS

As indicated in 2.1.1, understanding of the needs of autistic adults on the part of service providers is known to be patchy (Rosenblatt, 2008), and far less attention

has been paid by researchers to this group compared with children (Lawrence et al., 2010). For older adults, the picture is even less clear, with virtually no specific research attention paid to questions of autism and ageing (Happé and Charlton, 2012), despite long-standing calls for further inquiry (Perry et al., 2009). There are also likely to be significant numbers of people within the ageing population who would meet the criteria for AS but are living without a diagnosis, due to the fact that the diagnostic recognition has only been widely available since the 1992 (Baron-Cohen et al., 2007). Undiagnosed adults may face a 'double burden' in terms of living with the everyday challenges associated with their condition, as well as confusion and distress associated with difficulties that often have no obvious cause and may mark them out for discrimination and ill-treatment by others (Baron-Cohen et al., 2007; Juuso et al., 2011). These aspects may combine to produce particular challenges/profiles of difficulty – for example, late-life redundancy could precipitate changes in the routines of everyday life which increase problematic encounters with unfamiliar and socially/sensorily challenging environments. This could then reduce mobility and physical activity, with implications for social, mental and physical wellbeing (Phillips et al., 2010).

Apart from the ethical and legal responsibilities which society has to people in this population, this is a cohort that will increasingly be making use of services that put pressure on the public purse as they age. The National Autistic Society estimate,

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based on the 2001 Census, that the number of adults with an Autism spectrum condition may be in excess of 500,000, over 50% of which may have an average or above average IQ (NAS, 2013). Understanding their needs and assisting them in coping with the challenges of ageing may not only have ethical significance, but also cost saving implications in terms of reducing take up of services for acute or chronic mental and physical issues associated poor support (Rosenblatt, 2008; Allard, 2009). These savings are not limited to take up of services, but as Lawson observes (in Hill, 2000), in the preventing waste of socio-economic contributions that AS people as fellow citizens make to wider society.

Epilogue – The Missing Centre.

My aim throughout this project has been to pay close attention to the experiences of AS people, and for that reason the closing comments of this thesis reflect what I have come to understand as an important yet under-appreciated concern in research relating to AS people. In the middle and later stages of my project, I came into contact with the academic work of researchers and activists on the spectrum, and have been lucky enough to correspond, discuss and share ideas. Through these discussions, I have become aware of a number of issues that researchers on the spectrum have identified over the state of AS voices in contemporary research – and this includes social scientific investigations. The different groups and individuals that are subsumed under the category of ‘autistic self advocacy’ are not homogenous; however, there does appear to be a general level of agreement with the idea that research should be inclusive of people on the spectrum not merely as ‘subjects’ of research but as active participants in the creation of knowledge. This is encapsulated in the slogan ‘nothing about us, without us’, a phrase first used by South African disability campaigners and later adopted as an official slogan of the US-based Autism Self-Advocacy Network (ASAN) (Charlton, 1998; ASAN, 2013). In contemporary social science and allied disciplines, participant involvement and reflexive practice on the part of the researcher are cornerstones of epistemologically and ethically sound research practice (Wiles et al., 2004).

Unfortunately, there are indications that in some cases practice has failed to live up to these standards, whether intentionally or through ignorance, and this has resulted in distrust among some researchers and activists on the spectrum that I have encountered.

AS researchers and activists with whom I have spoken describe being wary of discussions with unfamiliar academics, in part because they feel that their AS status excludes them from the professional considerations that would automatically be afforded to other colleagues. Far from participating in an intellectual discussion or exchange, they feel that their thoughts and reflections are being 'mined' and 'plundered' for the advancement of other researchers. Claims have been made of blog posts and discussions in online forums appearing in peer-reviewed publications by non-AS academics, who were known to be frequenting these environments. Elsewhere arguments have been made regarding the exclusion of autistic voices in research by non-AS academics (sometimes referred to as 'colonisation'); for example, in his review of Stuart Murray's (a non-AS author) 2011 book *Autism*, Arnold argues:

It is an irony that this book (apart from its minor errors) says nothing wrong, but is wrong by being there, although one wonders what would be there if it was not. Murray and kindred academics are unfortunately squeezing out the authentic and autochthonous autistic strain that ought to be giving voice to the particular perspectives that he does (Arnold, 2012, 730).

Arnold's comments point to the danger that even well-meaning research that speaks *for* AS people, may itself serve to reinforce existing inequalities in knowledge production.

Two concepts originating from within the AS research community, have been used to describe the disabling and limiting features of framing AS researchers and contributors as mere objects of research rather than active participants in the creation of knowledge. 'Fish-bowling' denotes the process of framing an AS person who contributes to a conference or an edited collection, in such a way as to isolate them from wider intellectual consideration. Like a fish swimming in a bowl, they are separated from the audience and become an object to be observed rather than a person or colleague contributing to an investigation or discussion. This idea is compatible with the idea (discussed in 4.2.1) the 'self-narrating zoo exhibit' – one who is framed in such a way as to present an 'interesting case' for consideration and inspection by others (Sinclair, 2005).

The emergence of these concepts is indicative of two wider problems beyond plagiarism and attribution which appear in contemporary academic discussion of AS issues. The first of these is the issue of 'tokenism', where an event or publication on

AS, organised and framed by non-AS people, involves an AS speaker or writer who is invited to discuss 'their life' or 'their experience'. Often, this will be the extent of their involvement, and may be the limit of what some non-AS researchers and professionals expect them to either be capable of. Rarely are AS people invited to participate in organisational or agenda-setting aspects of such endeavours. This is problematic not only for the practice of research but for the quality of what is produced; for example, that which makes 'good life' or promotes wellbeing for different AS people may not be immediately visible or generalizable to non-AS people and may vary across the different people in the AS category. The second issue has to do with what I call the 'glass sub-heading', where the normative structure of research publications quarantines the ideas and reflections of AS people as 'data' within a discussion section in an academic paper. The consequences of this are that AS people are often exiled from the theoretical space which remains the preserve of non-AS academics.

To dismiss this as part of the inevitable development of an 'emerging' field in social scientific research would in my view be a mistake – AS people have been writing and theorising in this area for over fifteen years (Sinclair, 1993; Bovee, 2000; Shore, 2001; Sinclair, 2005; Sinclair, 2007; Baggs, 2008; Murray et al., 2005; Lawson, 2009; Arnold, 2010; Milton, 2011; Milton et al., 2012; Milton and Moon, 2012; Milton, 2012; Arnold, 2012). Moreover, this is clearly something recognised by parts of the

wider academic community who have made use of AS authored texts, websites and forums as sources of data for more than ten years. Researchers (AS and non-AS) in this area refer to the 'classics' and foundational texts of AS writing, such as the work of Jim Sinclair and others who helped establish some of the core concepts of the neurodiversity movement (many of which have been cited in academic publications). It is perhaps telling therefore that these core texts, the influence of which is clear in contemporary discourse of mainstream research, have yet to appear in a recognised academic volume.

It is important to clarify the context in which I highlight these points. Firstly, I am not suggesting any kind of conscious academic conspiracy against AS people; indeed such a situation might actually be easier to address, than what I believe to be the case. This is that despite rhetorical commitment to emancipatory ethics and reflexive practice, too often the demands and temptations of publication and prestige condition how people's experiences are used in research. I am not suggesting that the demands on researchers are not often arduous, intersecting other pressures, for example, to publish and generate impact. No one is perfect, and this is a question of degrees rather than absolutes. What might be beneficial therefore is to make conscious effort to bring those whom Bogdashina, now more than ten years ago, called the 'native experts' (Bogdashina, 2001, 1) into a central position in theorising AS experiences. Indications of more epistemologically and

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ethically sound models of knowledge production, for example, in the work of the Academic Autism Spectrum Partnership in Research and Education (AASIPRE) (Kidney et al., 2010; Raymaker and Nicolaidis, 2010; McDonald et al., 2011; Nicolaidis et al., 2011). Future researchers in this area may therefore reflect on what opportunities for reflexive consideration of research findings are provided by the practical process of participation in the projects that they design and implement

Secondly, this is not an argument for standpoint epistemology or the homogeneity of opinions within the diverse community of AS authors. If my experience at the *Theorising Autism* conference (a majority-AS one day seminar organised by and for researchers and activists on the spectrum) is any guide, the community of AS contributors have, unsurprisingly, different experiences and perspectives (as have the autobiographers whose experiences are explored in this thesis). They disagree, argue and engage in debate, just like most other social groups. The issue is not about privileging the subaltern or a particular standpoint – it is about addressing the interrelated epistemological and ethical issues of AS people not being able to contribute to theoretical knowledge due to artificial constraints.

Thirdly, I do not wish to denigrate the current and potential future contributions of social scientific perspectives, nor the work done by social scientists to enrich

understandings of AS and provide opportunities for participatory research. The theoretical resources of social science have been important for AS writers in a variety of contexts, not least for contestation of clinical narratives of their experiences (Shore, 2001; Arnold, 2010; Arnold, 2012; Milton and Moon, 2012; Milton, 2012). This is, again, not in any way to minimise the work of conscientious clinicians, many of whom may already be practising the kind of participatory ways of supporting and working with AS people that are suggested by the present thesis (indeed I am aware of examples of this). Rather, it is to recognise that one of the key intellectual struggles faced by AS people has been to counter overly general theoretical accounts of what they can and cannot do, that have been imposed by non-AS authors. In my own theoretical approach, I have attempted to avoid this by exploring the interdependence and contingency of dispositional, social conditions and biography in the production of pre-diagnostic identities.

Finally, the points I have made here stem from discussions with a particular group of AS people; academically trained, engaged with contemporary research and personally invested in the types of issues here discussed. This does not mean, therefore, that these concerns are relevant to all AS people; there may be those who, upon receiving the diagnosis, may simply wish to concern themselves with making a liveable life, or conversely use this as a springboard to become involved in wider debates. Whatever the case, the points I have raised reflect what I believe to

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be important issues for contemporary sociological research, attention to which can help develop future research programmes on more ethically and epistemologically sound bases, and thus contribute to the production of knowledge that is useful in promoting wellbeing.

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