LIVING WITHOUT A DIAGNOSIS: FORMATIONS OF PRE-DIAGNOSTIC IDENTITIES IN THE LIVES OF AS PEOPLE DIAGNOSED IN ADULTHOOD

1—Background and research questions: Asperger Syndrome (AS) is currently understood as a neurodevelopmental condition associated with difficulties in social communication, social interaction, and social imagination (Baron-Cohen, 2008; Tantam, 2012). Many AS people also experience differences in sensory sensitivities and perceptions of the surrounding world, when compared with those typical of non-AS people (Bagidahina, 2003; Baron-Cohen 2008). Most diagnoses are now made in childhood; however, there remain a number of people who are diagnosed in adulthood (Baron-Cohen, 2007). 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 either without a diagnosis or with an incorrect diagnosis (Baron-Cohen, 2007). This is an under-researched group, whose pre-diagnostic experiences have thus far not been subject to detailed investigation, and as such are often partly or consistently understood both academically and by service providers (Rosenblatt, 2008; Allard, 2009).

The aim of this PhD project was to explore 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?

2—Theory: My conceptual approach is based on Bourdieu’s interrelated concepts of practice, habitus, field and forms of capital (social and economic) (Bourdieu, 1986, 1990). However, I argue that Bourdieu’s assumptions about how the world is presented and dealt with by agents (i.e. primarily through tacit, intuitive know-how or a ‘practical sense’, interspersed by moments of reflexive activity) need to be rethought in light of differences in AS people’s perceptions of and dispositions towards acting in the everyday social world. What for non-AS people can often be taken for granted in their experience of the everyday world is often not so for AS people, and as such alternative ways of negotiating interactions and environments must be developed, often through systematic observation and the generation of rules (Sterponi, 2004; Ryan and Räisänen, 2008). Therefore, in this case Bourdieu’s ‘logic of practice’ needs to be understood in terms of a different logic (Ryan and Räisänen, 2008), rooted in a range of perceptual ‘terms of engagement’ with the developed, often through systematic observation and the generation of rules (Sterponi, 2004; Ryan and Räisänen, 2008), leading me to adopt a comparative life story approach (Goodley, 2000). The sources of empirical material for this investigation were autobiographies, which appear at present to be the only sources of available qualitative data suitable for exploring pre-diagnostic experiences across broad periods of life. The seven monographs were analysed using the NVivo CAQDAS software package.

3—Methods and Sources: Existing literature indicates that the relationship between AS and identity is subject to change across the life course (Molloy and Vasil, 2004; Bagidahina, 2003; Davidson and Henderson, 2010), leading me to adopt a comparative life story approach (Goodley, 2000). The sources of empirical material for this investigation were autobiographies, which appear at present to be the only sources of available qualitative data suitable for exploring pre-diagnostic experiences across broad periods of life. The seven monographs were analysed using the NVivo CAQDAS software package.

4—Findings: How do AS people understand their dispositional selves in the pre-diagnostic phase of life? For those who grow up without a diagnosis, feelings of confusion and distance in relation to dispositional ways of being appear common. Early understandings of dispositional self can involve strengths and limitations that develop through encounters with everyday situations. As the person grows older and moves into wider fields of 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. These feelings may lead the person to view their dispositions as illegitimate, and they may therefore seek to manage these behaviors by consciously adopting the actions of others, which can have implications for the person’s wellbeing by restricting opportunities to enact and experience dispositional appropriately ways of being. However, for some feelings of difference may have the opposite effect, as the person comes to see their ways of being as legitimate, and opposes them to the dominant habitus.

5—Ongoing work The findings of this project have informed the design and implementation of a service evaluation current at the Autism Diagnostic Research Centre Southampton. The focus of this project is on post-diagnostic experiences of people diagnosed with an autism spectrum condition in adulthood. The questions under investigation in the service evaluation are:

- How has everyday life changed post-diagnosis?
- What post-diagnostic needs remain unmet?

Ongoing work will explore the themes identified above, as well as specific areas arising from the survey (which will be processed prior to the interview).

Supportive relationships can help mediate practical difficulties, but also mitigate internalisation of those difficulties as negative feelings. In the process of understanding and support, internalised feelings of failure can have significant implications for wellbeing.

Authenticity, accountability and legitimacy. Nettleton (2006) highlights authenticity as an important aspect of the ‘double burden’ of living with an undiagnosed condition. The social stress is caused to the person due to their inability to account for the difficulties created by their condition. While Nettleton’s work dealt with conditions that can be more readily described as illnesses (whereas AS is a condition involving a range of associated strengths and limitations), 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. I suggested that issues relating specifically to formations of pre-diagnostic identities as AS people can be framed as involving relations between authenticity, accountability and legitimacy. Authenticity 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 authentic ways of being can be mediated by the acceptance (or not) of these 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, the degree to which the implicit and explicit ‘calls to order’ (e.g. given in gestures or speech etc.) which shape these conditions are intelligible to the AS person, their ability to respond appropriately, and/or whether they are able to renegotiate the practical conduct of interactions as necessary.

Making space for authentic ways of being can be highly significant in terms of wellbeing, while conversely not having to fit into dispositional inappropriately performances can not only reduce stress but help the person 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 biographic conditions in which the person is situated, and the resources to which they have access. While diagnosis may help the person to develop a more coherent understanding of themselves and their life events, it is neither a necessary nor sufficient condition for the development of a liveable sense of self.

The contingency of the diagnosis. While the impact of the diagnosis was not the main focus of this thesis, this needs to be understood in relation to the specific social and biographic context into which it enters. 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 people come to understand and present themselves, it often appears as a part of 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 Gerard’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 the individual.