

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

in adulthood.

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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 (Bogdashina, 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 living 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 poorly or inconsistently 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?

These questions were explored through comparative analysis of seven autobiographies, authored by AS people who were diagnosed in adulthood, through which I develop an account of relations between

- **authenticity** (i.e. one's ability to experience dispositionally appropriate ways of being)
- **accountability** (i.e. referring to the social and cultural conditions of exchange with others)
- **legitimacy** (i.e. 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 so doing, I draw attention to the interrelation of dispositional and social circumstances in shaping individual life experiences.

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 everyday world, which shape different dispositions to acting in it. The need to make sense of everyday situations, knowledge of which is not intuitively 'given' to the person, also means that reflexivity often plays a larger part in negotiations of the social world than in Bourdieu's original formulation.

My approach to identity is informed by Bottero (2010), whose developmental critique of Bourdieu frames three aspects of self:

- **Dispositional** identities— those 'expressed through implicit modes of being' rooted in agents' taken-for-granted and dispositionally conditioned ways of acting in the world.
- **Reflexive** identities— explicitly affirmed and expressed through conscious identifications.
- **Collective** identities—relating to those which arise in the behaviour and mobilizations of groups of actors.

4—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; Bagatell, 2007; 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.

Table of sources:

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

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 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. These feelings may lead the person to view their dispositions as illegitimate, and 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. 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.

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

While dispositions shape orientations to actions, reflexive and collective aspects of self can shape understandings of those dispositions, by contextualising dispositional differences through particular cultural lenses. Meeting of dispositions and habitus can result in different degrees of identification with different collectives. 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 in interactions 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. 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.

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

Understanding and presenting the pre-diagnostic self is also bound up with how a person understands and negotiates everyday insecurities. This can relate to how a person sees their dispositional self relative to potential future events, for example, parenthood. 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.

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

Authenticity, accountability and legitimacy.

Nettleton (2006) highlights accountability 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 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 in 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 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 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 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 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 been the main focus of this thesis, this needs to be understood in relation to the specific social and biographical 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 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 the individual.

5—Ongoing work

The findings of this project have informed the design and implementation of a service evaluation project currently being undertaken by 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?*
- *How has the diagnosis changed perceptions of self (if at all)?*
- *Has having a diagnosis changed the behaviour of others towards the person diagnosed, and if so how?*
- *What post-diagnostic needs remain unmet?*

The main aims underpinning these questions are to assess the degree to which post-diagnostic needs are being met, and what additional support may be necessary. Additional aims of the service evaluation are to evaluate the methods used in this project, as a basis for designing an on-going monitoring service, and to inform the design and implementation of post-diagnostic support services for adults. ≤25 participants who were diagnosed in adulthood by ADRC will be asked to complete a standard questionnaire based on the WHO Quality of Life survey (WHO-QoL-BREF), the ONS Social Capital Survey (core questions), and the four ONS questions for overall wellbeing. This will be followed by a semi-structured interview in which the four questions listed above will be explored, as well as specific areas arising from the survey (which will be processed prior to the interview).