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‘How can a chord be weird if it expresses your soul?’ Some critical reflections on the diagnosis of Aspergers syndrome

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This paper questions the way in which the diagnosis of Aspergers syndrome has come to be widely accepted and used as an essentially medical category. It does so by drawing upon sociological and historical analyses of society, psychiatry and psychology, as well as the writings of service users, other practitioners in the autistic spectrum disorder field and the author’s own clinical experience. It is argued that the seeming popularity of this label within Western society may have as much to do with widespread social and cultural change during recent decades as with the supposed deficits of those who attract the diagnosis. The aims are to ask what this might mean for health and social care practice in this field and to encourage the growth of theories and approaches that are grounded more firmly in an awareness of the social environment, while also reflecting the varied experiences and standpoints of people who carry this label.

Keywords: Aspergers syndrome; social and historical context; embodiment; disability

Background

The history of mental illness is littered with examples of diagnostic categories, which in hindsight we can read as the expression of vested interests. (Gomm 1996)

He had to close himself off in one direction, in order to be open in another. (Burnside 2007)

Over the last 20 years there has been a huge expansion in the number of people receiving the diagnosis autistic spectrum disorder/Aspergers syndrome in Europe and the USA – up to 1000%, according to some estimates (Grinker 2007; Fombonne 2005a). The reasons for this increase are still disputed, but they may include a greater awareness of autistic spectrum disorder categories amongst health and social care professionals, educationists and the general public, the acceptance of more positive images of autism – especially at the high ability end of the spectrum (Fitzpatrick 2008) – and a broadening of the concept of autism spectrum disorder to include a wide range of educational and behavioural difficulties, many of which were once grouped together under the heading ‘mental retardation’ or ‘schizophrenia’ (Grinker 2007; Fombonne 2005b; Wing 1996).

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My own involvement in this area came about as a result of working in an NHS Adult Learning Disability service which had been asked to provide a small-scale service for adults who had been diagnosed with Aspergers syndrome. In order to do this, we consulted people who had the diagnosis and who were already known to our service. Most of the individuals that we consulted expressed a desire to meet with others who shared their designation and to discuss what the latter might mean on a personal level, and we therefore decided to set up a social support and discussion group for these individuals. This paper represents a distillation of many discussions within and relating to the Shropshire Aspergers' Support Group and at conferences and seminars in the autism field over a period of 4 years. This piece also represents my own efforts to understand some of my experiences and observations in the light of that portion of the critical mental health literature that seeks to place psychiatric theories and practices in their social and political context (see Ingleby 1981; Kotowicz 1997; Laing 1960). Above all, this paper aims to build upon previous literature in this area and to contribute to the creation of more helpful perspectives and practices for working with anyone with a diagnosis of Aspergers syndrome.

The diagnosis of Aspergers syndrome: how reliable, how valid and what does it mean?

According to current psychiatric manuals such as the DSM IV Aspergers syndrome is defined by a so-called triad of impairments relating to social and communication skills and, less tangibly, with regard to the person's ability to imagine the viewpoints or feelings of others. People with Aspergers syndrome may also show a strong preference for routines, they may show an unusually narrow or intense commitment to a particular area of interest, such as fossil collecting or the study of maps for instance, and they may also display unusual postures, repetitive and stereotyped movements and be prone to clumsiness (American Psychiatric Association 1994; Wing 1996). In practice, those who receive the diagnosis will often be characterised by their social isolation and their failure to successfully negotiate those institutions that determine vocational and personal success (Attwood 1991; Romanowski Bashe and Kirby 2005). Attempts to find a neurological basis for the syndrome have not been lacking and some psychologists have gone so far as to argue that recipients of the diagnosis are missing an adaptive neuropsychological 'module' which allows the rest of us to infer the likely viewpoints and motivations of our fellows (see, for example, Baron-Cohen and Bolton 1993; Wing 1996).

Some prevalent myths of diagnosis

For some mental health professionals there is a strong suggestion that helping people with this diagnosis must equate with finding ways to control or restructure aberrant brain mechanisms via the use of individual psychological techniques or medical interventions (Romanowski Bashe and Kirby 2005). In their narrow emphasis on symptom reduction these approaches can sometimes be experienced by service users as a form of ill considered and coercive technical fix (Dawson 2004; Fitzpatrick 2008). It is also common to find people with a diagnosis of Aspergers syndrome who have been prescribed high levels of psychotropic medication, sometimes over many years (Boyle 2003). In my own experience this can apply to at least one-third of people with the diagnosis. These drugs often seem to successfully blunt the unhappy thoughts and

feelings of the individuals who take them, but often with little obvious improvement in their ability to solve their underlying problems – a verdict that is supported by large-scale surveys in which psychiatric service users were asked to evaluate the medications that they received (see, for example, Moncrieff 2008).

Such ‘care’ and ‘treatment’ seems to be informed by a general tendency in both the mental health literature, the popular media and some sections of the user movement to view ‘Aspergers syndrome’ as an immutable thing that the person possesses, or even as that which defines them. People are portrayed or may portray themselves as ‘having Aspergers syndrome’ or even as being ‘an Aspy’ (see, for example, the Aspy’s for Freedom website). When it comes to many health and social care professionals and, perhaps (particularly), to parents and partners there may be a strong expectation that once the diagnostic category has been applied to the individual then we might possess a kind of key that can unlock their problems, leading to clearly specifiable and effective ‘management’ strategies (Holmer-Nadesan 2005; Solomon 2008).

This is what might be called the essential myth of psychiatric diagnosis, the fallacies and dangers of which have been pointed out by the psychologist Mary Boyle:

Most of what we think of as diagnostic labels are ... more accurately thought of as concepts, as abstract ideas. The distinction is crucial for two related reasons. First, concepts are provisional, that is, they are always subject to abandonment or change if challenged by new observations. Second, concepts are just that: concepts, or abstractions, rather than things with a spatio-temporal location. (M. Boyle 1999, 240)

There are good grounds for treating the diagnosis of Aspergers syndrome as a provisional concept. To begin with, the medical classification of this syndrome is questionable, even within its own terms. Thus, it is widely recognised that there is large variability between clinicians in interpreting the behaviours that might meet the criteria for Aspergers syndrome, that the diagnostic boundaries between this condition and others are highly porous and that for children and younger people the medical presentation can change with maturation, making the value of the diagnosis moot for that individual (Molloy and Vasil 2002).

Furthermore, in common with many other familiar psychiatric classifications, Aspergers syndrome constitutes what we might call a disjunctive category (Pilgrim and Bentall 1999), i.e. no two persons who share the classification need have any specific symptoms in common. Indeed, anyone who makes a serious attempt to get to know and understand people who have been described as having Aspergers syndrome is likely to be struck by the diverse personal strengths, aptitudes and difficulties that they and others will describe. This has certainly been my own clinical experience, and this is a theme that recurs in the growing autobiographical and journalistic literature in the autism and Aspergers syndrome fields (see, for example, Wolman 2008; Sinclair 1993).

The people with the diagnosis that I have met so far have included warehouse workers, industrial cleaners, teachers and university lecturers, college students, housewives and househusbands and even a life coach. It is not unusual to find that people have received a dual diagnosis which, for example, may include ‘obsessive compulsive disorder’, ‘personality disorder’, ‘mild learning disability’ or any one of a host of other labels. This is a common feature of the epidemiological literature for autistic spectrum disorders, which reveals the difficulty of distinguishing Aspergers syndrome from other conditions (Gernsbacher, Dawson, and Hill Goldsmith 2005).

Furthermore, there is still no compelling evidence for any single kind of shared neurological deficit that might underlie the problems experienced by people who attract this diagnosis. Thus a number of neurological explanations for Aspergers syndrome have been adduced, including impairments in central executive function, in synchronisation between the cerebral hemispheres or in the capacity to shift attention, and in poor functioning of the so-called mirror neurons that are believed to support the capacity for empathy (Frith 1991). For all of these putative mechanisms the evidence remains equivocal. It seems likely that, at best, some of them may turn out to contribute to the difficulties that some people with the diagnosis can experience (Happé, Ronald, and Plomin 2006). Perhaps the most popular theory is that people with Aspergers syndrome either lack or have a defective evolutionary neuropsychological 'module' – effectively, a set of mind reading hardware that supposedly enables more perceptive and nuanced communication in the rest of us (Baron-Cohen 2008; Baron-Cohen, Cosmides, and Tooby 1997; Cosmides and Tooby 1997).

There is a paradox here. The 'modular idea' of empathy does not seem to fit well with the widely accepted idea that what we choose to call 'autism' should be seen as a continuum of traits that can vary between individuals (Baron-Cohen 2008). This notion fits even less well with the reports that such traits can even vary to some extent within the same individual, according to their circumstances. This is certainly the view of some health and education practitioners who have worked closely with autistic children. For example, in a detailed account of his work as an educational psychologist Tom Billington described how such children can show surprising levels of emotional insight and perceptiveness, depending upon how secure they feel and upon the sensitivity and thoughtfulness of the adult who is seeking to work alongside them (Billington 2000, 2006). One implication of Billington's work is that, at the very least, the received notion of a person being fixed at one point in an immutable autistic spectrum needs to be replaced by the image of a sliding scale or meter, which gives differing 'read outs' according to the given context, which will also include the person 'doing the reading'.

None of this is to claim that the difficulties experienced by people with the diagnosis are somehow 'unreal' or completely unrelated to the functioning of their individual nervous systems. If what we normally think of as our immaterial 'psychology' is in fact the result of an interaction between embodied biological characteristics and cumulative exposure to social and material influence (Cromby 2004; Smail 2005), then it may not be irrelevant that many people diagnosed with Aspergers syndrome seem to describe themselves as being 'thin skinned' with regard to a broad range of social situations or in regard to quite specific kinds of light, sound, smell or fabric texture, for instance. These sensitivities can lead to feelings of anxiety and discomfort that can disrupt the person's ability to think clearly or to engage with others, unless the latter are willing to try to meet the autistic individual on their own terms (Jackson 2003; Williams 1996).

Indeed, Billington (2000, 2006) drew upon the published accounts of people with this diagnosis (such as Donna Williams), as well as the child psychotherapy literature and a variety of neuropsychological theories, all of which highlight how our thinking is foregrounded by feeling. Billington then used this literature to illuminate his own encounters with children with an autism diagnosis and to suggest that, far from being unresponsive to others, such individuals may in fact be:

hypersensitive to incoming stimuli from their environment ... their feelings may often be of an intense and overwhelming nature – leading them to avoid interactions with

others by a process of 'shutting down' or shutting out. On this view, unresponsiveness can be construed not as a lack of thinking or feeling, but as an indication of the very intensity of these states. (Billington 2006, 4)

In a similar vein, the philosopher David Buller argued that autistic individuals often appear to have failed to acquire a degree of insight into the actions and feelings of others because they have habitually shunned the painful social contact that is required for learning the tacit interpersonal and psychological skills of everyday life (Buller 2005; see also Gerrens 2002).

If the issue is really about sensitivity to complex or changing environmental stimuli as these accounts suggest, then selected diagnostic traits such as the repetition of involuntary gestures and body movements, continual rehearsal of specific phrases and thoughts or even harmful activities like substance abuse might be seen as functional ways of damping down unpleasantly intense external stimulation. This is not the same as claiming that individuals with this diagnosis lack a discrete neuropsychological 'module' for empathy and social communication and are effectively isolated from the rest of us – as the possessors of 'Mr Spock-like' alien minds. Rather, it might be that a propensity for high levels of nervous system arousal could make some individuals very uncomfortable in the kinds of self-conscious, competitive activities that make up much of our educational, employment and 'leisure' experience (Elliot 2008; Harber 2005; Hylland Eriksen 2001).

A common and sometimes indignant retort to this argument is that the distressing experience and conduct upon which the diagnosis is based is somehow being denied. This is not so. The distress of the individual or their relatives is real enough, it's just that the causes are likely to be found as much if not more outside the labeled person as within their supposedly internal psychobiological world. Some of the reasons why it can be so hard to grasp this point include the widespread (and unquestioned) promotion of psychiatric diagnoses by the popular media and the mental health treatment industries (Conrad 2007; Furedi 2003) and, in Britain, the growing (and understandable) tendency for parents and teachers to seek a 'special educational needs' or 'SEN' label for many children, as a way of ensuring that they receive the scarce educational support and resources that they need (Davies 2000; Fitzpatrick 2008). For each designated client or patient these processes are abetted by the tendency for their psychiatric label to be conflated with the description of the behaviours from which it has been inferred in the first place. In this way tautology becomes prophecy (see M. Boyle 1999; Tamimi 2002).

An alternative view: moving away from the diagnosis of Aspergers syndrome and looking outwards to the wider world

In discussions and debates about the category of Aspergers syndrome I have found that one way of helping people to think critically about the former is to take a historical view of the question of how the notion of Aspergers syndrome might have come to be so widely accepted and promoted. Even the briefest glance at the psychiatric literature suggests that diagnostic systems have always been shaped by their context – much more than is the case for physical medicine. Rather than the natural entities that many of us take them to be, mental health categories may be much more like weather vanes: pointing towards the changing social values and expectations that define what it means to be normal in any given era (Newnes 1999; Kutchins and Kirk 1997; Levine 2001).

The construct of Aspergers syndrome was devised during World War II, but has risen to prominence in the public eye only during the last 30 years (Fitzpatrick 2008). Perhaps it is no accident that the growing popularity of this diagnosis has coincided with a period of intensified social and economic ferment in the Western world. Described by the historian Eric Hobsbawm as 'the age of extremes' (Hobsbawm 1994), the last third of the previous century saw the final replacement of an industrial manufacturing economy with one that is geared more and more to consumerism and to the provision of services. These trends have continued to the present time and have been accompanied by rising social inequality and economic insecurity (Bauman 2007; Elliot 2008; Wilkinson and Pickett 2009). Not surprisingly, these developments seem to have had an equally strong impact upon how we view ourselves and relate to one another. Taking his lead from the post-structuralist analyses of Foucault (see, for example, Foucault 1978), the sociologist Nikolas Rose has shown how varieties of psychological and psychotherapeutic discourse have come to saturate every facet of our lives, to the point where:

The self is not merely enabled to choose, but obliged to construe life in terms of its choices, its powers, and its values. Each of the attributes of the person is to be realized through decisions, justified in terms of motives, needs and aspirations, made intelligible to the self and others in terms of the unique search to find meaning and satisfaction through the construction of a life for oneself. (Rose 1989, 226)

The cultural historian Eva Illouz extended this analysis. She revealed how psychologists have taught us to distrust those who are unable or unwilling to look inside themselves as the supposed source of their own problems (Illouz 2008). And yet this twin focus upon our interior lives and upon our ability to project and manipulate 'emotional intelligence' does not seem to have led to a reduction in overall levels of distress, nor does it seem to have improved our ability to tolerate the anguish of others. Instead, it has been accompanied by a widespread relabelling of intense or uncontrollable feelings (and of the unusual behaviour that sometimes appears to go with them) as signs of pathology. For instance, sadness has given way to 'depression', irritability or 'naughtiness' in children has been replaced by 'Attention-deficit hyperactivity disorder' (ADHD) and shyness or eccentricity by 'social phobia' or 'avoidant personality disorder', respectively (Conrad 2007; DeGrandpre 1999; Horwitz and Wakefield 2008; Johnstone 2000; Lane 2007).

Drawing upon the work of scholars like Rose, Illouz and Hobsbawm and others I have charted some of the more obvious cultural and social changes of the last century in Table 1.

This picture is painted in the broadest of brush strokes and can do no more than sketch what is really a complex, tangled and often contradictory pattern of changes that have brought greater autonomy and choice for some, together with greater impoverishment and malaise for others (for further discussion see Bauman 2005; Freidli 2009; Wilkinson and Pickett 2009). For the purposes of the discussion that follows, however, one way to summarise these transformations might be to think about the contrast between the human drama as portrayed in a typical Charles Dickens novel and the outlook offered by a more recent work, such as the Quentin Tarantino film *Pulp fiction*.

If we use the traits that are associated with Aspergers syndrome as a lens through which to view these social currents then our present world seems to present more obstacles to anyone who prefers routine, stable and predictable environments over

Table 1. Some key social and cultural changes in Western society in the 19th and 21st centuries.

Late 19th–mid 20th century: the ‘modernist era’	Late 20th–early 21st century: the ‘late or post-modernist’ era
Relatively stable and cohesive communities	Communities are fragmented and diverse – for many anonymity is a norm and public space/engagement experienced as inherently threatening
Opportunities to participate actively in community life	Much greater geographical mobility: regular house moves, commuting significant distances to workplace, and so on
Relatively little geographical mobility – same house/street/town or village for decades or even for life	Gender roles and relationships – more fluid and negotiable
Gender roles – relatively fixed	Nuclear family/single households – relative lack of support for many
Extended families – potential source of support/stability	Cultural pluralism: rise of secularism, mass media, mass immigration, global travel
Cultural/religious values – relatively fixed	Sexual relationships and mores – greater diversity and negotiability
Sexuality – a limited number of official mores and norms	Ethical pluralism and diversity: a more tolerant but also a more complex society
Ethics – moral norms/values relatively fixed	Consumerism – proliferation of ‘choice’ in services, products and lifestyle accessories as standard for the bulk of the population.
Very limited ‘consumer choice’ in relation to products, services, lifestyles – unless you happen to be rather wealthy	Flexibility/high turnover in personal material consumption as a badge of citizenship.
<i>Work environment</i>	
Relatively stable organizational structures, hierarchies and workplace settings; e.g. farmsteads, factory shop floor/work shop	Continual organisational change – ‘a job for life’ no longer guaranteed or expected for many. Emphasis upon the ‘need’ for worker mobility in all senses
Strong emphasis on practical/technical skills	Technical skills rapidly become obsolete
Predictable/repetitive/routine tasks	Emphasis on ‘people skills’ – self-presentation/marketing, ‘team player’, management of emotions and relationships according to corporate/managerial goals
<i>Mental health services</i>	
Preoccupation with the treatment and segregation of deviant individuals – away from the community	Preoccupation with the identification and ‘management’ of ‘risk’ and of ‘disruptive behaviour’ within the community

Table 1. (Continued).

Late 19th–mid 20th century: the ‘modernist era’	Late 20th–early 21st century: the ‘late or post-modernist’ era
<i>The ‘ideal self’</i>	
Modernity: emphasis upon fixity - a limited number of relatively stable roles, identities and externally imposed (formal) obligations. Relatively firm sense of self as ‘a character’	Post-modernity: emphasis upon flexibility – multiple identities that need to be continually renegotiated and reconstructed, according to context
Limited need for self-scrutiny/evaluation – especially with regard to the ability to manipulate the expression of empathy and intimacy	Self-consciousness as both an injunction and a norm: epitomised in the growth and popularity of the psychotherapy and counselling industries, on the one hand, and the advertising sector, on the other

complex and fast changing ones and who shuns social engagement in favour of tightly focused instrumental or intellectual tasks, whether in the classroom, the workplace or the home (for further discussion of these issues see Ecclestone and Hayes 2008; Furedi 2003; Sennett 1998).

Insofar as such a person failed to conform to the norms preferred by the main economic and political interests that help to shape our lives, then they might come to be seen as 'odd' or even as 'pathological', in time attracting the attention of educationists and clinicians eager to expand their professional domains in response to parents and other carers, many of whom will have understandable fears that their children will not fit in or might miss out in some way. The creation and dissemination of other widely accepted psychological categories and diagnoses, such as 'alcoholism', 'ADHD', 'panic disorder', 'avoidant personality disorder', 'depression' and so on, can be readily understood in this way (Lane 2007; Tamimi 2002; Horwitz and Wakefield 2008).

One advantage of this perspective is that it clears a critical space in which to ponder the meaning of Aspergers syndrome and its relationship to the social and material environment in the widest sense. Rather in the way in which the fuller meaning of a painting becomes clearer as we step away from it and begin to see the larger patterns.

Some possible implications for working with people with Aspergers syndrome

When it comes to thinking about how to work with individuals with this diagnosis and with their families, friends, employers and communities, then a number of possibilities are suggested, some of which might allow us to extend the work of other writers in this field while also building upon current disability policy and practice guidance in the UK, with its emphasis upon partnership work and upon social models of disability (see, for example, Department of Health 2009), all of which locate the wider context as the main root of the problems experienced by disabilities (see, for instance, Oliver 2004). I have briefly sketched some of these possibilities below under the headings 'The restoration of the concept of character', 'Moving away from the diagnosis and thinking about the context of distress', 'Listening to the user voice' and 'Drawing upon biographical sources'.

The restoration of the concept of character

Whatever we might think about the vagueness of the Aspergers syndrome diagnosis, in working with individuals with this designation we often appear to be confronted with biological aspects of personhood, i.e. we seem to find a relative immutability of key feeling dispositions, which in turn appear to shape conduct and thinking as evoked by the diagnosed person's social and material milieu. This is not to suggest that for any of us history is always destiny, but that particular situations will inevitably call forth distinct ways of feeling, being and action (Burkitt 2008; Cromby 2004) – to the extent that our embodied experience 'does not give us a mere *version* of the world [but] gives us the world itself' (Cromby and Harper 2009, 345, emphasis in original).

The clinical psychologist David Smail has long argued that one of the least useful aspects of twentieth century psychology and psychotherapy has been to falsely imply the plasticity of identity and selfhood. From the viewpoint of the helper a more ethical, and indeed scientifically informed, goal might be to try to bring the world into line with the sufferer instead of the other way around, where of course this is possible (Smail 1996, 2005). Smail therefore suggested that clinicians might benefit from seeking to

restore the literary and philosophical concept of character into their work, as a source of illumination, insight and reassurance for both themselves and their clients:

We would do well to regard ourselves as characters with an experience of life and a unique knowledge of the world which, far from hiding it in a shamed silence, we should be ready to impart to those less expert than we. Only you have been where you have been and only you know what it felt like: you are indeed the expert in your own existence and it may well be the case that there are things others could usefully know which only you could tell them. (Smail 1996, 118)

In the autism and disability field a similar respect for individuality can be found in Tom Billington's writings. All of which show that constructive work can take place only where the practitioner is content to sometimes be with the person rather than continually seek to change them, while remaining open to the idea that the service user might experience the world and communicate that experience in ways that are in some respects unique (Billington 2000, 2006)

Moving away from the diagnosis and thinking about the context of distress

Even where it is conceded that biological factors might play a role in the difficulties that some people with the Aspergers syndrome label have experienced, we still need to be cautious because, like nearly every other psychiatric judgement, this one remains rooted in descriptions of behaviour – with all the potential for misinterpretation and for question begging that this entails. In her general critique of psychiatric diagnosis Mary Boyle has argued that the most productive course may therefore be to abandon (or at least critically distance ourselves from) the idea of a hypothesized disorder or illness, instead concentrating upon what people say about their distressing experiences and upon the social and interpersonal context in which their problems arise (M. Boyle 1999).

Once again, this line of thinking comes very close to what Smail (1991) called a 'radical environmentalist psychology of help', deriving from his own clinical experience and from a critical reading of the mental health treatment literature. In common with many other critical therapists (for example Laing and Esterson 1970), Smail suggested that personal distress results not so much from individual failures of insight or learning as from the interplay between social and material power, on the one hand, and the individual's own embodied history, on the other. Where conventional therapeutic approaches appeal to thinly disguised versions of 'will power', with the aim of supposedly enabling the client to change their lives, Smail suggested a more modest and realistic goal – in essence helping the sufferer to access or develop the kinds of resources or environments that might have some chance of improving their mental health, where of course these resources can be found in the first place. Although he did not use Smail's language, a similar appreciation of the interweaving of setting and character sits at the heart of the systemic and psychoanalytically informed approaches advocated by Tom Billington and others in the area of autism work. Billington enjoined the practitioner to, first, acknowledge how feelings and actions arise not exclusively from the interior pathology of individuals but from the relationships and situations in which they are enmeshed and, second, to recognise how their own feelings of puzzlement, frustration or anxiety are part of this picture, helping to shape the kinds of dialogue and situations in which they and their service users find themselves, for better and for worse (Billington 2000; see also Boucher 1996).

Listening to the user voice: looking for strengths rather than weaknesses

A further resource can be found in the works of the many service users who campaign for respect for difference and who emphasise the many strengths as well as weaknesses that can go with the diagnosis of Aspergers syndrome (Williams 1996). For instance, advocates of the neurodiversity movement argue that autistic spectrum disorders should not be regarded as forms of disease, but as ways of perceiving, thinking and acting that are outside the 'mainstream' but completely valid in their own terms. A good insight into this 'social rights' standpoint is provided by the satirical activist website entitled 'The Institute for the Study of the Neurologically Typical'. Giving the lie to the notion that individuals with Aspergers syndrome are at best restricted to a concrete sense of humour, this website successfully parodies what many such service users see, in ironic terms, as the rigidity and narrow mindedness of some health and social care professionals working in the field (Institute for the Study of the Neurologically Typical 2009). Advocates of neurodiversity eschew the depiction of autistic people as inherently tragic and instead argue that they are individuals who should be accepted both for who they are and for who they cannot be (Fitzpatrick 2008).

Drawing upon biographical sources

Finally, a more reflective and less pathologising kind of practice can be greatly aided by insights gleaned from the biographical writings of people with the diagnosis. Much of this literature shows that the notions of personal social deficit that dominate the clinical literature capture so little that is meaningful or useful for anyone wanting to understand or help the distressed individual. In the attempt to develop services and practices, biographical accounts provide useful hints for moving away from a narrow focus upon a supposed triad of impairments and for grasping and weighing the importance of the wider situation with which the client may be struggling:

I was a member of a distinguished family with an intellectual elite who could be eccentric to their heart's content. ... I was supported and encouraged to feel good about myself. Small differences in my temperament or circumstances could have a major shift in the way I behaved. So I acknowledge my kinship with all those autistics who are judged to be low functioning. (Burne 2005, 38)

Conclusions

As a worryingly elastic diagnostic label, Aspergers 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. 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' (Fitzpatrick 2008).

And yet this kind of intervention and support can come at a price. Erstwhile helpers can become focused upon imparting narrow psychological or social skills based

'solutions' at the expense of seeking a broader understanding of the social and familial roots of the individual's problems or of trying to challenge conventional ideas of what is normal or natural (Molloy and Vasil 2002). While there are no medical treatments aimed specifically at Aspergers syndrome, the indications of high rates of psychiatric drug prescribing for people in this group is worrying. This is a situation that cannot be altogether unwelcome to drug manufacturers keen to market their wares and the suspicion that autistic spectrum disorders are being widely promoted with an eye to future developments in pharmaceutical technology, or simply as a way of finding an expanded market for currently available products, is not altogether implausible (see, for instance, D. Boyle 2003).

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 unless, of course, such difference can be repackaged as a form of deviancy, illness or developmental difficulty, ready and waiting to be 'managed' by a set of self-appointed experts.

Perhaps as health professionals and even as friends and relatives of 'people with Aspergers syndrome' we might, in the words of one service user, try to embrace the sentiments expressed by the singer Joni Mitchell, who is reputed to have said in defense of one of her tunes 'How can a chord be weird if it expresses your soul?' Such acceptance (and the ability to genuinely listen that implicitly goes with it) would surely not represent anything like a complete answer to the difficult and complex questions that have been raised here, but it might be a good place to start.

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References

- American Psychiatric Association. 1994. *Diagnostic and statistical manual of mental disorders – IV*. Washington, DC: APA.
- Aspies for Freedom. Homepage. MyBB Group. <http://www.aspiesforfreedom.com>.
- Attwood, T. 1998. *Aspergers syndrome: A guide for parents and professionals*. London: Jessica Kingsley.
- Baron-Cohen, S. 2008. *Autism and Asperger syndrome: The facts*. Oxford: Oxford University Press.
- Baron-Cohen, S., and P. Bolton. 1993. *Autism: The facts*. Oxford: Oxford University Press.
- Baron-Cohen, S., L. Cosmides, and J. Tooby. 1997. *Mindblindness: An essay on autism and theory of mind*. Cambridge, MA: MIT.
- Bauman, Z. 2005. *Work, consumerism and the new poor*. Maidenhead, UK: Open University Press.
- Bauman, Z. 2007. *Liquid times: Living in an age of uncertainty*. Cambridge, UK: Polity Press.
- Billington, T. 2000. *Separating, loosing and excluding children: Narratives of difference*. London: Routledge Falmer.
- Billington, T. 2006. Working with autistic children and young people: Sense, experience and the challenges for services, policies and practices. *Disability & Society* 21, no. 1: 1–13.

- Boucher, J. 1996. The inner life of children with autistic difficulties. In *The inner life of children with special educational needs*, ed. V. Varma. London: Whurr.
- Boyle, D. 2003. The syndrome that became an epidemic. *New Statesman*, October 6, p. 27.
- Boyle, M. 1999. Diagnosis and psychiatry. In *This is madness: A critical look at psychiatry and the future of mental health services*, ed. C. Newnes, D. Holmes, and K. Dunn. Ross-on-Wye, UK: PCCS Books.
- Buller, D. 2005. *Adapting minds: Evolutionary psychology and the persisting quest for human nature*. Cambridge, MA: MIT.
- Burkitt, I. 2008. *Social selves: Theories of self and society*, 2nd edn. London: Sage.
- Burne, J. 2005. Say it loud, autistic and proud. *Observer Magazine*, November 13, pp. 35–40.
- Burnside, L. 2007. *The Devil's footprints*. London: Jonathan Cape.
- Conrad, P. 2007. *The medicalization of society*. Baltimore, MD: Johns Hopkins University Press.
- Cosmides, L., and J. Tooby. 1997. Dissecting the computational architecture of social inference mechanisms. In *Characterizing human psychological adaptations*, ed. G. Bock and G. Cardew, 132–56. New York: Wiley.
- Cromby, J. 2004. Between constructionism and neuroscience: The societal co-constitution of embodied subjectivity. *Theory and Psychology* 14, no. 6: 797–821.
- Cromby, J., and D. Harper. 2009. Paranoia: A social account. *Theory and Psychology* 19, no. 3: 335–61.
- Davies, N. 2000. *The school report*. London: Vintage.
- Dawson, M. 2004. The misbehaviour of behaviourists: Ethical challenges to the autism ABA industry. Michelle Dawson. http://www.sentex.net/~nexus23/naa_aba.html.
- DeGrandpre, R. 1999. *Ritalin nation: Rapid-fire culture and the transformation of human consciousness*. London: W.W. Norton.
- Department of Health. 2009. *Valuing people now: A new three-year strategy for people with learning disabilities*. London: Department of Health.
- Ecclestone, K., and D. Hayes. 2008. *The dangerous rise of therapeutic education*. London: Routledge.
- Elliot, L. 2008. *Making the cut: How cosmetic surgery is transforming our lives*. London: Reaktion Books.
- Fitzpatrick, M. 2008. *Defeating autism: A damaging delusion*. London: Routledge.
- Fombonne, E. 2005a. The changing epidemiology of autism. *Journal of Applied Research in Intellectual Disabilities* 18: 281–94.
- Fombonne, E. 2005b. Epidemiological studies of pervasive developmental disorders. In *Handbook of autism and pervasive developmental disorders*, 3rd edn., ed. F.R. Volkmar, R. Paul, A. Klin, and D. Cohen. Hoboken, NJ: Wiley.
- Foucault, M. 1978. *Discipline and punish*. Hamondsworth, UK: Penguin.
- Freidli, L. 2009. *Mental health, resilience and inequalities*. Copenhagen: World Health Organization.
- Frith, U., ed. 1991. *Autism: Explaining the enigma*. Oxford, UK: Blackwell.
- Furedi, F. 2003. *Therapy culture: Cultivating vulnerability in an uncertain age*. London: Routledge.
- Gernsbacher, M.A., M. Dawson, and H. Hill Goldsmith. 2005. Three reasons not to believe in an autism epidemic. *Current Directions in Psychological Science* 14, no. 2: 55–8.
- Gerrans, P. 2002. The theory of mind module in evolutionary psychology. *Biology and Philosophy* 17: 305–21.
- Gomm, R. 1996. Reversing deviance. In *Mental health matters: A reader*, ed. T. Heller, J. Reynolds, R. Gomm, S. Muston, and S. Pattison. London: Palgrave/Open University.
- Grinker, R. 2007. *Unstrange minds: Remapping the world of autism*. Philadelphia, PA: Basic Books.
- Happe, F., A. Ronald, and R. Plomin. 2006. Time to give up on a single explanation for autism. *Nature and Neuroscience* 10, no. 9: 1218–20.
- Harber, C. 2005. *Schooling as violence*. London: Routledge.
- Hobsbawm, Eric. 1994. *The age of extremes: The short twentieth century 1914–1991*. London: Michael Joseph.
- Holmer Nadesan, M. 2005. *Constructing autism: Unravelling the truth and understanding the social*. London: Routledge.

- Horwitz, A.V., and J.C. Wakefield. 2008. *The loss of sadness: How psychiatry transformed normal sorrow into depressive disorder*. Oxford: Oxford University Press.
- Hylland Eriksen, T. 2001. *Tyranny of the moment: Fast and slow time in the information age*. London: Pluto Press.
- Illouz, E. 2008. *Saving the modern soul: Therapy, emotions and the culture of self-help*. Berkeley, CA: University of California Press.
- Ingleby, D., ed. 1981. *Critical psychiatry: The politics of mental health*. Harmondsworth, UK: Penguin.
- Institute for the Study of the Neurologically Typical. 2009. *Criteria for staff personality disorder*. <http://isnt.autistics.org/dsn-staff.html>.
- Jackson, L. 2003. *Geeks, freaks and Aspergers syndrome*. London: Jessica Kingsley.
- Johnstone, L. 2000. *Users and abusers of psychiatry*. London: Routledge.
- Kotowicz, Z. 1997. *R.D. Laing and the pathways of anti-psychiatry*. London: Routledge.
- Kutchins, H., and S. Kirk. 1997. *Making us crazy: DSM the psychiatric bible and the creation of mental disorders*. New York: The Free Press.
- Laing, R.D. 1960. *The divided self: An existential study in sanity and madness*. Harmondsworth, UK: Penguin.
- Laing, R.D., and A. Esterson. 1970. *Sanity, madness and the family: Families of schizophrenics*. Harmondsworth, UK: Pelican.
- Lane, C. 2007. *Shyness: How normal behaviour became a sickness*. London: Yale University Press.
- Levine, B.E. 2001. *Commonsense rebellion, debunking psychiatry, confronting society: An A to Z guide to rehumanizing our lives*. London: Continuum Publishing Group.
- Molloy, H., and L. Vasil. 2002. The social construction of Asperger syndrome: The pathologising of difference? *Disability & Society* 17, no. 6: 659–69.
- Moncrief, J. 2008. *The myth of the chemical cure: A critique of psychiatric drug treatment*. London: Palgrave Macmillan.
- Newnes, C. 1999. A history of psychiatric treatment. In *This is madness: A critical look at the mental health system*, ed. C. Newnes, K. Dunne, and G. Holmes. Ross-on-Wye, UK: PCCS Books.
- Oliver, M. 2004. *If I had a hammer: The social model in action*. In *Disabling barriers – enabling environments*, ed. J. Swain, S. Barnes, and C. Thomas. London: Sage.
- Pilgrim, D., and R. Bentall. 1999. The medicalisation of misery: A critical realist analysis of the concept depression. *Journal of Mental Health* 8, no. 3: 261–74.
- Romanowski Bashe, P., and B. Kirby. 2005. *The OASIS guide to Asperger syndrome: Advice, support and inspiration*, rev. ed. New York: Crown.
- Rose, N. 1989. *Governing the soul: The shaping of the private self*. London: Routledge.
- Sennett, R. 1998. *The corrosion of character: The consequences of work in the new capitalism*. New York: Norton.
- Sinclair, J. 1993. *Don't mourn for us*. <http://www.edmonds-institute.org/dontmour.html> (accessed March 20, 2009).
- Smail, D. 1991. Toward a radical environmentalist psychology of help. *The Psychologist* 4: 61–4.
- Smail, D. 1996. *How to survive without psychotherapy*. London: Constable.
- Smail, D. 2005. *Power, interest and psychology: Elements of a social materialist understanding of distress*. Ross-on-Wye, UK: PCCS Books.
- Solomon, A. 2008. *The autism rights movement*. New York Magazine. <http://nymag.com/news/features/47225> (accessed March 20, 2009).
- Tamimi, S. 2002. *Pathological child psychiatry and the medicalisation of childhood*. London: Routledge.
- Wilkinson, R., and K. Pickett. 2009. *The spirit level: Why more equal societies almost always do better*. London: Allen Lane.
- Williams, D. 1996. *Autism: An inside out approach*. London: Jessica Kingsley.
- Wing, L. 1996. *The autistic spectrum*. London: Constable.
- Wolman, D. 2008. Yeah, I'm autistic. You got a problem with that? *Wired Magazine*, March. Available at: <http://www.wired.com/images/press/pdf/autism.pdf> (accessed February 19, 2009).