So what exactly is autism?

Damian Milton

1.1 Introduction

Autism was once considered to be an extremely rare ‘disorder’ that affected a tiny proportion of the population, however in recent decades the numbers of those diagnosed as being somewhere on the wider ‘autism spectrum’ has massively increased to an approximated figure of 1 in 100. Autism has been variously described as everything from an evil spirit that robs parents of their children, to a fundamental asset to human evolution as a person with a differing style of thinking. It is no wonder that the ‘enigma’ still evades simplistic description, as scientists and psychologists search in vain for the cause of ‘what it is’. This article attempts to help the reader navigate through the maze of explanations that have been suggested and some of the problems such explanatory models possess. Such a text can never be fully comprehensive however, and so the reader is encouraged to never think that they understand what ‘autism is’, but to strive to understand the ‘autistic people’ they work with as well as they can, and to see this as an ongoing process and mutually respectful interaction.

The term autism was first used by a psychiatrist called Bleuler in 1911 to try and describe a type of what was then called ‘childhood schizophrenia’. His descriptions however, only show a passing resemblance to how autism is thought of today:

“The schizophrenics who have no more contact with the outside world live in a world of their own. They have encased themselves with their desires and wishes...they have cut themselves off as much as possible from any contact with the external world. This detachment from reality with the relative and absolute predominance of the inner life, we term autism.”

(Bleuler, 1911, cited in Parnas et al., 2002: 131).

In the 1940’s two psychiatrists called Kanner, and working separately Asperger, were like Bleuler, studying small groups of children deemed as having some form of ‘childhood schizophrenia’. Both found that with the groups of children they were working with a set of distinct symptoms were being identified that were markedly different from schizophrenia as it was conceived of at the time. Kanner’s work laid the foundation for early accounts of autism, whilst the work of Asperger was left largely undiscovered until the 1970s. Definitions of what autism is, and also what caused an autistic developmental pattern in children have been hotly contested ever since, including an unfortunate era where autism was thought to be a reaction to ‘refrigerator mothers’, a theory long since shown to be totally untrue.

A note on terminology

There is much current debate regarding the terminology related to autism. This article will resist ‘people first’ phrasing, in accordance with other ‘autistic voices’ (Sinclair, 1993; Sainsbury, 2000):

“We are not people who “just happen to have autism”; it is not an appendage that can be separated from who we are as people, nor is it something shameful that has to be reduced to a sub-clause.” (Sainsbury, 2000: 12).
The descriptors of ‘autistic person/people’ and ‘autistic spectrum’ will be used, and the use of the terms Autistic Spectrum Disorder/Condition (ASD/ASC) avoided due to the ‘medical model’ connotations (see section 3.5) associated with these phrases and the offense that they may cause.

1.2 Diagnosis

One of the most important developments in the history of autism in Britain was the work of Wing and Gould (1979) and the subsequent widening of the ‘autism spectrum’ to include ‘Asperger syndrome’. This work largely created the definition of autism as a ‘triad of impairments’ in: social communication, social interaction, and imagination (repetitive interests/activities), a definition which was used to inform diagnostic systems until very recently.

In May 2013 the American Psychiatric Association (APA) revised its diagnostic manual, known as the Diagnostic and Statistical Manual (DSM), making a number of changes:

- In DSM-5, the terms ‘autistic disorder’, ‘Asperger disorder’, ‘childhood disintegrative disorder’ and ‘PDD-NOS’ have been replaced by the collective term ‘autism spectrum disorder’.

- The previous use of three domains of ‘impairments’ has been reduced to two domains:
  > Social communication and interaction
  > Restricted, repetitive patterns of behaviour, interests or activities.

- Unusual interest in the sensory environment or hyper/hypo-reactivity to sensory input, are included in the criteria for the first time, under the ‘restricted, repetitive patterns of behaviours’ descriptors.

- The emphasis during diagnosis will change from giving a name to a condition to identifying all the needs that someone has and how these affect their life.

- DSM-5 has introduced ‘dimensional elements’ which give an indication of how much someone’s condition affects them. This is designed to help identify how much support an individual needs.

- DSM-5 now includes a new condition called ‘social communication disorder’.

The diagnostic system most often used in Britain is the ICD-10 (1992), which is currently under revision. It is as yet unclear whether this diagnostic system will follow suit or not.

The changes are also designed so as to not result in anyone losing their diagnosis of autism — all individuals who currently have a diagnosis on the autism spectrum, including those with Asperger syndrome, will retain their diagnosis.

The most commonly utilised definition of autism that one sees today remains that it is a:

“…lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.” (NAS, 2012a).
Although this definition of autism is much contested (see section 3.4), such a definition of behavioural deficit and impairment has come to characterise both the DSM-IV (1994) and ICD-10 (1992) diagnostic criteria. Autism is thus diagnosed according to ‘qualitative’ impairments in all three areas.

2.1 Cognition – an impaired theory of mind?

One of the most enduring psychological theories concerning autism has been the assertion that the key universal core ‘deficit’ found in autistic spectrum conditions is an impaired ‘theory of mind’ (Baron-Cohen et al. 1985). ‘Theory of Mind’ refers to the ability to empathise with others and imagine their thoughts and feelings, in order to comprehend and predict the behaviour of others (also called ‘mind-reading’ and ‘mentalising’). Baron-Cohen et al. (1985) found that 80% of autistic children between the ages of 6-16 failed at false belief tasks. These findings were also repeated in subsequent studies using people rather than dolls, such as in the ‘Sally-Ann’ test (Leslie and Frith, 1988).

False Belief Task (Kerstin and Martin go for a picnic)

(Illustration based on Sally and Anne False Belief Task in Frith, U., 1989, Autism: Explaining the Enigma)

This theory has been criticised on a number of levels however: Task failure on false-belief tasks could be due to difficulties in language processing or memory (Eisenmajer and Prior, 1991), or a lack of motivation to deceive (DeGelder, 1987). Some theorists questioned its applicability to all on the spectrum when 20% of children passed such tests, or its value for explaining all the aspects of what constituted the autistic difference (Happe, 1994a).

‘Theory of mind’ deficit as a general theory has been subsequently revised in order to differentiate between an ability to ascertain the feelings of others, and the development of ‘affective’ empathy once those feelings are recognised. Later studies by Baron-Cohen (1992) and Happe (1994b) also found that the ability to successfully complete theory of mind tasks increased with age and IQ, suggesting a delayed ‘mentalising’ capacity.
It has also been argued that a deficit in ‘social functioning’ cannot be solely located within an individual, and that what is being seen as a ‘theory of mind’ deficit is more to do with a breakdown in communication between two people who process information very differently. In this sense, there exists a ‘double empathy problem’ in that both autistic and neurotypical people have a severe difficulty in understanding each other (see section 3.4), as neither share the same frame of reference within social interactions (Milton, 2012a). This is most evident by how empathetic autistic people seem to be with the similarities they share with one another, an opportunity that has vastly improved with the use of Internet technology.

2.2 Executive functioning

Executive function refers to the ability to maintain an appropriate problem-solving strategy in order to attain a future goal. Evidence from first-hand accounts suggest that autistic people have ‘difficulties’ with switching attention, and adverse reactions to interference with attention (Tammet, 2006). However, there is also evidence that individuals diagnosed with Asperger syndrome have performed well on executive functioning tests such as the ‘Tower of London’ test, and that other clinical groups can struggle with such tests, suggesting a lack of specificity to people diagnosed autistic.

Dawson et al. (2007) found that autistic people can often do very well at non-verbal IQ tests and problem-solving tasks that do not require verbal processing. This would suggest that executive planning for non-verbal tasks is separable in brain functioning from verbal tasks, or that this weakness in verbal response tests is not due to an executive functioning deficit. It could be suggested that rather than such evidence suggesting an overarching deficit in executive processing, that there is a difference that exists within the way autistic executive processing operates, yet rather than an impairment or deficiency, this is better articulated by the theory of monotropism (see section 2.5).

2.3 A weak drive toward central coherence

In her review of psychological theories regarding autism, Happé (1994a) suggested that one of the major difficulties with the theories of ‘theory of mind deficit’ (see section 2.1) and ‘executive functioning deficit’ (see section 2.2) was their lack of explanatory value when considering autistic ‘strengths’ and ‘talents’. For example Shah and Frith (1983) found that autistic people outperformed non-autistic people at ‘embedded figure tests’, and picking out details from a visual array.
These tasks required the ignoring of ‘overall meaning’ in order to solve, and was followed by similar findings using a ‘block design’ task (Shah and Frith, 1993).

The Gestalt psychologist Koffka (1935) suggested that great effort is needed for people to resist a tendency to see a forcefully-created ‘gestalt’ or whole picture, in order to see constituent parts of that whole.

Happe (1994a) suggested that autistic people had a ‘weak drive for central coherence’, and so have problems accounting for overall contextual meanings, whilst simultaneously having advantages in processing details or parts of an overall context.

Mottron et al. (1999), as well as Baron-Cohen (2008) point out a difficulty for this theory to contend with, that being how autistic people are able to process the ‘whole picture’. For instance, in the Navon test (a letter made up of smaller letters of a differing character – e.g. an A made up of H’s), autistic people are able to process the larger letter, yet have a tendency to be drawn to the smaller.

2.4 Empathising-Systemising (E-S) Theory

In part a response to the criticisms made of the ‘theory of mind’ hypothesis (see section 2.1) that it did not take into account the non-social differences involved in autism, Baron-Cohen (2008) argued that along with ‘delays and deficits’ in empathy, the strengths found amongst autistic people could be explained by an intact or even superior skill in ‘systemising’. This area of strength refers to the drive to analyse and construct systems, defined by rules that govern them, in order to predict how systems will behave. Baron-Cohen (2008) distinguishes a number of systems from collectible systems (for example distinguishing between a set of inanimate objects like stones) to abstract (such as musical notation), and social systems (such as management hierarchy). Rules are obtained by noting if two phenomena are associated in a systematic or causal way.

Baron-Cohen (2008) explains the commonly associated feature of autism of a ‘lack of an ability to generalise’ between situations, as symptomatic of a systemising mentality, as a ‘strong systemiser’ sees each system as unique, where differences between systems are of greater interest than their commonalities.

‘A good systemiser is a splitter, not a lumper, since lumping things together can lead to missing key differences that enable you to predict how these two things behave differently. Seen in this light, it is the neurotypical person who has a difficulty, skating over differences that might be very important.’ (Baron-Cohen, 2008: 70-71).

This ability to systemise can be a seen as a defence against inaccurate conclusions being drawn through an under-analysis, and premature generalising of any given phenomenon. The E-S theory
of autism has also been extended to the ‘extreme male brain’ theory of autism (Baron-Cohen, 2008). This theory was derived initially by how women show a preference for empathising and men systemising. From this standpoint, the autistic ‘cognitive style’ can be seen as an extreme example of a typical male outlook (a view first postulated by Asperger, 1944, cited in Baron-Cohen, 2008). Baron-Cohen (2008) supports this theory through the use of quotient personality profiles, yet also the development of different skills at different points of development between typically developing boys and girls, and furthermore, that men on average are quicker in the embedded-figures test.

Baron-Cohen’s (2008) use of quotient questionnaires to measure personality are very reminiscent of psychometric personality testing, a tradition highly influenced by personality trait theory, exemplified in the work of Eysenck and Rachman’s (1965). Trait theory rests upon the assumption that a consistent structure of personality resides in each individual person, yet perceptions of attributes related to others may have more to do with those doing the perceiving, than those being perceived. Traits from this view are nothing more than constructions in the ‘eye of the beholder’ that reflect a world view of the perceiver, rooted within cultural ideologies and not a reflection of inner psychological dispositions of those being rated. Mischel (1968, cited in Butt, 2007) also criticised the questionnaires used in psychometric testing, with words such as ‘often’ being construed to mean different things to different people and are thus an invalid indicator of some ‘underlying trait’, accordingly, behaviour is theorised as much more context specific and socially situated.

Richards (2002) suggests that traits may be no more than an artefact of the measurement system used to analyse them. Richards (2002) also criticises the circularity of trait theories and questions whether ‘attitudes’ even exist as ‘natural’ phenomena. It can be argued that the approach adopted by trait theory offers little more than a description of behaviour and displays a circularity of reasoning, for example: explaining aggressive behaviour by saying someone is aggressive.

2.5 Monotropism – a different cognitive style?

The theory of Monotropism (Murray et al., 2005) argues that the central core feature in autism refers to an atypical strategy being employed in the distribution of attention, which is suggested to be the basis of the ‘restricted range of interests’ criteria inherent in the diagnostic criteria of both the DSM-IV (1994) and ICD-10 (1992), and further found in the testimonies of subjective experience from autistic people themselves (Grandin, 1995; Lawson, 1998; Williams, 1994). Monotropism suggests that the amount of attention available to an individual at any one time is necessarily limited, as can be found amongst numerous cognitive studies. Thus the shaping of many cognitive processes depends upon a competition between mental processes for this scarce resource. Murray et al. (2005) propose that strategies for the way attention is used is normally distributed, and to a large degree genetically determined, between those with a broad use of attention, and those who concentrate attention on a small number of ‘interests’ (likened to the difference between a dissipated ‘diffused light’ and a ‘torch beam’). The authors propose that those at the tightly focused end of this spectrum are those diagnosed as on the autism spectrum. It is suggested by Murray et al. (2005) that social interaction, the use of language, and the shifting of object attention (implicated by other psychological theories) are all tasks that require a broad attention, and are inhibited by a narrow use of attention.
This theory suggests a number of features found in autistic subjective accounts that are not attended to by the other psychological theories, including E-S theory (see section 2.4). For instance, how individuals on the autism spectrum show a tendency toward either being passionately interested in a task or phenomena, or not interested at all, or how an unanticipated change ‘within the attentional tunnel’ can lead to a catastrophic disconnection from a previously ‘safe’ state of mind.

If employing a monotropic interest system, the ability to use information gained in the past is compromised, as information is gained only in relation to a narrow set of interests. Thus ‘top-down’ or ‘whole picture’ processing is not ‘dispreferred’ as such, but will tend to be idiosyncratic and resistant to change or criticism. This resistance is not fully explained by a ‘systemising’ tendency (Baron-Cohen, 2008).

Monotropism also suggests a reason for the sensory integration difficulties found in the accounts of autistic people, as they suggest there is a ‘hyper-awareness’ of phenomena within the attentional tunnel, but hypo-sensitivity to phenomena outside of it. Also, that an interest in the social world may not occur in the early years of life:

‘We suggest that the uneven skills profile in autism depends on which interests have been fired into monotropic superdrive and which have been left unstimulated by any felt experience.’ (Murray et al. 2005: 143).

Indeed, the recognition of others may only occur if connected to the fulfilling of interests that the autistic individual has, otherwise the existence of others may not be registered at all. A monotropic focus leads to a fragmented view of the world, and from such a viewpoint it is exceptionally hard to make sense of social interactions, leading to potentially both apparent and real ‘theory of mind’ difficulties. Rather than being a ‘core deficit’ however, this is described as a tendency produced as a consequence of a monotropic interest system.

3.1 Autism from the ‘inside-out’

Psychological models of autism tend to work on the cognitive level of explanation, with some attempting to make links to biological and neurological data. In order to produce cognitive models, all of them rely on accounts of behaviour to make inferences from. A major criticism of these models, is that they are formed (with the exception of monotropism theory, see section 2.5) from a perspective of a cognitive psychology overly restricted by its total adherence to scientific method as the gold standard, which do not value the input of ‘autistic voices’, or that of sociological viewpoints on autism. This has come about for a number of reasons, one of which being the splitting of levels of explanation into subject ‘silos’ (Arnold, 2010). Another was the triumphant victory that biomedical explanations earned at the expense of Bettelheim’s (1967) theory of the ‘refrigerator mother’. This victory would not just produce a rejection of this theory however, but it seems a total rejection of psycho-sociological reflection upon what it is to be autistic, a fatal flaw that only alienated the voices of autistic people further. The victory spared the mother, yet lay the blame at the neurology of the ‘autistic person’ themselves, in the sense that there was something medically deficient about the ‘autistic person’, and if one could only find the site of the ‘lesion’ one could find a ‘cure’ (Happe, 1994a). Assumptions of what autism is are enshrined in the diagnostic criteria of the DSM-5 (2013) and ICD-10 (1992) and based
upon interpretations of observed behavioural traits. All the psychological theories base their models within this criterion of behaviour led framework, although in the monotropism theory (see section 2.5), this is thankfully balanced by the accounts of lived experience of ‘autistic people’ themselves, including one of the authors of the paper, Wendy Lawson.

The current psychological models seem somewhat inadequate at drawing the links between biology and behaviour, but even more so, between biology and the lived experience of autistic subjectivity, often attempting to obscure the ‘autistic voice’ or ignore it, in an attempt to reduce autistic behaviours to definable objective criteria. The theory of monotropism, is a welcome departure from this theoretical dominance however, largely basing its account in subjective accounts. In so doing, this theory is more applicable to the vast array of subjective differences experienced by autistic people, although perhaps not all. Unfortunately, it does not seem to have achieved the widespread recognition enjoyed by the other theories.

“...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.” (Williams, 1996: 14).

### 3.2 The spiky profile, stress and sensory overload

One of the key aspects of the experience of being autistic is that of having a ‘spiky’ or ‘uneven’ set of abilities and capacities. It is the feeling of many on the spectrum however, that this spiky profile is often unrecognised by service providers and support workers. Verbal ‘autistic people’ are often incorrectly assumed to be capable in areas in which they struggle, whilst those with less verbal skills are often incorrectly assumed to be lacking in skills, ‘strengths’, ability or potential. E.g.

One of the most important aspects of autism that for many years went fairly unrecognised was that of sensory sensitivities. Autistic people often report both hyper-sensitivities to sounds, lights, smells, and touch, but also ‘hypo’ sensitivities, where such sensations fail to register. Like most things about the autism spectrum, such sensitivities will vary from person to person and across contexts, and can be quite unpredictable from the viewpoint of someone not on the autism spectrum to observe and understand.

A common pattern found (but not universally) is that of hyper-sensitivities to sensations of external events, and hypo-sensitivities with internal feelings, such as a sense of balance, or knowing...
where one’s own body ‘begins and ends’ (perhaps due to a ‘monotropic’ sensory focus when acting upon the environment – see section 2.5). With a fragmented information processing style, sensory integration can become a challenge for ‘autistic people’, thus a ‘low-arousal’ approach in educational environments is often needed.

There is a growing body of evidence that has begun to link autism with irregular levels of the hormone cortisol, which affects ‘arousal’ and levels of stress. The experience of stress is one that is nigh-on universal amongst autistic people, along with the sense of overload (whether sensory or emotional). Such irregularities could lead to a person becoming overly lethargic and/or overly stimulated at different times throughout the course of a day. This can produce difficulties in everything from wrongly attributed ‘laziness’, to challenges getting to sleep at night. The reactions of autistic ‘meltdown’ and ‘shutdown’ can be viewed as extreme expressions of the ‘fight or flight’ response.

To an outsider perspective, one may see no immediate stressor and trigger to such events, yet this is generally less the case when viewed from someone who is autistic themselves. Thus, working closely with the autistic person in their care, is essential for practitioners to learn how that individual operates within a variety of contexts, what external events are likely to cause distress, and take a general ‘low-arousal’ approach to managing the learning environment. When in a state of meltdown or shutdown, the best option where possible, is to leave the autistic person alone, to reduce all external stressors, and then when they are able to calm themselves, attempt to engage with something predictable and comforting to the ‘autistic person’. Ethically speaking, behavioural outcomes should never be prioritised over reflection regarding the processes that one uses to accomplish such tasks and the stress that such processes can create for the autistic person.

“[Behavioural strategies]...may feel like a senseless ritual of abuse, regardless of its ‘good’ intentions.” (Williams, 1996: 51).

3.3 Episodic and factual memory

The fragmentation of experience often cited by autistic people can cause difficulties with regards to constructing an autobiographical narrative of self (Millward et al. 2000). Both Millward et al. (2000) and Crane and Goddard (2008) suggest that a ‘deficit’ can be found in the personal ‘episodic memories’ of people on the autism spectrum, yet not with regard to semantic factual memory. It is argued here however, that factual information can also become fragmented in the consciousness of autistic people and that this is again dependent on the particular ‘spiky profile’ of an individual [see section 3.2] and the context one is situated within. Potential challenges regarding episodic memory were also found in the research of Goddard et al. (2007), where longer periods of time were needed for autistic people to retrieve personal memories, and with fewer specific episodes remembered. Goldman (2008) found that there was a reduced number of emotional ‘high points’ to be found in the personal narratives of autistic people (although this must also be read in context of the social lives that autistic people lead). Milton (2012b) suggests that the use of photography as memory aides can be of great use to autistic people with regard to ‘putting the self back into the picture’, not just in the sense of visual timetables, but in a host of other techniques, including: photo-montage, collage, scrap books, photo sorting, and where possible, building and reconstructing narratives regarding particular photographs or...
sets of them. It should also be remembered though that not all autistic people are visual learners, and need more direct and tangible symbols of meaning in order to navigate an environment, and to begin to build a sense of self over time. In these instances, methods such as ‘objects of reference’ would be recommended (Community Matters, 2012).

3.4 Intersubjectivity – the ‘double empathy problem’

The models of autism as presented by cognitive psychological theories, much like the triad/dyad of impairments, locate the difficulties faced by autistic people solely within the brains/minds of the ‘autistic person’, rather than the world in which they inhabit, or in the relations and interactions people have, that can lead to a sense of total disconnection through to a mutual shared sense of ‘social reality’.

A number of sociologists view ‘versions of perceptual truth’ as contested and negotiated in interaction. Milton (2011, 2012a) argues that the social subtext of a situation is never a given, but actively constructed in the interactions people have with one another. From this point of view, it is illogical to talk of an individual having a ‘social’ deficit of some sort. Rather, that in the case of when autistic people and those not on the autism spectrum attempt to interact, it is both that have a problem in terms of empathising with each other: a ‘double empathy problem’. Indeed, autistic writers have been talking of empathy being a ‘two-way street’ for many years (e.g. Sinclair, 1993).

A more serious problem ensues however, when one side of an interaction are able to impose their own views of a situation onto the other. This can also lead to the subsequent internalisation of this dominant outsider view and a loss of connection with one’s sense of authentic selfhood.

“I had virtually no socially-shared nor consciously, intentionally expressed, personhood beyond this performance of a non-autistic ‘normality’ with which I had neither comprehension, connection, nor identification. This disconnected constructed facade was accepted by the world around me when my true and connected self was not. Each spoonful of its acceptance was a shovel full of dirt on the coffin in which my real self was being buried alive…” (Williams, 1996: 243).

3.5 The medical and social models of disability

Within wider disability politics and advocacy, as well as the sociological study of disability, there are a number of ‘models’ that have been implemented. The two most frequently mentioned are those of the ‘medical’ and ‘social’ model of health, illness and disability. The traditional medical model would view disability as a functional deficit that belonged to the disabled person. This view of disability was widely challenged however by disability activists and sociologists that suggested that it was society that created barriers to the participation of disabled people in social life. For instance, the problem of access to a building for a wheelchair user being the steps needed to enter it. The social model of disability suggests that society disables people by the way structures are designed. Many theorists go further, and suggest that people are further psychologically ‘disabled’ by a culture and ideology of ‘normalcy’ (Goodley, 2011, Reeve, 2011, Milton, 2012c).

The widespread recognition of a social model approach to making adjustments to increase
inclusive practices has been greater for those with ‘visible disabilities’ than those that are more ‘hidden’. An important aspect of the social model would suggest that it is the disabled person who is the ‘expert’ on their own requirements.

In the case of autism however, it is not always possible for the autistic person to achieve communicating their intents to those who provide care for them. This has as much to do with the service provider as it does the autistic person though (see section 3.4).

A model widely used in health and social care theory is that of the ‘bio-psycho-social’ model of health (Engel, 1977). This model suggests that when looking at the needs of a ‘client’, one needs to approach a ‘medical’ issue in terms of the biological, psychological, and social state/situation that the person is in.

This is a vague model at present though, with little agreement between academic theorists to the weighting of these areas, or how they interrelate to produce disability. In terms of the education of autistic people, the tradition has been to highlight the biological and psychological aspects of the ‘syndrome’, but it is argued here that this has been a mistake (see section 3.4 and 4.2).

### 3.6 A case in point: mental well-being

Much literature on autism would suggest that autistic people are in some way predisposed to difficulties in psychiatric ill-health, including anxiety, depression, and catatonia (NAS, 2012b).

This view however is a ‘medical model’ view of mental well-being (see section 3.5) that does not account for the ‘problems of living’ people on the autism spectrum have in navigating a social world that was not designed for their needs (to apply a more social model to the situation). The lack of opportunities ‘autistic people’ have in society, coupled with the social stigma of being seen as having a pathologically deviant cognition, is added to further by the trauma of ‘passing as normal’ (Lawson, 2008).

In 2010, a group of young people on the autism spectrum made a film for the NAS regarding mental ill-health and relevant service provision entitled ‘Open Your Mind’ (NAS, 2010). It is recommended here that such initiatives are seen as the start of further exploration into how best to support autistic people who experience mental ill-health.

### 4.1 The language of autism – not just semantics

For many philosophers, the way we talk about something is ‘more than just words’, but frames the way we think about ourselves and one another.

By viewing the ‘autistic person’ as the ‘disordered other’, it can reduce an individual’s sense of self-worth and self-esteem. Dekker (2011) suggested that autistic advocates used a language that carried more positive connotations when talking about the autistic difference.
Here are some examples (produced by the author of this article):

<table>
<thead>
<tr>
<th>Lacking a theory of mind</th>
<th>Engaging in social life from a different perspective</th>
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<tr>
<td>Lacking executive functioning skills</td>
<td>A strength in problem-solving that doesn’t require verbal processing</td>
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<tr>
<td>Lacking flexibility</td>
<td>A different way of being flexible</td>
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<td>A weak drive toward central coherence</td>
<td>A good eye for detail</td>
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<tr>
<td>Evidence based practice</td>
<td>Not listening to the voice of ‘autistic people’</td>
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<tr>
<td>Passing as normal</td>
<td>Failing to pretend to be something one had no intention of being in the first place</td>
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<tr>
<td>‘Semantics’</td>
<td>Essential difference in perception and outlook</td>
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4.2 Implications for practice – from modification to mutuality

There is a spectrum in theory and practice more generally regarding service provision for autistic people, between at one end those adhering to techniques of behavioural modification, so that children are socialised into what are deemed appropriate behaviours of socially functional future roles. At the other extreme of this spectrum is an ethos of interactive mutuality concerned with the empowerment of individuals and communities, and where dominance and imposition of authority is seen as ‘dysfunctional’.

Expressions of these extremes could be said to be found more frequently in discourses regarding best educational practice for autistic people, ranging from the efforts of the Lovaas model of Applied Behavioural Analysis, through to child-focused and democratic educational ideological preferences.

These narratives and practices can be said to be embedded within the wider discursive debate that exists between the medical and social models of disability as played out in the field of autism (see section 3.5). It is the view of this author that there is an increasing complacency around the idea that leads professionals and practitioners to have a good understanding of what ‘good autism practice’ entails, for me this is an ongoing imperfect process of interaction and should never be seen as a given.

“We have to challenge these myths and stereotypes about autism and work to advance an understanding that is based on better quality research, but also on the real life experiences of those of us on the autism spectrum rather than a conversation that talks about us, without us. By taking that step together, we will see more progress for self-advocates, providers and families.” (Ne’eman, 2011).
4.3 Five key points for educational practitioners to remember:

- Respect the individual learning style of the pupil – work with it, not against it
- Always consider sensory issues
- Always consider how your processing of information may be very different to that of the pupil in your care (utilise interests)
- Stress is a key issue – reduce input when people are over stressed
- Collaborate for consistency in approach

4.4 About the author

Damian Milton is currently studying for a doctorate with the Autism Centre for Education and Research (ACER) at the University of Birmingham, the working title for this thesis being: ‘Educational Discourse and the Autistic Student: An ‘Inside-Out’ Approach’. He is a member of the ACER steering group and a member of the programme board for the Autism Education Trust. Damian holds a number of academic qualifications in a range of subjects (sociology, psychology, philosophy, and education) and has a number of years experience as a lecturer in both FE and HE. Damian’s interest in autism began when his son was diagnosed in 2005 as on the autism spectrum at the age of two. Damian was also diagnosed as being on the autism spectrum in 2009 at the age of thirty-six.

4.5 References


