



Autonomy, the Critical Journal of Interdisciplinary Autism Studies

Volume 1. No. 1

THE NORMALISATION AGENDA AND THE PSYCHO-EMOTIONAL DISABLEMENT OF AUTISTIC PEOPLE.



Artwork © Lyte

October 7, 2012

By Damian Milton and Lyte

Abstract:

This paper critically analyses the use of normative social scientific principles in the 'treatment' of autistic people and utilises the concept of psycho-emotional disablement (Reeve, 2002, 2004), to suggest that such a dominant normalising agenda has led to the silencing of the autistic voice in knowledge production and community awareness. Reflecting upon the researcher's own insider situated knowledge, and findings from a number of pilot studies conducted in the course of a doctoral research programme, this paper examines the insider/outsider positionality of parent and self advocates within the autistic community, before challenging the 'legacy of Lovaas' and recent attempts in Britain to modify such techniques. The paper finishes

with a reflection upon how such measures have led to the further disablement of autistic people and their subjective lifeworld. This paper also includes a contribution from Lyte, who is an individual who I have met recently in the course of my studies. As an emerging 'voice' regarding neurodiversity, Lyte puts their own point of view to some of the issues that have arisen in the course of my research and are highlighted by this paper.

Key words: Autism, Behaviourism, Normalisation, Psycho-emotional Disablement, Voice. Positionality, and situated knowledge, or a case study in psycho-emotional disablement?

The normalisation agenda and the psycho-emotional disablement of autistic people.

By Damian Milton, and Lyte

For some years now, I had been meaning to write a deconstruction of the theoretical rationale and practice in the application of Applied Behavioural Analysis (ABA) as an 'early intervention' for the 'treatment' of autistic people. Yet, I had then realised that in order to do so I needed to look deeper into the issue. In order to explore the issue further, a review of the philosophical underpinnings of the 'normalisation agenda' whether implicitly or explicitly manifested in the treatment of autistic people was needed. Followed by the highlighting of the disabling effects this agenda has had on the invasion and occupation of the autistic lifeworld.

Before I was diagnosed myself, I had been a budding sociologist. Early in my career I had been interested in the Sociology of Health particularly mental health, having been misdiagnosed by several psychologists as a teen. I was also interested in the classic theorists of the field such as Emile Durkheim, often cited as the founder of Functionalist sociology. In teaching first-year undergraduates Durkheim's sociological theory of suicide, it occurred to me that Durkheim had made a fatal mistake. He had assumed, as had the later Functionalists such as Talcott Parsons, that consensus in society lay in the stability of social norms and the dominant value system. Deviation from the said norm was deemed pathological, leading to anomie, and even suicide due to a lack of moral regulation and also social isolation. Having known a dear friend (who I now suspect may have also been on the autism spectrum herself) commit suicide a few years previously, I thought that it wasn't her inability to fit into society that drove her to suicide so much as it was society's inability to

adapt to fit to her needs as an outlier from the norm. Indeed, attempts at normalisation and focusing upon her weaknesses did little to help her.

So what was Durkheim's mistake? He assumed that people were healthiest when normalised, this reification of the norm was then to become formalised into healthcare practices with the adoption of models such as Talcott Parsons' 'Sick Role' (1951). Parsons was a great believer in equilibrium, but what if the outliers natural state of equilibrium was something or somewhere else? What about hermits I thought, did they really want to be socialised? What about anarchists? Is their natural equilibrium to be 'morally regulated' and 'socially controlled' by outside agencies? Perhaps not I thought. Indeed, people (like me) who were outliers occupied diverse positionalities within society, each with their own dispositional equilibrium. More than that: attempts to normalise people through behaviourist means or any other, would send them into disequilibrium and a state of personal anomie and possibly rather than leading someone away from a state of mental ill-health, be actually leading someone toward it. It was only fairly recently following my son's diagnosis and then my own as being on the autism spectrum, that I discovered that what I had been theorising about all those years ago, was neurodiversity and the psycho-emotional disablement (Reeve, 2002, 2004) that autistic people had suffered at the hands of the normalisation agenda (Arnold, 2010). What is even clearer to me now, is that my own lack of awareness of the neurodiversity movement was a form of disablement in itself.

Lyte:

Roughly 6 years ago after a lifetime of not belonging I finally figured out where to go to get tested in my efforts to discover what had always been clear to me: that I was not able to learn or even *think* in the ways everyone around me (including family) seemed to demand and expect of me. There was initial reluctance to believe the need for tests because I had scraped by, by doing my best to appear 'normal'. I knew I was doing this, and that I had unrealised intellectual and creative potential and it was causing me indescribable misery but I could see no alternative. I had to survive somehow in a culture I simply could not make sense of despite what the tests then revealed as a rather high level of intelligence (much to my amazement). Once the process of my search revealed triangulated evidence that I 'was made or had grown in a way that is not typical', I hunted for support, which came after a great deal of searching, from a thin thread that became thicker as I sought my way blindly towards the Neurodiversity (I prefer the term Neurodivergence) movement, where I rapidly realised 'I belonged'.

DM:

There is much current debate regarding the terminology related to autism. This project will resist 'people first' phrasing, however 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, unless referring to the arguments of other researchers, due to the 'medical model' connotations associated with these phrases and the offense that they may cause.

Perceptions of diversity and the parent/self-advocate divide

The definition of what autism 'is' has gone through a number of changes since the original formulations of Kanner (1943) both in official diagnostic criteria and personal narratives, with an ever-increasing number of

autistic narratives joining the public discourse. The dominant model of definition however, is the medicalised model of diagnosis based upon the observable behavioural manifestations of the 'triad of impairments', leaving those with better strategies at passing as normal as less likely to receive a diagnosis based on a Galtonian normative deficit model of pathological difference. A simplistic yet less deficit based categorisation of autistic types is also given by Wing (1988): passive, aloof, and active-but-odd. These loose categorisations are not exclusive though. It is somewhat useful in highlighting to practitioners that not all educational practice regarding autistic people is about managing challenging behaviour. Another popular distinction is that of low and high functioning autistics. This categorisation is somewhat of a misnomer given the uneven spiky cognitive skill profiles that autistic people tend to show, and also leads to the underestimation of the abilities of the low functioning and an often over-estimation of some of the abilities of the high functioning, and thus, is somewhat of a disabling narrative. All differences are subsumed into the further distinction of the 'non' or 'pre' verbal and the 'verbal', placing primacy of ability and categorisation on the formation of functional communication (as defined by a non-autistic outsider positionality). A similar argument can also be used against the distinction often made between severe and mild forms of autism. It would seem that the current narrative of many cognitive psychologists and scientists is to talk of a cognitive difference and spiky profiles, however there is still a tendency to locate challenges that autistic people face within individual cognition, while largely ignoring the social context within which such constructions are made and practised.

Such concerns inevitably lead one to a discussion regarding the dominant medical model of disability (and autism) and the social model. Many theorists have questioned the applicability of either in their respective extreme forms, but much like the nature vs. nurture debate, narratives tend to arrive at a preference for one or the other (or some odd contradictory position being taken up). Taking a phenomenological perspective, it is argued here that identities (including autistic ones) are the reflection of embodied lived experiences constructed within the confines of historical and cultural positionality, with the autistic positionality representing an outlying dispositional personal equilibrium.

Some suggest that people such as myself could not have insight into my own son's autism, due to my own autism being so 'qualitatively different' to his (deemed low-functioning), yet I could have an insight into it purely by being his parent (according to the arguments of some 'parent advocates', Jager, 2010), however my son and I also share many similarities. Both of us utilise a monotropic interest/attention system and are 'detail-focused', both of us have a high sensitivity to sensory stimuli and are creatures of comfort, and both of us like open 'natural spaces'. My son and I love music, gadgets, and are 'clumsy', we even have a similar taste in food. What we perhaps share most strongly however is an autistic dispositional equilibrium of 'dynamic quality' (Pirsig, 1991, Milton, 2012), a different embodied habitus (Bourdieu, 1977), a consciousness dominated by a perceptual 'being in the world' (Schutz 1967).

The 'dynamic quality' of the autistic person however, is constructed from the outside as a pathological deficit, particularly by theorists and practitioners utilising a Durkheimian/Galtonian idea of positivistic social science, but also by many parents (particularly those of children deemed non-verbal), and even some self-advocates, who could be said to have internalised the negative semantic connotations of this ideological labelling process in a self-fulfilling prophecy (Becker, 1963). Many parents new to having discovered that their child has been labelled autistic also seek out any and every 'treatment' and 'intervention' in an attempt to 'help' their children in a 'you can't rule it out approach' (Milton, 2011b), whilst others become advocates on dubious practices such as ABA as it 'worked with their kid', and they believe in 'what works' (Maurice, 1993, Jager, 2010). Such phenomena leave both autistic people and their families at the mercy of a vast and exploitative autism industry:

“...the whole ABA movement appears increasingly more like a cult than a science: there is a charismatic leader, a doctrine, a failure to engage with criticisms, inquisition and denunciation of any who criticise (however mildly), misrepresentation of critics, and proselytising exercises to gain more converts and spread the word.” (Jordan, 2001, cited in Fitzpatrick, 2009, p. 141).

One of the earliest inklings that ‘I was not alone’ in my theorising came from my first reading of the seminal essay ‘Don’t mourn for us’ (Sinclair, 1993). This essay ably depicted the bereavement process in the ‘becoming’ of an autistic child’s ‘warrior mum’. It would seem to me that the normalisation agenda of dominant models of autism, not only disable the autistic person, but also their parents.

The legacy of Lovaas

How one perceives autism naturally leads to a perception of what is considered best with regard to educational practice. One of the most prevailing trends is that of the notion that the most important educational period in an autistic person’s life is pre-school and the first few years of school. This discourse has produced an ever-growing range of early interventions. It is interesting to note how this emphasis is at a time when the autistic person themselves has no say in the matter. These methods, although aimed at early childhood development, have also been used by schools throughout the curriculum and have also been applied to adult services. ABA (being the most popular of these methods) developed through the work of Lovaas (1987), and is supported by many practitioners (TreeHouse, 2010), theorists (Hewitt, 2005, Brock et al., 2006), and parents (Maurice, 1993), yet other theorist and practitioner literature either places it on a par with other approaches (Jones, 2002), or suggests that it is a flawed approach (Jordan, 1999).

Positivist social science uses a narrow band of criteria to judge the validity of claims to knowledge. Ontologically speaking, it is argued by Positivists that there exists regularities in the social world that can be observed and measured; that researchers can distinguish between value judgements and factual statements; and so in epistemological terms, knowledge is seen to be empirically testable. Positivist research is thus aimed at the nomothetic and universal rather than the idiographic and particular. Outhwaite (1987) states how the traditional scientific method employed by this hitherto dominant paradigm, derived from three generations of philosophical thinking: 19th century writers such as Comte and Spencer, Logical Positivism (e.g. Ayer); and Hempel’s emphasis on value-free evidence to support policy making. Deeply entrenched in this position, is the Behaviourist paradigm employed by Lovaas (1987); who attempts to utilise the theories of Skinner (1953) and apply them to the education of autistic people. The tenets of Behaviourism suggest that objective empirical knowledge can be produced from direct observation of human behaviour, whilst ‘invisible entities’ are rejected.

Lovaas (1987) defined autism by first referring to Kanner’s (1943) original definition, before citing his own research (Lovaas, Koegel, Simmons & Long, 1973) and suggested this provided a ‘more complete behavioural definition’. Lovaas (1987) argued that a behavioural definition was the most that science could provide, as the neurology of autism was not known. The ontology of autism, for Lovaas (1987), suggested that autism was a chronic disability without a known cure, defined by pathological behaviours that deviated from the psychological norm. The aim of the intervention being to make autistic children ‘indistinguishable from their peers’.

Lovaas (1987) referenced Lotter (1967) in suggesting that higher scores on IQ tests, communicative speech, and appropriate play were prognostic of better outcomes. This notion led Lovaas (1987) to argue that early behavioural intervention for improving IQ scores would help the long-term outcomes for autistic people. Due to the lack of evidence to support medical therapies, Lovaas (1987) suggested that ‘the most promising

treatment for autistic persons is behaviour modification as derived from modern learning theory', citing DeMyer, et. al. (1981).

For Lovaas (1987) the ontology of autism was that of the disordered and damaged other, as having a retarded IQ and not capable of 'normal functioning', leading to a poor prognosis and a dysfunctional individual (possibly with negative associations of an impact on 'normal' society). Behaviourist treatment was put forward as the only effective treatment available to improve the outcomes for this 'disordered' group.

"The conceptual basis of the treatment was reinforcement (operant) theory...Various behavioral deficiencies were targeted, and separate programs were designed to accelerate development for each behavior. High rates of aggressive and self-stimulatory behaviors were reduced by being ignored; by the use of time-out; by the shaping of alternate, more socially acceptable forms of behavior, and (as a last resort) by delivery of a loud "no" or a slap on the thigh contingent upon the presence of the undesirable behavior." (Lovaas, 1987, cited at neurodiversity.org, 2009).

By the 'targeting of behavioural deficiencies', Lovaas' (1987) assumed that there was a 'normal' way to play with toys (following prescribed function of design) and that self-stimulatory behaviour was in need of modification and was thus framed as pathological:

"...it is difficult to distinguish low levels of toy play (simple and repetitive play associated with young, normal children) from high levels of self-stimulatory behavior (a psychotic attribute associated with autistic children)." (Lovaas, 1987, cited at neurodiversity.org, 2009).

The ontological status of stimming was thus seen as a deeply pathological psychotic behaviour. 'Stimming' (self-stimulation) is a commonly recognised behavioural feature of children on the autistic spectrum, the function of which is highly contested (Sainsbury, 2000); yet attempting to modify a behaviour that provides comfort for autistic people could lead to upset, confusion, and a breakdown of trust with the therapist. Lovaas (1987) therefore assumed the existence of social and behavioural 'norms' consensually agreed upon (for example: not obviously stimming in public), and furthermore, that deviance from these norms could be classed as pathological and in need of remediation. A worrying ontological issue is that at no point did Lovaas (1987) identify an ethical dilemma with the use of aversives. In fact:

"In the within-subjects studies that were reported, contingent aversives were isolated as one significant variable. It is therefore unlikely that treatment effects could be replicated without this component." (Lovaas, 1987, cited at neurodiversity.org, 2009).

Lovaas (1987) suggests in the above passage that long-term behavioural change is not likely to be attainable without the use of aversives. Despite this recommendation, current ABA practitioners (TreeHouse, 2010) are advised not to use them. Having said this, ABA practitioners will use the ignoring of behaviour and time-out's as a non-reward, perhaps underestimated as a punishment, especially in certain contexts and interactions dependent on the ideologies and actions of those involved.

"Considerable effort was exercised to mainstream subjects in a normal (average and public) preschool placement and to avoid initial placement in special education classes with detrimental effects of exposure to other autistic children." (Lovaas, 1987, cited at neurodiversity.org, 2009).

In the above passage, Lovaas (1987) represented autistic people as having a detrimental effect on one another. One can only presume that what he meant by this comment, was that if autistic children are not exposed to 'normal' children, then they will not be able to model behaviour on their appropriate actions. One

could also read this discourse as suggesting that autistic children could learn pathological behaviours from modelling behaviour on one another.

IQ and school placement were seen by Lovaas (1987) as 'comprehensive, objective, and socially meaningful' measurable variables. Lovaas (1987) invoked the positivist mantra that objective social / psychological facts are not only measurable, but the only meaningful data concerning social science research. Analysis of subjective narratives was viewed within the Behaviourist paradigm as beyond measurement, so no data was collected on the views of the children (after follow-up) or the parents. Also, the reasons why two of the families involved in the experimental group withdrew from the study were not explored.

By using a Behaviourist paradigm, Lovaas (1987) was presuming that the human brain is a '*tabula rasa*' (Locke, 1690) that develops through conditioning of behaviours from reactions to rewards and punishments in the social environment. By offering educational interventions as capable of producing 'normal functioning', Lovaas (1987) was seriously underestimating the biological conditions that influence the expression of autistic behaviour patterns and the difficulties that autistic people with normal IQ measures and educational placements can have with their impairments and with the social expectations and structures imposed upon them (Sainsbury, 2000).

Challenging Behaviourism

"Positivism is dead. By now it has gone off and is beginning to smell." (Byrne, 1998:37).

Despite positivism's many critics, it is still the dominant ideology informing what is deemed good evidence-based practice in health and educational policy. The power embedded in the knowledge produced by research based upon positivistic ontological and epistemological axioms can profoundly affect the lives of those being researched, especially when those being researched are a recognised vulnerable and marginalised group within society with little political voice of their own. Increasingly, positivist social science has been led by ideas of falsification and the predictive power of theory, as standards for judging the production of knowledge. The question should be asked however, can the practice of ABA reach such lofty intentions? In order for debates on the education of autistic people to move forward, a researcher must move beyond the objectifying gaze of the scientific tradition to be truly participatory with those they seek to produce knowledge about.

The critics of ABA are also growing in number. A study by Remington et al. (2007, cited in Fitzpatrick, 2009) compared those who had home-based ABA to those who did not over a two-year period. Using measures of intelligence, language use, daily living skills, and a statistical measure of 'best outcomes', the majority made no significant advances. Magiati et al. (2007) found no significant differences in a range of outcome measures either, although large differences were found regarding 'outcomes' within both control and experimental groups. Fitzpatrick (2009) suggests that ABA may benefit some autistic people, yet the majority not, with some making improvements without any behavioural intervention being used. He suggests that researchers are no further advanced in discovering which children will make improvements, or which aspects of the intervention are having a positive effect. Autistic researchers such as Dawson (2004) on the other hand, have been quite scathing of ABA theory and practice on a number of levels. These concerns are also found amongst parental accounts (Milton, 2011b).

Nadesan (2005) argues that ABA has many methodological shortcomings and practitioners and theorists tend to exaggerate its benefits, yet have much potential to shape the development of autistic children (for better

or worse), producing certain kinds of subjects requiring professional surveillance and intervention. She argues that in such an instance 'biolooping' (Hacking, 1990, 2009) is inevitable, but may be difficult to identify and predict.

"Given the dangers of [ABA] inappropriate early diagnosis, the lack of replication, the lack of specificity, the ethically and culturally questionable nature of the 'treatment' and its impractical and expensive nature, like all other treatments that have claimed to be specific to autism, it has failed to establish itself as a definitive treatment." (Timini et al., 2011, p. 204).

Lyte:

Do autistic people have the status of being 'human'? It is my view that Behaviourists think I have to 'do' something to be human, or that I am not intrinsically 'okay'. The idea of 'human' that they hold has been toxic and limiting to me and my inner spirit, to the 'me-ness' of me. It dumbs down all my gifts and renders me disabled. It cannot be otherwise: that which makes me the gifted, sensitive, perceptive, creative, original and intelligent being that I am, is, by their processes of trying to turn me into something I am not, yanked and wrenched as though my guts are being pulled out of me: and thus suitably disabled, enables the breaking of my spirit, just as surely as one would do with breaking-in horses. I became a frightened passive prisoner in a world I was alienated from by their violent attempts to avoid seeing who I really was and what I may contribute to humankind. A lifetime spent aping a socialised 'human' in a despairing attempt to substitute for my lost autonomy and spirit, but now with little available ability to express my experience of the world and the gifts of my own 'humanity'. Luckily I was not subjected to ABA. I expect they may have broken the very spirit that I have managed by the skin of my teeth to honour and defend, though there are times when my human need to belong, to be loved and be respected for who I am was so profoundly and deeply unmet that I almost caved in - almost making that Faustian deal. Skinner whose heart I believe was in the right place, seems to have had little insight into what makes a self, or preferred not to look at these issues since he was firmly entrenched within a positivist-behavioural paradigm in terms of theorising only upon measurable function i.e. behaviour.

The re-branding of behaviourism

DM:

Perhaps the best exemplar of current ABA practice in the UK can be found in the 'ABA competencies framework' (2011). This framework lays out how ABA is aimed at all those working with autistic people, before listing competencies in terms of knowledge and the demonstrable behaviours of practitioners. It is stated in the introductory section of this framework that ABA is primarily concerned with understanding 'why behaviour occurs' in order to address a 'wide range of social issues' (including helping individuals to learn), which when applied to autistic people can be said to be an overly narrow focus on surface appearances (Williams, 1996). Within behaviourist theory, there is nothing to indicate why behaviour occurs, other than the general theory of operant conditioning. It clearly states that ABA can be equally applied across a number of settings, and how it is not designed to be autism specific, yet can be made to fit educational practice with autistic pupils.

"What distinguishes ABA from other disciplines is not just that it focuses on behaviour and the context (environment) in which behaviour occurs, but that for behaviour analysts, behaviour and environment are broadly defined." (ABA framework, 2011).

It is argued here however, that what distinguishes ABA is a Galtonian view of psychological normality and deficit, although Skinner (1953) could be said to have used a Wundtian methodology, and that the environment and the causes of behaviour are extremely narrowly defined, although this can vary in practice due to the practitioner.

“Behaviour analysts use principles of learning and laws of behaviour that have been scientifically demonstrated, and use clearly defined procedures to specify how to change behaviour. The primary focus of ABA is on behaviour that is important to individuals, in terms of enabling them to lead more fulfilling lives.” (ABA framework, 2011).

The ‘laws of behaviour’ may well have been demonstrated successfully on pigeons in controlled experiments (Skinner, 1953), yet they have not been so in the education of autistic children (Magiati et al., 2007). The continual use of a narrative of support from a ‘scientifically [proven] evidence-base’ is confidently stated without question by ABA advocates, when the evidence for its effectiveness, even by the measurement standards of its own supporters is virtually nil. The above quote also highlights the primary focus of behaviourism: behavioural change or modification. Despite protestations that this no longer has anything to do with normalisation, who exactly is defining what is ‘appropriate behaviour’, or which behaviour enables (or disables) the autistic person? This is not a mutual contract between equal partners in an exchange, but a power relationship and imposition from an outsider perspective and positionality.

Lyte:

They judge me on the bit they can see and what they are able to ‘see’ sadly will itself be limited by their own conditioning, which appears in concepts such as that of ‘normal’. I feel and I am in touch with my inner self despite the internalised violence and applied violence implicit in a conditioning process that is concerned with trying to pass me off as ‘normal’. Thus I have to question who the beneficiary of such an ‘intervention’ is. I can affirm that a great part of my life has had to be concerned, at incalculable personal cost, with the literally vital need to reclaim my disempowered self. I recognise the extent of my personal courage and valour in following this essential quest in the face of a largely uncomprehending social structure and those who regard ‘normal’ as equivalent to ‘healthy’.

DM:

In the ABA framework (2011), it is stated that the ethical principles and values of ABA practitioners are ‘in common with other helping professionals’, and that there is the priority not to cause harm, however the definition of harm can be a contested one, particularly from those of differing social and neurological positionalities. Like the behaviourists that came before them, there is also the point made of: being ambitious of what is possible for someone to learn, without setting limitations based on someone’s disability. This is fine in one context, but not if perceived as one’s disability (or rather neurological diversity) not impacting upon the way someone learns, or how such a diverse positionality may give someone propensities to succeed in certain cognitive capacities. One of the best principles offered by the ABA competencies framework is that of building upon an individual’s interests and preferences in the facilitation of learning, although one needs to develop strengths in their own right, and not just as a way of minimising difficulties. Although the stated principles of the framework also recognise that learning is a lifelong process, this statement is linked to one concerning skills in all areas of life. It must be acknowledged however, that not all learning is the attainment of measurable skills by sets of criteria.

One can see that ABA theory and practice has moved on from the days of Lovaas, but as a theory and method for educational practice, it still has just as many flaws as ever. It was suggested to me recently by a behavioural therapy specialist (Talakaboutautism.org, 2012) that maybe what was needed was to 're-brand' ABA to reflect the changes that it had gone through. I replied that if one were serious about investigating the cognitive and social factors of the education of autistic people and not just their outward behaviour (as a main focus and priority), then it would no longer be the science of behaviour as proposed by Skinner (1953) and ABA theorists since, but a model of 'applied bio-psycho-social analysis' (ABPSA). This, if it were to acknowledge the value of the autistic voice in knowledge production regarding autism, would be a model that I could potentially adhere to, yet this was not an exercise in re-branding but an essential theoretical and discursive change in focus - ironically from the restrictively narrow to the broad and eclectic.

The psycho-emotional disablement of autistic people and the raising of a revolutionary consciousness

Lyte (in personal communication with DM):

I can 'get a bit lost' to who I am, when I am in too much contact with neurotypical people. I'm not strong enough yet to be 'who I am', so I conform and 'act' and then feel horrible inside and get exhausted and worried because then I get told 'who I am and what I am or am not capable of'. I still have too much self-doubt, but I do think I have more hope now there are more like-minded advocates amongst us, or at least, I am more aware of them.

DM:

Reeve (2002, 2004) utilised the Foucaudian concept of 'technologies of power' to investigate the way society reinforces 'psycho-emotional' dimensions of disability, and the way in which the medicalised 'self-surveillance' of one's own body left people feeling worthless and unattractive. Reeve (2002) also states however, that disabled people were not just the passive victims of a dominant and disabling discourse, but exercise personal agency and resist. Interestingly, she likened the process of resistance to negative stereotypes to a process of 'coming out', mirroring a term often used within the neurodiversity movement. Reeve (2002) frames disabled identities as fluid, and representing diversity of phenomenological experience, rather than situating personal identity within an essentialist paradigm.

Within the dominant discourse of the medical model of autism however, the autistic person is framed as being incapable of self-surveillance, a potentially dangerous individual lacking in empathy, and in need of external and potentially coercive techniques in order to manage and control their 'challenging behaviour', albeit with the caveat of attempting to instruct the autistic person to be able to manage their own behaviour more 'appropriately'. The autistic person is thus constructed within this discourse as having no agency and simply the subject to be worked upon, to be socialised as best one can, so that one can 'pass as normal' in the adoption of the rehabilitation role (Safilios-Rothschild, 1970). It is of no coincidence one fears, that the silencing of autistic voices on such matters, coinciding with the focus on early intervention before the individual is able to consent to the intervention, leaves one at the mercy of those who would financially exploit the situation.

Autistic people are certainly left with an uphill battle regarding their sense of self-worth, often separated from the one thing that can give them a more positive perspective: the neurodiversity movement. One cannot 'come out' when one's own culture is still publicly in the dark. Attempts at such humanist self-actualisation and

combating the damaging effects of alienation and anomie are thus hampered, often leading to 'problems in living' and mental ill-health (Milton, 2012).

Reeve (2004) suggested that psycho-emotional dimensions of disability constitute a form of social oppression, operating at both a public and personal level, affecting not only what people can 'do', but what they can 'be'. Reeve (2004) categorises the dimensions of psycho-emotional disability into three main areas: responses to the experience of structural disability, in the social interaction one has with others, and in internalised oppression. These issues can be particularly marked in a marginalised group stigmatised by their differences in 'social interaction' itself (Milton, 2011a).

"...emphasis on the barriers 'out there', has the rather ironic consequence of leaving aspects of social life and social oppression which are so keenly felt by many disabled people (to do with self-esteem, interpersonal relationships, sexuality, family life and so on) 'open season' to psychologists and others who would not hesitate to apply the individualistic/personal tragedy model to these issues." (Thomas, 1999, pp.74).

It is this 'personal tragedy model' and resultant 'normalisation agenda', supported by some of the world's largest autism charities, and the resultant need induced in parents of autistic people to 'behaviourally modify' them, that has done most to disable autistic people living in society today, many of whom remain undetected by those who would potentially provide them with support, i.e. the neurodiversity movement.

"Society's played him a terrible trick, and sociologically he's sick" (West Side Story).

References

- Arnold, L. (2010) *The Medium is the Message*, accessed from: www.ucl.ac.uk/cpih/Arnold, on 16/02/12.
- Becker, H. (1963) *Outsiders*. New York: The Free Press.
- Bourdieu, P. (1977) *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.
- Brock, S., Jimerson, S., and Hansen, R. (2006) *Autism at School: Identifying, Assessing, and Treating*. New York: Springer.
- Byrne, D. (1998) *Complexity Theory and the Social Sciences: An Introduction*. London: Routledge.
- Dawson, M. (2004) 'The misbehaviour of behaviourists: ethical challenges to the autism-ABA industry', accessed at: http://www.sentex.net/~nexus23/naa_aba.html, on 12/02/11.
- DeMyer, M. K., Hingtgen, J. N. & Jackson, R. K. (1981). Infantile autism reviewed: A decade of research. *Schizophrenia Bulletin*. 7. 388-451.
- Durkheim, E. (1897, p. 1951) *Suicide: A Study in Sociology*. London: Routledge.
- Fitzpatrick, M. (2009) *Defeating Autism: A Damaging Delusion*. London: Routledge.
- Hacking, I. (1990) *The Taming of Chance*. Cambridge: Cambridge University Press.
- Hacking, I. (2009) Autistic autobiography, *Philosophical Transactions of the Royal Society: Biological Sciences*. Vol. 364(1522), p. 1467-1473.

- Hewitt, S. (2005) *Specialist Support Approaches to Autism Spectrum Disorder Students in Mainstream Settings*. London: Jessica Kingsley.
- Jager, E. (2010) *Autism Self Advocates: Please Speak for Yourself*. Accessed at: <http://autismparents.wordpress.com/2010/11/03/autism-self-advocates-please-speak-for-yourself>, on 04/01/12.
- Jones, G. (2002) *Educational Provision for Children with Autism and Asperger Syndrome*. Abingdon: David Fulton.
- Jordan, R. (1999) *Autistic Spectrum Disorders: Practical Strategies for Teachers and Other Professionals*. London: David Fulton.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2. 217-250.
- Locke, J. (1690) *An Essay Concerning Human Understanding*. Ed. Roger Woolhouse. (1997). Harmondsworth: Penguin.
- Lotter, V. (1967). Epidemiology of autistic conditions in young children: II. Some characteristics of the parents and children. *Social Psychiatry*, 1. 163-173.
- Lovaas, O. I. (1987) *Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children*. Los Angeles: University of California, cited from www.neurodiversity.org, accessed on 28/12/09.
- Lovaas, O.I., Koegel, R. L., Simmons, J. Q., & Long, J. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis*, Vol. 6. pp. 131-166.
- Magiati, I., Charman, T. and Howlin, P. (2007) 'A two-year prospective follow-up study of community-based early intensive behavioural intervention and specialist nursery provision for children with autism spectrum disorders', *Journal of Child Psychology and Psychiatry*. Vol. 48 (8), pp. 803-812.
- Maurice, C. (1993) *Let Me Hear Your Voice: A Family's Triumph over Autism*. London: Robert Hale.
- Milton, D. (2011a) "'Filling in the gaps", a micro-sociological analysis of autism'. *Theorising Normalcy and the Mundane*, 2nd International Conference. Manchester Metropolitan University.
- Milton, D. (2011b) 'Parenting, discipline, and educational preferences for children on the autistic spectrum – a survey of parental attitudes.' 10th Annual Postgraduate Education Conference. University of Birmingham.
- Milton, D. (2012) "'Problems in Living' and the mental well-being of people on the autism spectrum'. *Asperger United*. Editions 71-72.
- Nadesan, M. (2005) *Constructing Autism: Unravelling the 'truth' and understanding the social*. Abingdon: Routledge.
- Outhwaite, W. (1987) *New Philosophies of Social Science: Realism, Hermeneutics and Critical Theory*. London: Macmillan.
- Parsons, T. (1951) *The Social System*. New York: The Free Press.
- Pirsig, R. M. (1991) *Lila: An Inquiry into Morals*. London: Black Swan.

Reeve, D. (2002) 'Negotiating Psycho-emotional Dimensions of Disability and their Influences on Identity Constructions', *Disability and Society*. Vol. 17(5), pp. 493-508.

Reeve, D. (2004) 'Psycho-emotional Dimensions of Disability and the Social Model', In C. Barnes and G. Mercer (ed's) *Implementing the Social Model of Disability: Theory and Research*, pp. 83-100. Leeds: The Disability Press.

Safilios-Rothschild, C. (1970) 'The Study of Family Power Structure: A Review 1960-1969' *Journal of Marriage and Family*. Vol. 32(4), Decade Review. Part 1 (Nov., 1970), pp. 539-552.

Sainsbury, C. (2000) *Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome*. Bristol: Lucky Duck.

Schutz, A. (1967) *The Phenomenology of the Social World*. Evanston: Northwestern University Press.

Sinclair, J. (1993) "Don't Mourn For Us", http://www.autreat.com/dont_mourn.html, accessed on 10/11/09.

Skinner, B. F. (1953) *Science and Human Behaviour*. New York: Macmillan.

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

Timini, S., Gardner, N. and McCabe, B. (2011) *The Myth of Autism*. Basingstoke: Palgrave.

Williams, D. (1996) *Autism: An Inside-Out Approach*. London: Jessica Kingsley.

Wing, L. (1988) The continuum of autistic characteristics. In E. Schopler and G. Mesibov (Eds.), *Diagnosis and Assessment in Autism*. New York: Plenum Press.

UK ABA (Applied Behaviour Analysis) *Autism Education Competence Framework* (2011), accessed at: www.ambitiousaboutautism.org.uk/page/what_we_do/research/aba_competencies.cfm, on 16/02/12.

www.talkaboutautism.org (2012), accessed on 16/02/12.

www.treehouse.org.uk (2010), accessed on 07/02/10.