Milton, Damian (2014) *So what exactly are autism interventions intervening with?* **Good Autism Practice, 15 (2). pp. 6-14. ISSN 1466-2973.**

So what exactly are autism interventions intervening with?

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Editorial comment

Often the first question after receiving a diagnosis of autism, is what can we do to help? The answer to this is by no means simple and is generally met with the reply – "it depends". This paper by Damian Milton, an autistic adult, explores the complexity of this question and in particular draws attention to the fact that often the answers given are from a non-autistic perspective and fail to discover what the general view of autistic children or adults would be to what is suggested or what the particular individual would wish for. He argues that there is little, if any, robust research evidence to support the interventions currently offered and that this may never be so, given the issues in conducting such research. Professionals, parents, autistic children and adults have different views depending on their experiences, their training and their own personal preferences and these will all affect what is offered or searched for.

Damian declares his own biases and this is an important first step in considering the options for intervention. He and others maintain that the proponents of some interventions have little experience outside that intervention or indeed of autism, and reviews of research show that studies are often conducted by those who developed the intervention, creating bias from the start (Jordan and Jones, 1998; Parsons et al, 2009).

This paper will cause readers to consider their own work and choices for the children and adults they live or work with and is likely to prompt them to consider ways in which they find out how the person receiving the intervention perceives this prior to and during its delivery. In a new edited book to be published by BILD on promoting happiness and wellbeing, Vermeulen (in press) makes the point that intervention studies often measure levels of skill, anxiety, stress, IQ etc, but how often do we ascertain whether the autistic child or adult is now happier as a result? This is an apt question given the arguments put forward in this paper by Milton.

Introduction

A cursory look on an Internet search engine regarding autism will soon have the viewer coming across the notion of intervention, and in particular a narrative of early intervention to help the development of autistic people. Today, the Research Autism website lists over one-thousand named interventions in the field of autism, along with indications of the amount of research evidence there is to support the claims they make. Yet, with so many on the market, it is quite obvious that they are not all trying to achieve the same goals. With discussions regarding intervention, what is often left out, is:

- What is it all for?
- What is one trying to achieve and why?
- Are there ethical issues regarding these purposes, or the means by which one tries to achieve them?

This paper gives an overview of the spectrum of ideology underlying current debates in the field, and the tensions that exist between different viewpoints. I use a number of research studies in the area to highlight these tensions and why they exist by reviewing a number of currently popular practices (eg Applied Behavioral Analysis (ABA) (eg Lovaas, 1987), Relationship Development Intervention (RDI) (Gutstein and Sheely, 2002) and Intensive Interaction (Caldwell, 2014; Nind and Hewett, 1994)), and will offer some suggestions as to a way forward that is more open about such disputes, rather than trying to build a false consensus between them.

A conflict of interests

First, it needs to be pointed out that I, like everyone else working in the field of autism, am biased by my own experiences. These being, that I am someone who is on the autism spectrum themselves and also a parent to an autistic child, as well as a person with training in a number of academic disciplines. My work is often critical of established models of practice in the field of autism, particularly those based on behaviourism (Milton and Moon, 2012).

As I will attempt to show in this article however, such biases are perhaps inevitable, as they are founded upon some fundamental questions about our philosophy of life, what it is to be human, a social being, to learn, and what it is that one ought to be learning, and so on.

Secondly, this leads on to a second kind of 'conflict of interests' within the field of autism, that is, that there are great tensions and controversies between different points of view, often between people who passionately believe in the approach that they are taking and the supposed benefits that taking such an approach can bring. Often, however, such debates and discussions are hidden from view, as if all those involved in the field are in general agreement or consensus. Yet to what extent is a consensus possible? What aspects of learning are there any level of agreement about? What are the main areas of tension and why do they exist? In this paper, I hope to explore these issues.

Theories of learning

Early on in teacher training courses, students are introduced to a number of theories of learning. These provide conceptual frameworks within which to try and understand how learning takes place. *Table 1* below (adapted from Merriam and Caffarella, 1991: 138), shows the main differences in these approaches.

Table 1:   Different theories of learning

	Behaviourist	Cognitivist	Humanist	Social / Situational
Theorists	Watson, Skinner	Piaget, Bruner	Maslow, Rogers	Bandura, Salomon
View of the learning process	A change in behaviour	Internal mental processes (such as insights and information processing)	Actions toward fulfilling potential	Interaction within social contexts, inclusion in a community of practice
Primary locus of learning	External stimuli*	Internal cognition	Affective and cognitive needs	Learning seen as a relationship between a people and their environment
Purpose of education	Produce behavioural change in a desired direction	Develop capacity to learn new skills	Exercising autonomy and becoming a self-actualised learner	Full participation and inclusion in communities of practice
Role of educator	To arrange the environment to elicit a desired response	Structures the content of a learning activity	Facilitates personal development (holistically)	Establishing participatory communities of practice
Practical examples	Competency-based education	Comparisons made to stages of development	Self-directed learning	Participatory activities

*It should be noted that Skinner also looked at 'internal stimuli' or 'private behaviour'

Although any such breakdown gives a generalised overview of such theories and not an in-depth understanding, one can see that there are a number of ways of viewing learning, what the purpose of education is, and how best to achieve the outcomes one aspires to. Behaviourists following Skinner see learning largely in terms of conditioning through external stimuli that is processed as either something negative or something positive, reinforcing or extinguishing behaviours from being repeated. Cognitivist theory looks more closely at the attributes of the learner rather than making changes in the environment to influence behaviour. Humanists emphasise subjective understandings, while social constructivists suggest that learning should be a mutual and tailored process of construction. In practice, a teacher may use a mixture of the above approaches, whilst others may be more devoted to a particular approach. This spread of views is also found across the field of intervention research and practice with autistic children.

Applied Behavioural Analysis (ABA)

"Viewing autism as a list of deficits that can be corrected through a series of discrete trials will not make an autistic person any less autistic. Teaching autistic people how to 'pass' so they can blend in better with non autistics is similar to the belief that a closeted gay person will live a happier and more fulfilled life by being closeted than someone who is 'out'." (Zurcher, 2012).

When studying the field of autism, the influence of behaviourism as a theory of learning can appear dominant, through the work of Lovaas (1987) to contemporary debates regarding autism interventions, such as the documentary *Autism: challenging behaviour* that was aired on BBC4 in 2013. Those researching autism for the first time will come across a plethora of interventions generally based upon the principles of Applied Behavioural Analysis (ABA). According to the NHS guidelines for autism treatments (NHS, 2014), ABA is said to be based on the breaking down of skills into small tasks in a highly structured way, and reinforcing behaviour thought to be positive, while discouraging

behaviour deemed inappropriate. ABA programmes are then described as an intensive therapy of 40 hours of work a week, over a number of years. This intensity is not followed by all theorists or practitioners who support ABA methods though. It should be noted that there is a vast array of approaches that have been influenced by ABA and many of them are at odds with one another in various respects. For instance, the early aversive punishments used by Lovaas (1987) and colleagues, and their goal of making autistic children "indistinguishable from their peers" are now largely and rightly frowned upon. One popular approach, especially in America, is that of Early Intensive Behavioural Intervention (EIBI). This intervention often uses the method of 'discrete trial learning', used it is said, to build foundational learning skills. The behaviour of children is subjected to a functional assessment, where the teacher describes a 'problem behaviour', identifies antecedents for why the behaviour is occurring, and analyses the consequences of the behaviour. This analysis is thought to indicate what influences and sustains such behaviours. Other methods include Pivotal Response Therapy (PRT) which attempts to use behaviourist principles in more naturalistic settings, where 'natural reinforcers' such as a favourite toy are preferred to rewards such as a chocolate treat.

Despite widespread support and the mounting piles of research papers extolling the virtues of ABA-based practices of various iterations, such approaches have also come under much criticism from scientists, ethicists, autistic people and their families. ABA, like many other therapies and interventions purported to help autistic people, is often sold as if it is a 'miracle treatment', and if not, as the only recognised approach to be 'scientifically proven', and needed as quickly as possible in order not to miss the 'window of opportunity'. One of the clearest examples of such an extreme position can be seen in the account of ABA given by Maurice (1994). In her book entitled, *Let me hear your voice: a family's triumph over autism*, she claims that ABA had saved her children's lives, likening it to chemotherapy as a treatment for cancer. Whatever approach favoured, it is important that such zealotry be avoided by practitioners working with autistic children. Since, in my view, it will lead to poor practice, as Ariane

Zurcher (2012), a mother of an autistic child describes:

"...when she did not show the sort of monumental leaps promised, the ABA therapists said it was because we were at fault. Never once did any of the therapists, supervisor or agency waver in their firm belief that ABA was a solid, 'scientifically' backed methodology. It was spoken of as fact." (Zurcher, 2012).

Similarly, John Lubbock (2001), in the UK, the father of a boy with autism who followed an ABA programme, whilst an advocate of the principles of ABA was critical of the fact that often the therapists and some of the supervisors, "had a fundamental lack of wider knowledge and experience" and that this "will tend to make people inflexible, as they have no response to problems other than more Lovaas." (p. 319).

This concern can equally be applied to other interventions where the proponents and/or practitioners only have knowledge of that particular intervention and also sometimes very little knowledge of autism.

In recent years, a North American group of autistic writers began a project entitled the Loud Hands Project (2014), named after an online article from an autistic person who critiqued the therapy they had received when younger, and the request for 'quiet hands'. One of the biggest criticisms made of behaviourist approaches is that the behaviours deemed as either positive or negative are being decided upon by non-autistic others, often with little idea of what it is subjectively like to be autistic, or to have an unusual autistic learning style. Methods such as discrete trials can be intensive to the extent of being overloading, particularly when staged in a face-to-face manner, and distress can be ignored when viewed as inappropriate behaviour. When concentrating on outward behaviour, it is essential (in my view) that practitioners do not forget about autistic cognition and subjective understandings, and how these influence one's interactions with the social situations one finds oneself in. One area of ABA-based theory and practice which states clearly that they are against notions of cure and normalisation

is that of Positive Behaviour Support (PBS), yet it is still open to the criticism of who gets to decide what is and what is not positive about behaviour, and that perhaps some of the nuances of these ideas are lost on many people practising ABA in the hope of some kind of miracle transformation. As an example, I would recommend watching the parental narratives in the film *Autism: challenging behaviour* (2013).

The phrases 'scientifically proven' and 'evidence-based' often used in pro-ABA literature also need to be critiqued. Gernsbacher (2003), for example, reviewed these exaggerated claims within the field, as well as showing the flaws in the often cited article by Lovaas (1987). More recently, Michelle Dawson (2007) has critiqued the methodology of ABA-related research, and a number of reviews and studies have shown no significant difference between ABA-based approaches and other approaches (Magiati et al, 2007; Fernandes and Amato, 2013; Boyd et al, 2014). Hogsbro (2011) compared the progression of children on the autism spectrum receiving ABA programmes, with those in ordinary placements, specialist autism day-care units, and those receiving a mixture of provision. Hogsbro utilised measures often used by studies that had found positive gains from ABA, such as IQ scores, and measurements for language comprehension, self-help skills, and the capacity for social contact. Hogsbro found that on average, the ABA provision had a negative impact on all of these factors, and the group which performed best were those receiving support from 'specialist autism units'. This study also looked into parental and professional attitudes toward the provision the children were receiving, and found that within the ABA group, the parents had the highest expectations for their children, and that professionals and parents using this model subjectively rated improvements in these areas higher than all of the other groups. Such evidence raises questions as to the validity of anecdotal accounts of change, yet also with accounts that suggest the ABA is a 'proven' method or indeed 'medical treatment'. Hopefully such findings will lead to research into the common factors between approaches, beneficial factors within them, and influential factors such as maturation which have little to do with what educational approach one takes.

Relationship and developmental approaches

Discussions regarding autism interventions often refer to alternatives to behavioural approaches as relationship-based or developmental approaches. This is a very broad category however which encompasses a number of differing approaches, most with a strong cognitivist or functionalist basis (looking at levels of psychological and social functioning, often compared to normative averages), yet also often using humanist and/or social or situational ideas. Also, with the so-called cognitive revolution in psychology, one could say that there has been a general shift in education theory toward a cognitivist approach, such as that derived from the work of Piaget (1896 – 1980). Such theories often look at measurements of functioning against normative (average) stages of development. Indeed, one can see elements of a functionalist perspective in some behaviourist narratives, particularly PBS. Piaget also highlighted peer relations and active learning experiences. Social or situational approaches however, often draw upon the ideas of Vygotsky (1896 – 1934) who looked at learning as a socially situated process, and saw the teacher as more involved in scaffolding learning for their pupils/students. Ideas originating from both these theorists, and indeed those of humanist theorists, can be found within the theoretical explanations of a number of autism interventions. One firmly established cognitivist approach is that of TEACCH (Treatment and Education of Autistic and Communication handicapped CHildren) or structured teaching (Schopler and Mesibov, 1995). This approach places emphasis on the structure and predictable sequencing of activities, as well as visual schedules and prompts. More recently the Social Communication, Emotional Regulation and Transactional Support (SCERTS) approach (Prizant et al, 2002) has been formulated, that looks to be a child and family-centred approach, and highlights the development of 'functional' social communication, regulating emotions, and mutual transactional support.

Some approaches highlight the building of relationships with others as the primary focus for attention. Early examples would include the Option or Son-Rise programme (Kaufman, 1994), often criticised for its outlandish claims of miracle cure and high cost of the programme for parents, and the floortime approach developed by Greenspan (2014). This approach focuses on the sensory differences experienced by autistic people, and in following the child's lead and interests, rather than being adult-led. A somewhat more humanistic approach, it still however keeps a foot in the functionalist camp by suggesting that the approach helps children to climb the 'developmental ladder', conceived as operating in a number of stages. Like other approaches, its starting point is a view regarding autistic 'deficits', in this case deemed to be disturbances in the sensory system, motor planning, communication, relating to others, and an inability to connect one's desire to intentional action. While there are elements of truth in seeing these areas as those found difficult by autistic people, an entirely deficit model of what autism is, has its own disadvantages (see later in this paper). It is the view of the proponents of this approach that autistic people miss out on stages of development, yet such progress can be re-strengthened by meaningful interactions and play with caregivers.

Relationship Development Intervention (RDI) shares many similarities in theory and practice with the floortime approach, in terms of 'functional relationships' being the main aim of the intervention. This programme is based on the concept that autistic people are deficient in what is termed 'dynamic intelligence', a somewhat umbrella term that includes thinking flexibly, theory of mind, coping with change, and processing more than one piece of information at the same time. By working upon these qualities, those who follow RDI suggest that the quality of life for children on the autism spectrum can improve. Unfortunately, RDI supporters seem to have fallen into the same trap as previous approaches, with large claims being made from scant evidence. Also, the use of the term 'dynamic thinking' can be criticised for being too all-encompassing a term, especially when others have used the exact same words to describe a more direct and sensory experience of one's environment (Pirsig, 1991).

Finally, there is the approach of intensive interaction. Similar to floortime and RDI, it is a relationship-based model, which seeks to make functional gains in communication. However, the focus here is primarily building trust and rapport on the child's own terms. This approach is the one that I personally favour, and a fine

exponent of this approach would be Phoebe Caldwell (2014). An issue with all of these approaches is that the scientific evidence (mentioned earlier) does not seem to favour any approach, at least not in terms of making significant changes in communication (often a key target that approaches share). Studies show massive variance in terms of the outcomes of interventions, whatever the purpose they are set to. There is certainly not enough evidence for me to suggest one over another as a one-size-fits-all approach. Thus, I would recommend avoiding taking such a stance, whatever one's leanings may be in favour of one approach or another. More research is needed too, to see if there are any active factors that do make a significant difference. Yet, such studies should also involve the views of autistic people and their families regarding what one wishes to intervene with in the first place. Perhaps with its model of mutual respect in interactions, engaging with autistic interests, and taking into account autistic cognition and sensory differences, it is little wonder that I find intensive interaction the most favourable of current approaches for children on the autism spectrum.

The concept of neurodiversity and its implications

Instead of trying to give a full account of the history of the concepts of neurodiversity and self-advocacy, given one would be trying to account for over two decades of culture, I will give my own understanding of neurodiversity as someone who identifies as autistic. For me, the concept of neurodiversity suggests that variations in neurological development are part of natural diversity, rather than something to be pathologised using a purely medical model of disability, defined by one's deviation from statistical or idealised norms of observed behaviour. This is not to say that those who identify as autistic people or other forms of neuro-identity do not find life challenging.

> *"Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum."*

(Milton, 1999, unpublished masters dissertation). Spectrum in this case refers to the "human spectrum of dispositional diversity".

Embedded in more of a social model of disability (see Milton, 2012), such a conceptualisation of neurodiversity would suggest that autistic people are significantly disadvantaged in many aspects of life. Such a concept is not devoid of an understanding of embodied differences, indeed far from it, yet is a socially situated understanding of such differences. Other than from autistic scholars, such conceptualisations are rarely given much credence outside of the disciplines of sociology and critical disability studies. When looking at an educational programme that best suits such a conceptualisation, it is evident that one would favour one that did not focus on perceived deficits, less still behaviours deemed inappropriate. What would be highlighted would be an understanding of differing dispositions, a building of relationships in a respectful manner, engaging with an individual's abilities and interests and not just what they find difficult. Is this not how many people, whatever their disposition, would like to be treated within educational settings? For me, the closest any of the previously discussed approaches gets to such a social/situational approach is intensive interaction, particularly the variations and practice demonstrated by Phoebe Caldwell (2014). Does this mean that one should accept these methods as something to blueprint and reproduce everywhere? No. It does however, call into question whether any educational approach will ever be able to claim a stronger evidence-base than any other, as autistic voices keep saying – one-size does not fit all. Thus, for me, none can claim to have a scientific evidence base of effectiveness. For me, this has not been demonstrated, and is unlikely ever to be.

Tensions in the field reaching a tipping point?

Recently, Professor Simon Baron-Cohen (2014) posted an article in an online magazine in response to what he would like to see retired as a scientific concept. His answer to this question was "radical behaviourism", the form of behaviourism proposed by BF Skinner that is still influential upon ABA-based practices today. In this article, Baron-Cohen (2014) only alludes to the field of autism, without directly mentioning it. Given his work in the field of autism, however, one could view this as a political act. I did not find it at all surprising that he should disagree with behaviourist ideas, given that

one could describe his theories as based more within the cognitivist-functionalist camp. What was perhaps more surprising was that this article followed on from the publication of the NICE guidelines on intervention for autism in adulthood (NICE, 2012), which contained aspects of behaviourist theory, yet whose committee was chaired by Baron-Cohen. The article led to a stream of rebukes from behaviourist academics and practitioners, with one commentator giving him a C+ for his understanding if it was an undergraduate essay. In the defence of Baron-Cohen (2014), I believe he used the word 'scientifically' in exchange for theoretically, in order to appeal to a lay audience, and that his references of animal behaviours could have been used as a metaphor for the treatment of autistic people (both aspects of his article that were criticised, among others). As someone who favours a more sociological and social constructivist (social/situational) view of education and learning, I would have disagreements with both behaviourists and Baron-Cohen (2014), and this is the point: consensus in this field is about as likely as having a sustained political consensus between all political interest groups, from fascists to communists. The reason such a consensus is not possible, is because the debates are largely theoretical and ideological. Thus, there will not be any agreement regarding how to measure progress, or even if one can. The most important message here for parents and practitioners working with autistic children, is that there are no easy answers!

Concluding comments: what is a parent or practitioner working with autistic children to do?

The answer to this question is never an easy one. Due to the diversity of dispositions and learning styles of people on the autism spectrum, asking "what works?" in an educational setting, is like asking the same question about people who are not autistic. Thus, the common sense answer is: it depends on the child, what you are trying to teach and why, the environment one is in and the skills, expertise and personal style of teachers and parents. One thing that does not work though, speaking as an autistic person, is trying to 'cure' someone of being autistic. Autism is a description of someone's cognition, the way they behave, their way

of being and acting in the world. Thus, I prefer to call myself an autistic person, yet do not see autism as a cluster of behavioural deficits to be fixed.

> *"We need to see the world from the autistic perspective and apply approaches based on a mutuality of understanding that are rational and ethical – which respect the right of the individual to be different – yet recognises and deals with distress and offers practical help. We should encourage and motivate the person to develop strengths rather than focus on 'deficits'. This will mean offering opportunity for development while supporting emotional stability."* (Mills, 2013).

The National Autistic Society (NAS) promotes what it calls a framework, rather than an approach, known as SPELL (Structure, Positive, Empathy, Low-arousal, Links). The first aspect of this framework is 'structure'. This is an often cited area of need for autistic people, often assumed to be deficient in executive functioning (by some cognitivists), yet it is a part of any educational planning. Imposing structures that are not needed or indeed impinge on learning is something to be avoided, and care must be taken that structures are put in place that promote the autonomy of the learner and reduce their stress (not increase it!). Being 'positive' relates to focusing not only on what a learner finds challenging, but what they find interesting, or that they have an aptitude for. Self-esteem and self-worth can be badly affected by attempts to normalise one's differences (Milton and Moon, 2012), thus the old proposed goal of making autistic people "indistinguishable from their peers" (Lovaas, 1987) needs to be jettisoned. 'Empathy' may sound a great deal simpler than it actually is in practice. It is often commented that autistic people have a deficient theory of mind, yet how accurate are non-autistic theories of autistic minds? For me, due to dispositional and cultural differences, a 'double empathy problem' exists (Milton, 2012), that is, that both parties can have difficulties in understanding one another. Bridging this gap can take much will and effort from both parties, plus the building of a strong trusting relationship. Again, I would refer here to the work of Phoebe Caldwell (2014). A 'low-arousal' approach is one that recognises the harmful effects of stress and thus seeks to reduce

confrontations and sensory overload. It should be remembered though that low-arousal does not mean no-arousal and that some sensory activities can be great fun too (although favoured activities may vary widely from one person to the next). The 'links' aspect of this approach states that parents, other agencies and so on, work in collaboration and with consistency and respect. For more information on the SPELL framework, information about approaches and current evidence and research, I would advise parents and practitioners to look at the Research Autism website (2014) and Mills (2013).

Last but by no means least, in the words of Douglas Adams and the *Hitchhiker's Guide to the Galaxy*: "Don't Panic!"

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