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Applied Behavioural Analysis and the autistic community: time to listen

Dr. Damian E M Milton

A Mismatch of Salience
Explorations of the Nature of Autism from Theory to Practice
By Dr. Damian E M Milton

The Neurodiversity Reader
Exploring concepts, lived experience and implications for practice
Lead Editor: Dr. Damian Milton
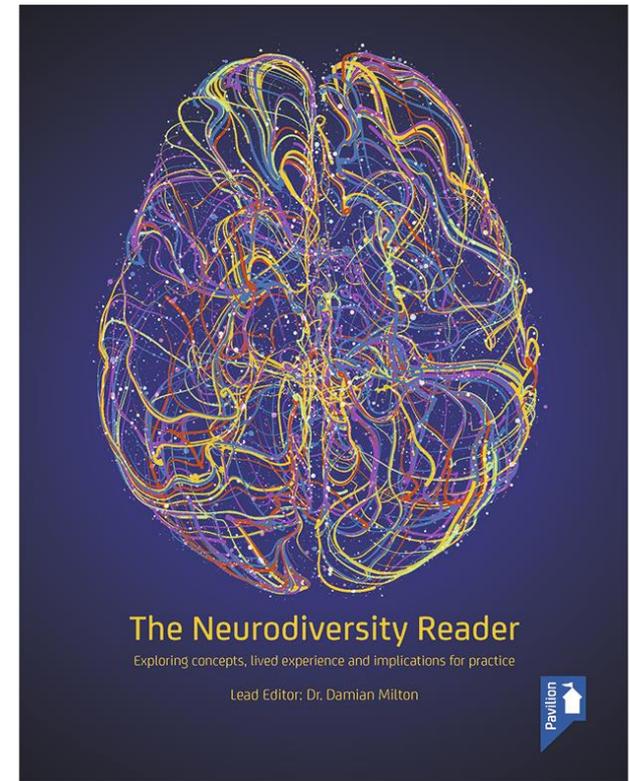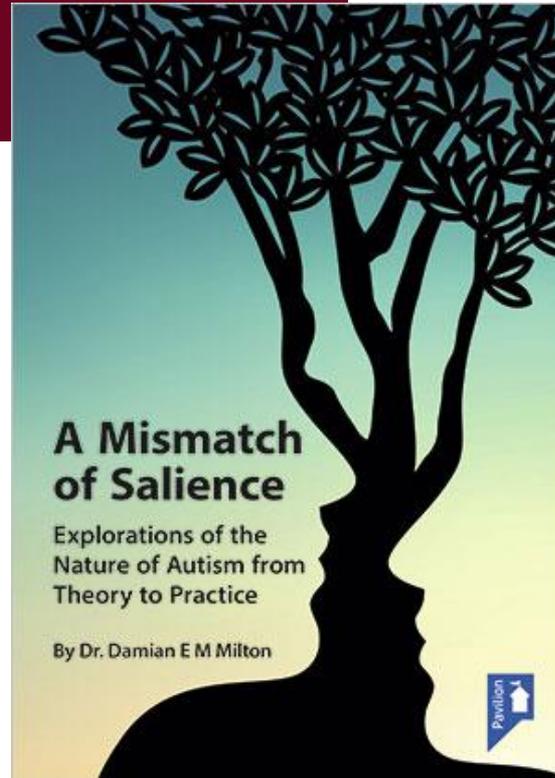
A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).

- A background in Social Science (initially Sociology).

- A quick note on my background in studying Behaviourism.

- Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent.

- Visiting Lecturer, UCL and LSBU.

- Chair of PARC and Director at NAT.

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Introduction

- Criticisms made of Applied Behavioural Analysis (ABA) and Positive Behavioural Support (PBS) and its implementation with autistic people.

- Ongoing controversy and deepening polarisation.

- Why criticise? Not to deny, but to improve: Narrative, goals of intervention, theory, evidence, accounts of harm, values.

- In preparation for this presentation – what does one find searching for information on the internet? Range of academic sources and personal accounts.

- My own interpretation and critique, I do not talk for 'all autistic people' anymore than anyone else does.

- Caution ahead…

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Searching for ABA + Autism online

- 'Healthline – Is ABA right for your child?'
- Searched within UK
- ABA4All
- Child Autism UK
- BeyondAutism

- UK-SBA
- PBS Framework
- Range of academic sources (see references)

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What is ABA?

- "Many experts consider ABA to be the gold-standard **treatment** for children with autism spectrum disorder (ASD) or other developmental conditions…These goals generally relate to **reducing problematic** or **harmful** behaviors, such as **tantrums** or self-injury, and increasing or improving communication and other **skills**." (Healthline, 2020).

- "ABA can help children **with ASD** to develop communication **skills** and progress academically…It also provides a structured way to tackle behaviour and sensory issues to help your child cope with the day-to-day demands that they find challenging…An ABA programme is a **positive experience for the whole family**." (ABA4All, 2020).

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What is ABA?

- "An ABA programme is typically made up of **skills** from several of the areas listed [e.g. social skills, communication skills]…and tailored to the **skill deficits** of the learner. It will teach skills that '**typically developing**' children often pick up without intensive teaching." (What is ABA?, ABA4All, 2020).

- "A main goal of ABA is to teach **socially significant** behaviours. It is a science devoted to the understanding and **improvement** of human behaviour. This means that targets of the programme should identify behaviours of **importance to the learner and their family** to increase (within reason). A programme should also, where appropriate, decrease **undesirable** behaviours by analysing why the **problem** behaviour is happening (the **function**)." (What is ABA?, ABA4All, 2020).

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What is ABA?

- "We enable choice and strive for **independence** whilst helping to **reduce** behaviours that limit pupils' **opportunities**. We teach complex **skills** step-by-step including daily living skills, communication, **functional** academic skills and social skills to ultimately allow pupils to be as independent as possible and to **access their community**." (BeyondAutism, 2020).

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'What does a behavioural analytic approach entail?' (UK-SBA, 2020)

- **Positive reinforcement** must be a key component to the teaching or **behaviour change**, and this reinforcement must be carefully **tailored** for each person.

- Any behaviour change (e.g., teaching new skills, reducing problem behaviours) must **clearly benefit** the individual and **improve their quality of life**.

- There must be careful recording of **data**, usually on a daily basis, to demonstrate progress or make changes to strategies as needed.

- Behaviour Analysts must receive ongoing **training** to stay up-to-date with scientific advances in the field.

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Goals of intervention

- "ABA therapists try to uncover causes of certain behaviors to help your child **change or improve** them." (Healthline, 2020).

- "We focus on teaching **skills** to enable them to become **active citizens** rather than **suppressing** these behaviours." (BeyondAutism, 2020).

- "Contemporary theory and practice, despite moving beyond the 'methodological behaviourism' that prioritised behaviour modification…still primarily focuses on reducing behaviour deemed 'aberrant' or 'inappropriate' and increasing behaviour deemed **socially 'valid'** and 'acceptable'." (Milton, 2018).

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Goals and outcomes do not always match

- "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).

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Normalisation

- "Another way to decide what to teach a child with autism is to understand **typical** child development. We should ask what key developmental **skills** the child has already developed, and what they need to learn next. The statutory curriculum in the countries of the UK also tells us what children **should** learn. Then there are **pivotal** behaviours that would help further development: teaching communication, social skills, daily living or academic skills that can support longer-term **independence** and choices." (Prof. Richard Hastings, 2013: http://theconversation.com/behavioural-method-is-not-an-attempt-to-cure-autism-19782).

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Applying philosophy and constructing theory

- Ontology and metaphysics – what is it?

- Epistemology and the theory of knowledge – how do we know what we know?

- Methodology – how do we practically test what we think we know, or explore what we do not?

- Differing answers to these questions have led to a number of paradigms, or 'schools of thought' being established in various disciplines and topic areas – particularly in the 'social' sciences.

- Other theories and methods are also available!

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Behaviourist theory

- Science? Doctrine? Paradigm? Psychology, theory of learning, philosophy of mind.

- "Strictly speaking, behaviorism is a **doctrine** – a way of doing psychological or behavioral **science** itself…That is, this approach retained overt behavior as an important dependent variable of **psychology** while acknowledging the existence and significance of unobserved behavior…He [Skinner] did not, however, grant special **causal** status to such phenomena. That is, rather than place causal status in hypothetical entities or constructs, Skinner's radical behaviorism attempted to **demonstrate orderly relations** between behavior and **environment**." (SEP, 2020).

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Behaviourist theory

- "Proponents of ABA suggest that it is a '**natural science**' of behaviour, rather than a '**social science**' dependent on hypothetical **constructs**." (Milton, 2018).

- "Behaviour Analysts are not **distracted** by the many **different theories** of the causes of autism." (Child Autism UK, 2020).

- Critics would suggest that rather than being an objective natural science however, it rather uses a flawed set of conceptual concepts at the expense of excluded concepts that have developed through other disciplines and perspectives.

- Championing an interdisciplinary approach vs. criticisms of an 'eclectic' approach.

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Criticisms of ABA: throughout history of autistic activism and scholarship

- Accounts of harm. The JRC.

- 'The misbehaviour of behaviourists' (Dawson, 2004).

- The Loud Hands project.

- Criticisms of the UK ABA Competency Framework.

- ABA Controversy Twitter account, and ABA related hashtags. The #TodayinABA example.

- The Autistic Not Weird survey.

- Growing tensions – the PBS conference 2020.

Generally speaking, I support ABA therapy for autistic children. [Autistic respondents]

- Strongly agree: 2.19% (75)
- Agree: 3.00% (103)
- Neither/not applicable: 16.93% (581)
- Disagree: 10.64% (365)
- Strongly disagree: 42.84% (1470)
- No answer: 24.40% (837)

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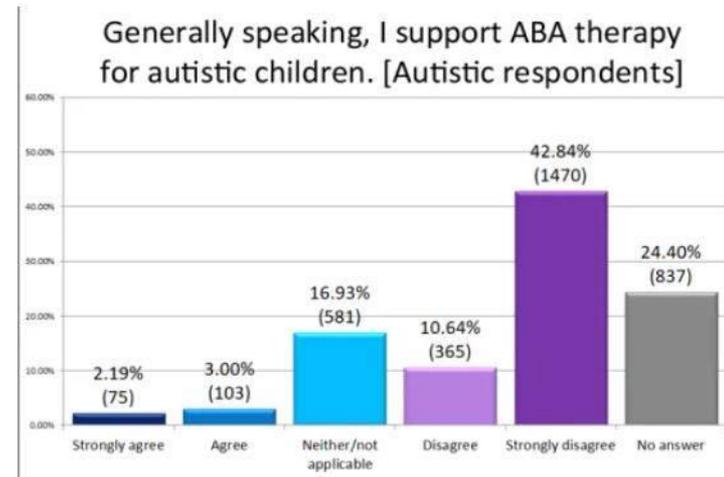
Criticisms of ABA: Neurowonderful masterpost

- "While not every resource here will contain explicit **triggering** content, much of the resources in this masterpost mention or deal with generally triggering material. Content warnings for **institutionalized ableism**, medical **abuse**, **restraint**, child abuse, **torture**, anti-autistic ableism, "**quiet hands**", emotional and psychological abuse, **manipulation**, **infantilization**, **nonconsensual** "therapy", **compliance** training, and **violence** against disabled children and adults." (Neurowonderful, 2020).

- Updated autism ABA resource 'masterpost'.

- Writing by professionals, parents and autistic people, and a section on links to trauma.

Criticisms of ABA: Alfie Kohn (2020)

- Dehumanising and infantalising.

- Ignores internal realities.

- Undermines intrinsic motivation.

- It's all about compliance.

- It creates dependence.

- It communicates conditional acceptance.

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Criticism of ABA: As a parent can you be seen as part of the problem?

- "ABA also **relies** on parents and caregivers to help reinforce **desired** behaviors **outside of therapy**…Your child's therapist will teach you and your child's teachers about strategies that will help to reinforce the work they do in therapy…You'll also learn how to safely avoid types of reinforcement that are less effective, such as **giving in to tantrums**." (Healthline, 2020).

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Criticisms of ABA: Historical antecedents

- The history of ABA is not without significant controversy outside of working with autistic people:

- "Rekers and Lovaas conducted the **treatment** in response to the **parents' concerns** not the child's. Furthermore, they challenged all four of the reasons Rekers and Lovaas stated for going forward with the treatment, including the need to relieve the boy's **suffering**, the idea that the "**problems**" would continue into adulthood, that an **early intervention** may be the only treatment that worked, and that "the parents were becoming alarmed."" (Wilhite, 2015).

- These remarks are eerily familiar with regard to the reasons given as to why ABA is often administered upon neurodivergent people.

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Criticisms of ABA: theoretical objections

- "Behaviorism is **dismissed** by **cognitive** scientists developing intricate internal information processing models of cognition…Its traditional relative indifference towards **neuroscience** and deference to environmental contingencies is **rejected** by neuroscientists…The deepest and most complex reason for behaviorism's **decline** in influence is its commitment to the thesis that behavior can be explained without reference to non-behavioral and inner mental (cognitive, representational, or interpretative) activity. Behavior, for Skinner, can be explained just by reference to its "**functional**" relation to or co-variation with the environment and to the animal's history of environmental interaction." (SEP, 2020).

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Criticisms of ABA: theoretical objections

- "For many critics of behaviorism it seems obvious that, at a minimum, the occurrence and character of behavior (especially human behavior) does not depend primarily upon an individual's reinforcement history, although that is a factor, but on the fact that the environment or learning history is **represented** by an individual and how (the manner in which) it is represented…some elements, in particular, of the conscious mental life of persons—have characteristic '**qualia**' or presentationally immediate or **phenomenal** qualities. To be in pain, for example, is not merely to **produce appropriate pain behavior** under the right environmental circumstances, but it is to experience a 'like-thisness' to the pain (as something dull or sharp, perhaps)." (SEP, 2020).

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Criticisms of ABA: theoretical objections

- "Chomsky (1959) charged that behaviorist models of language learning **cannot explain** various facts about **language acquisition**, such as the rapid acquisition of language by young children, which is sometimes referred to as the phenomenon of "lexical explosion."" (SEP, 2020).

- Autistic diversity in language acquisition from 'regression' to 'hyperlexia' are not due to reinforcement alone.

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Criticisms of ABA: Social validity

- "Social validity is concerned with measuring the impact of treatment goals, procedures, and effects on not only the **direct recipients** of treatment but **also on others** that may indirectly influenced by the treatment." (Common and Lane, 2017).

Criticisms of ABA: Social validity

- Wolf (1978) defined social validity as:

- (1) the social significance of the goals of treatment.

- (2) the social appropriateness of the treatment procedures.

- (3) the social importance of the effects of treatments.

- "The most frequent method for determining the degree of acceptance for a procedure or program has been to **ask those receiving, implementing, or consenting to a treatment about their opinions of the treatment**. These opinions are then used to make decisions about current or future uses of the treatment." (Common and Lane, 2017).

- Worth reflecting back on the title of this talk.

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Criticisms of ABA: Social validity

- "Behaviour analysts ensure that the **goals**, methods, and **outcomes** of any intervention are important, understandable, and acceptable to the person whose behaviour is being **changed**, as well as to those who care about the person (e.g., parents, carers, teachers)." (UK-SBA, 2018).

- Given that ABA is practised upon young children and less verbally articulate autistic people, coupled with the lack of understanding often found in non-autistic people's interpretations of autistic ways of being and actions (Milton, 2012, 2014, Chown, 2014), these values cannot be ensured.

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Criticisms of ABA: Social validity, skill acquisition and conformity

- "Any decisions made about how behaviour will be assessed or **changed** are sensitive to the individual circumstances of the person and are aimed at improving **quality of life**." (UK-SBA, 2018).

- Yet, when quality of life is defined in normative terms and without the input of neurodivergent people, or not addressing critique, it can only too quickly become ableist oppression.

- Behaviour analysts suggest that 'skill acquisition' should be seen as primary goal of intervention. This places the pressure on the neurodivergent person to conform to society, whilst not making the same effort in return (Milton, 2014, 2017).

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The evidence base

- Often described as 'scientifically proven', a 'gold standard', but the evidence base is also highly contested (see in particular the work of Michelle Dawson).

- "The research shows that ABA is most **effective** for children with autism when used **intensively** (30-40 hours per week)…Behavioural interventions have undergone the most **rigorous** assessment compared with non-behavioural and **eclectic** approaches. There are many decades of research concerning the effectiveness of ABA in general and hundreds of more recent studies demonstrating the effectiveness of EIBI (Early Intensive Behavioural Intervention) with young children with autism." (Child Autism UK, 2020).

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The evidence base

- "There are not many randomised controlled experiments in the field – there are rightly **ethical questions** around studies that provide children in one group access to something that could help them which is **denied to the control group**." (BeyondAutism, 2020).

- "This is what all of us do **every day** – for example, encouraging a child to try vegetables by either promising an exciting dessert, or saying that they won't get that dessert unless they eat their main meal. This is part of **how we all learn**." (BeyondAutism, 2020).

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The evidence base

- How much **compliance** is too much compliance: Is long-term ABA therapy **abuse**?. (Sandoval and Shkedy, 2019).

- Evidence of increased **PTSD** symptoms in autistics exposed to applied behavior analysis (Kupferstein, 2018).

- The possible **harms** of ABA therapy on individuals with autism (Hungate, 2020).

- 'Recalling hidden **harms**': autistic experiences of childhood Applied Behavioural Analysis (ABA) (McGill and Robinson, 2020).

- Thou shalt not ration justice…(Cernius, 2017).

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The evidence base: systematic reviews

- "Review authors examined and compared the results of all five studies. They found weak evidence that children receiving the EIBI treatment **performed better** than children in the comparison groups after about two years of treatment on scales of adaptive behavior, intelligence tests, expressive language (spoken language), and receptive language (the ability to understand what is said). Differences were **not found** for the severity of autism symptoms or a child's **problem** behavior. No study **reported adverse events** (deterioration in adaptive behaviour or autism symptom severity) due to **treatment**." (Reichow et al. 2018).

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The evidence base: systematic reviews

- "…when effect estimation was limited to RCT designs and to outcomes for which there was no risk of detection bias, **no intervention types showed significant effects on any outcome**." (Sandbank et al. 2020).

- "This review found **limited evidence** that early intensive applied behaviour analysis-based interventions may improve cognitive ability and adaptive behaviour, but the long-term impact of the interventions remains **unknown**." (Rodgers et al. 2020).

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Responses to criticism

- "Apart from academic **confusion** (**Baird** 2014) and **ideologically motivated** omissions (**Howlin** 2013) or **distortions** (Howlin et al. 2009; 2014), there are other issues that impact directly on efforts to disseminate accurate information on the effectiveness of developing interventions that stem from ABA." (Keenan et al. 2014).

- "**Misrepresentations** of ABA abound not only in government reports but also in the media and social media (**Baron-Cohen** 2014; The Skeptical Advisor, 2014) and even more **worryingly** in some peer-reviewed journal articles (Cassidy et al. 2007)." (Keenan et al. 2014).

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Constructive dialogue?

- "ABA has been **mocked** (Kaufman 2013), branded **controversial** (Lambert 2014; Scott 2014), related to **post-traumatic stress disorder** (PTSD; Research Autism 2014) and **attacked** for promoting a '**normalisation** agenda' (Lambert 2014; **Milton** 2012). Maurice (1999) captured these **absurdities** and controversial misrepresentations…" (Keenan et al. 2014).

- "Unfortunately, **straw man** arguments about behaviourism (e.g. **Milton** 2012; see Moore (1981, 1985, 2001, 2008) for an overview of B. F. Skinner's critique of methodological behaviourism) are **preventing the light** from the application of a science of behaviour (Heward 2003) reaching those who might benefit from its findings." (Keenan et al. 2014).

- Critique framed as preventing access.

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Constructive dialogue?

- "The late Herb **Lovett** used to say that there are only two problems with "special education" in America: It's not special and it sure as hell isn't education." (Kohn, 2020).

- Positive Behavioural Support – controversies and disagreements.

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The PBS framework (2015)

- "Gore and colleagues emphasise that PBS is a **multicomponent** framework for developing an understanding of **behaviour that challenges** rather than a single therapeutic approach, treatment or philosophy. It is based on the assessment of the broad social and physical context in which the behaviour occurs, and used to construct **socially valid** interventions which enhance quality of life outcomes for both the person themselves and their carers."

- "PBS combines the **technology** of behavioural intervention with the **values** of **normalisation**, human rights, and self–determination to deliver effective person-centred support for people whose behaviour challenges."

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Strydom et al. (2020)

- "Although Positive Behaviour Support (PBS) is a widely used intervention for ameliorating challenging behaviour (CB), **evidence** for its use in adults with intellectual disability (ID) and comorbid autism (ASD) is **lacking**. We report a planned subsidiary analysis of adults with both ASD and ID who participated in a randomised trial of PBS delivered by health professionals."

- "Results suggest **lack of clinical effectiveness** for PBS delivered by specialist ID clinical teams. Further evidence is needed from larger trials, and development of **improved interventions**."

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AET consultation data

Stakeholder group	Understanding the individual pupil	Building relationships	Curriculum and learning	Enabling environments
Practitioners	**Staff training**	Involving and supporting parents	Differentiated curriculum (social skills)	Quiet and safe spaces
Parents	Staff training and understanding the individual	**Communication between staff and parents**	Individually tailored curriculum	Structure and routine
Children and young people	Understanding from staff	**Bullying (including 'friends')**	Subject content and delivery	Crowds and personal space
Common ground	Staff training needed	Better communication needed and understanding	Differentiation / tailored curriculum	Structured break times and safety
Tensions	Potentially what staff are trained in	Communication not being good enough and a lack of understanding	Social skills training	Differences in view regarding how environments should be managed

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Stakeholder perceptions

- Findings from PhD research.

- Significant tensions over a number of issues:

- Celebrating the diversity of learners and not trying to 'normalise' them.

- Radical change in society.

- Pupil-led vs. teacher-led activities.

- Social skills training and the appropriateness of behaviour.

- The 'three-way dispositional problem'!

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- *"Because otherwise he is trapped in a world where he cannot communicate his hopes and fears, particularly when I am dead and cannot look out for him."*

- *"Difference should be accommodated, accepted and celebrated."*

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Correlation matrix

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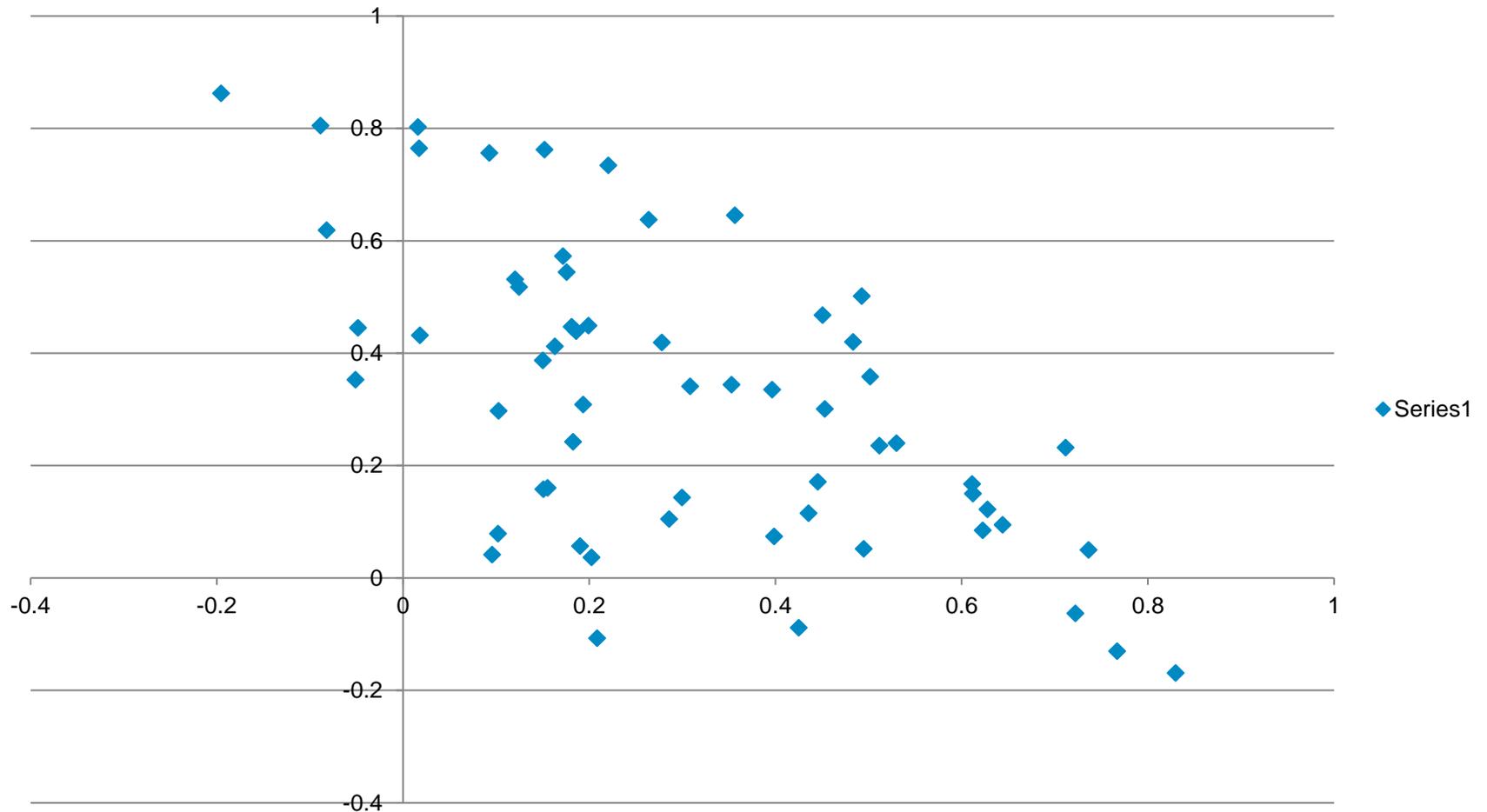
Spectrum of educational views

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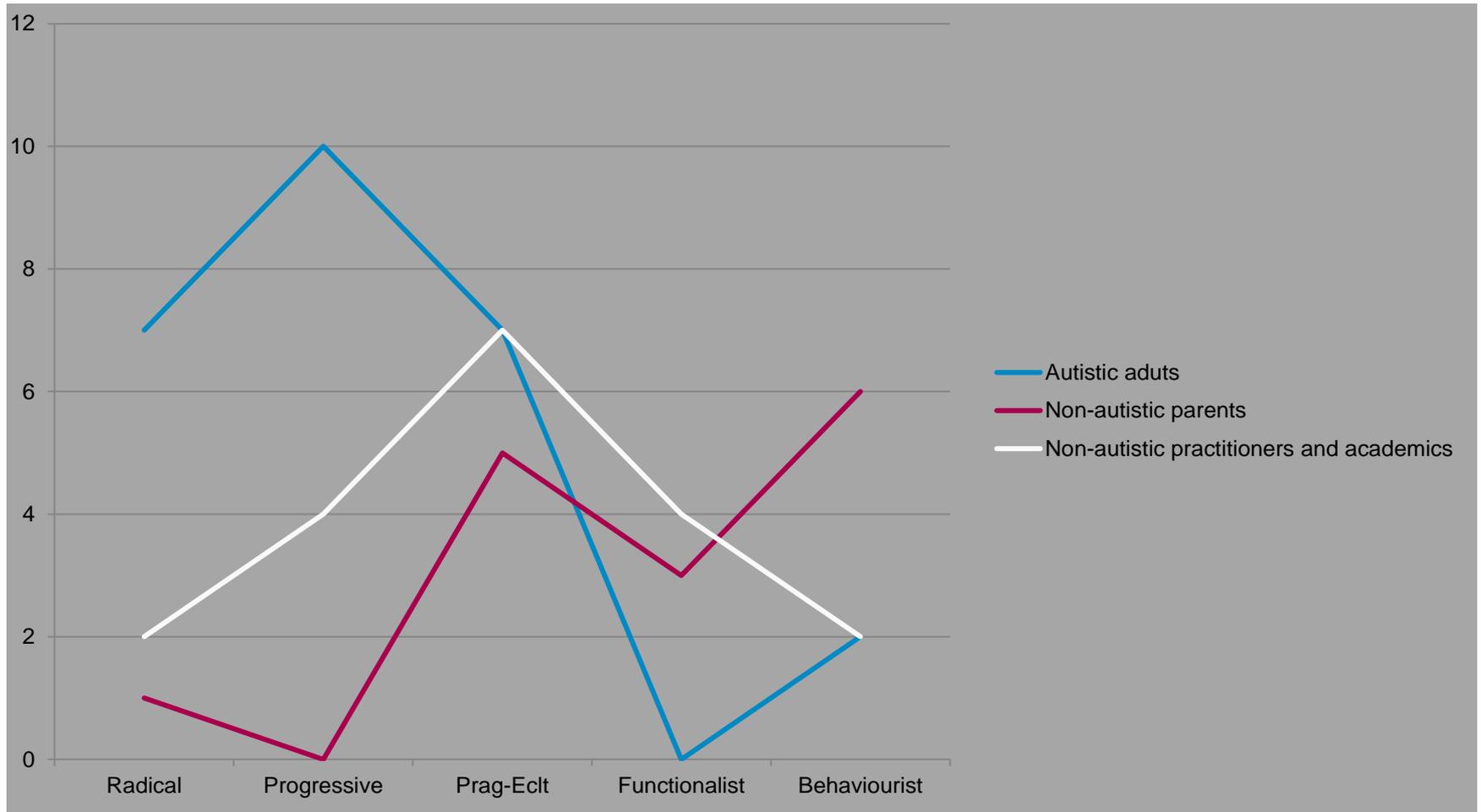
Common ground?

- Not a great deal!

- Against extreme normalisation?

- Enabling environments?

- Building relationships, communication and mutual understanding.

- Clashing values.

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The concept of neurodiversity

- Variations in neurological development as 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 embodiment or 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. Autistic people are significantly disadvantaged in many aspects of life.

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The main issues

- What behaviours are reinforced and deemed as functional and of social importance and relevance is often chosen by an outsider.

- 'Reinforcements' may be inappropriately given (e.g. the bombardment of emotionally laden praise, and hugging, and punishments being potentially internalised as rewards such as time-outs).

- The focus on behaviour at the detriment of subjective understanding and cognition.

- Often focuses on compliance and founded on normative assumptions.

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The main issues

- Reduces opportunity for natural curiosity and exploration.

- Utilises 'reinforcements' that are often extrinsic rather than intrinsic motivations for activities.

- The lack of generalising of newly learnt 'skills'.

- Sometimes punishment is endorsed as a 'last resort'.

- The intensity of programs (often suggested that one works on ABA programs for forty hours a week).

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The main issues

- Dismissing accounts of harm and the critiques of autistic people.

- Ignoring of distress.

- Reinforcing 'masking'.

- Understanding is two-way and takes mutual effort (Milton, 2012, 2014).

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Recommendations

- **Take a holistic and person-centred approach which therefore takes into account neurodivergent sensibilities, sensory perceptual differences, subjective accounts, cognitive and neuroscientific theory, and a social model of disability.**

- Building understanding and communication between all involved.

- Enabling environments to be more accessible.

- Reducing direct confrontation.

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Recommendations

- Ethical considerations must be built in to every step of the process of acquiring professional competencies.

- Use of dangerous restraint methods and forced seclusion should be seen as disciplinary offences.

- Rather than focusing on perceived weaknesses and absent skills, utilise strengths and interests.

- Neurodivergent perspectives built in to every step of the process of acquiring professional competencies.

- Building local expertise and communities of practice, drawing upon multi-disciplinary expertise, but places the neurodivergent person at the centre of considerations.

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Relationship / lowering stress based approaches

- Intensive Interaction.

- Low-arousal approach.

- PACT research.

- The nuances of the SPELL framework.

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SPELL framework: Very brief summary

	Structure	Positive approaches and expectations	Empathy	Low arousal	Links
What ?	-Reducing anxiety through increased predictability	-Play to strengths -Assume 'can do' - but with help	Mutual understanding of perspective of others	-Recognise stress caused by sensory differences -Confrontation	-Promote consistency -Promote involvement
Underlying Difficulties ?	-Organising, sequencing and planning – self monitoring	-Uneven skill development -Low or imposed expectations	-Mutual understanding / misunderstanding of other minds -Judgement of social situations -Literal interpretation	-Sensory processing -Stress -High anxiety	-Uneven processing of information - Detail v bigger picture -Response to change
Some examples	-Written or pictorial timetables/ instructions/ Diaries -Clear sequencing	-Positive /direct clear language -Use strengths and interests as motivators and to build confidence	-Reflection – Discussion -Pictorial aids -'Social stories' -Keep promises	-Audit sensory environment -Reduce noise/ clutter -Reduce confrontation	-Inclusive meetings - Access to 'mainstream' facilities - Consistent communication

- "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).

- #betterwaysthanABA #flipthenarrative

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Conclusion

- "Although individual practice by parents and indeed professionals may not seek normalisation in the use of ABA, the flaws in its theory and implementation mean that we should be **looking beyond** its scope. Therefore the endorsement of PBS by the Care Quality Commission, alongside the widespread use in schools and mental health services needs **urgent review**." (Milton, 2018).

- The need for person-centred, humble, informed and eclectic models of support.

- Time to listen!

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