

Behaviour Analysis, Autism and Learning Disability Fact and Fiction

The UK-SBA and other organisations in the field of behaviour analysis are aware of claims made on social media that ABA causes harm or is otherwise inappropriate in the field of autism care. Many of our registrants work in this field as well as in the field of learning disability and challenging behaviour and are troubled by accusations aimed at the discipline as a whole and therefore at our organisation and its members. These accusations are at odds with our experience of working in these areas and are not supported either by research evidence or by the endorsement of behaviour analysis by many organisations including governmental and otherwise public bodies concerned with health and social care provision for autistic and learning disabled populations.

Here we describe and reference the realities and actualities of the place of behaviour analysis in the modern world and the opinions and evaluations of behaviour analysis by scientific, governmental and professional organisations as well as regulatory public bodies, recipients of behaviour analysis services and the families of vulnerable communities. The reality of the impacts of behaviour analysis on health and social wellbeing of vulnerable groups and their loved ones is far removed from the characterisations appearing largely on social media. And, unlike those characterisations, is strongly supported by scientific evidence and lived experience.

Governments, Scientists, Professional and Public Bodies

As far back as 1999 the Surgeon General of the United States concluded that: *"Thirty years of research demonstrated the efficacy of applied behavioural methods in reducing inappropriate behaviour and in increasing communication, learning, and appropriate social behaviour"*.

Subsequently in the USA behaviour analysis has been evaluated, recognised and endorsed by numerous scientific and professional organisations and federal/state agencies as a positive and appropriate approach for autistic and learning disabled populations. See this link to the Kennedy Krieger Institute for a list of scientific, professional and government organisations supporting and recommending behaviour analysis in the "treatment of children and young adults with severe and treatment-resistant behavioural disorders and development disabilities":

<https://www.kennedykrieger.org/patient-care/centers-and-programs/neurobehavioral-unit-nbu/applied-behavior-analysis/scientific-professional-and-government-organizations-position-on-the-aba-from-the-neurobehavioral-unit-nbu>

Currently in the USA health insurance providers in all fifty of its states are mandated to fund ABA provision for autism, and children of US military personnel diagnosed with autism are eligible for ABA services regardless of what country they live in (for example, US military personnel are provided with ABA services in the UK at no cost to them). ABA is accepted as a mainstream intervention throughout Canada where twelve of thirteen provinces fund ABA services for autism, and in New Zealand the Ministries of Health and Education have formal guidance on behaviour analysis procedures that should be provided in services for Autism Spectrum Disorder.

<https://www.health.govt.nz/system/files/documents/publications/nzasd-supplementary-paper-on-applied-behaviour-analysis-mar16.pdf>

Currently in the UK, behaviour analysis is included by NICE, the NHS England/Local Government Association (NHS England/LGA) and the Scottish Intercollegiate Guidelines Network (SIGN) in recommendations for good practice in the treatment and care of autism and learning disability, including challenging behaviour. In its guidance NG11 (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges) NICE recommends that behaviour analysts should be part of specialist teams dealing

with some of the most complex challenging behaviours (see section 1.1.4/5). In its Transforming Care Model “the national service model for people with a learning disability and/or autism who display behaviour that challenges” NHS England/LGA includes behaviour analysis as one of the specialist skill sets **required** to deliver the functions described in its service specifications. In its national clinical guideline, SIGN (2016) recommends the consideration of behavioural interventions “to address a wide range of specific behaviours, including those that challenge, in children and young people with ASD, both to reduce symptom frequency and severity and to increase the development of adaptive skills” (p.6) and “Access to support from staff trained in applied behaviour analysis-based technologies (e.g. Picture Exchange Communication System, discrete trial training, task analysis, prompting, fading or shaping) to build independence in adaptive, communication and social skills should be considered for children with ASD” (p.24).

The overwhelming conclusion of this wide range of governmental, professional and regulatory bodies who have studied and evaluated, no doubt rigorously, the available evidence is that behaviour analysis is to be recommended as a positive and beneficial approach to improving the lives of vulnerable communities in the field of health and social care.

ABA in Schools, Clinics and Social Care: public authority evaluations

In addition to these official recommendations for participation of behaviour analysts in areas of health and social care, behaviour analysis is widely applied and relied on by a large number of service providers, schools and charitable bodies working in the fields of autism and learning disability. Consequently, behaviour analysis is appropriately scrutinised, evaluated and reported on by public authorities such as Ofsted, the Care Inspectorate of Wales and the Care Quality Commission. If behaviour analysis was doing harm in these settings or its practice(s) considered “inappropriate”, this would be highlighted in assessments and reports published by these authorities and remedial actions required. We have yet to see this happen. On the contrary, these three authorities respond very positively to what they see in settings using behaviour analysis – schools, clinics, learning disability services. Here are some examples.

First, examples of inspections and evaluations of ABA schools by Ofsted (bullet points are direct quotes from Ofsted reports).

Jigsaw School in Surrey whose curriculum is “based on the proven principles of behaviour analysis that encourages self-esteem and respect for others” has been rated **Outstanding** in all areas in its last four Ofsted inspections. According to Ofsted:

- The task of preparing pupils with the skills and attitudes needed to lead rewarding and purposeful lives lies at the heart of the school’s work.
- Pupils flourish in the school’s safe, supportive and encouraging atmosphere. They make friends, develop interests and learn exceptionally well.
- The provision for pupils’ spiritual, moral, social and cultural development is outstanding.
- Pupils’ personal development is promoted extremely well by the very wide range of activities and opportunities available. Positive behaviour teaching and development of social skills are at the heart of the school’s ethos and, as a result, pupils’ behaviour is outstanding.
- Pupils also show increased ability to manage their daily lives due to improvements in their communication skills and the focus on life skills. This is further enhanced through parent workshops and activity days for siblings that help to build family bonds and understanding of pupils’ special needs.

- Parents are overwhelmingly supportive of the school, with one writing: “My son loves coming to school every day and without Jigsaw, our life with our autistic child would be much harder. Jigsaw is an outstanding school which provides more than education”.

Snowflake School in London has been rated **Outstanding** in all areas in each of its Ofsted evaluations. According to Ofsted:

- Staff listen to parents’ views about what they would like their children to achieve. Sometimes, these goals relate to overcoming challenges at home, such as managing a trip to the supermarket or having a check-up at the dentist. Staff support parents and the pupils remarkably well in achieving these goals. For example, using a range of well- established and well-planned approaches, staff have supported pupils in shaving for the first time, having their hair cut at the barbers and tolerating injections at the doctors.
- The excellent work of tutors, supervisors, teachers and therapists all contributes to pupils’ outstanding progress in all areas of their learning and development. They make particularly strong progress in developing their language and communication skills.
- Underpinning everything is the goal of helping pupils to move on to a less intense environment where they can be as independent as possible. Staff always keep this in mind. Over time, pupils’ independence, social skills and skills for life improve considerably.

Treetops School in Essex was rated **Outstanding** in its recent Ofsted inspection following on from its previous **Outstanding** result prior to becoming an Academy. Ofsted reported:

- Parents and carers greatly value the education the school provides. In many cases, pupils have had a difficult educational journey by the time they reach the school. Parents said that arriving at Treetops felt as if their child had ‘come home’. One parent said, ‘Treetops has changed my son’s life.’ Another wrote: ‘My child is like a different child at this school compared to his last one, he is totally included in all different activities, he wakes up happy to get on his school bus.’ These comments are typical of those made by parents.
- The communication curriculum is a particular strength of the school. Rightly, it has a very high priority. Staff use a wide range of approaches to communication. They are skilled in ensuring that they use the right approach for each pupil. For example, many pupils are taught a simplified form of sign language. This enables them to make themselves understood. Other pupils learn how to make or respond to requests in a socially acceptable manner.
- Pupils behave very well. Staff are skilled in managing pupils’ behaviour. For example, many pupils display challenging behaviour that is a result of their difficulty or disability. The way that staff deal with these behaviours lessens their frequency and severity. The school is a very calm place, where pupils are able to learn well.

Tram House School in London was rated **Outstanding** at its 2018 Ofsted inspection. According to Ofsted:

- Almost every parent who contributed their view during the inspection was overwhelmingly positive. Parents told the inspector “Tram House is a great school; my child is happy and thriving in their care” and “Every day I leave my child at school, knowing not only that they are safe, but also learning and achieving.”
- The outstanding curriculum, personalised for every pupil, is bespoke. At the core of the curriculum is the effective preparation of pupils for life in society, focusing on communication, social skills, independent living and, when pupils are ready, the world of work.

- Pupils typically make very good progress in managing their emotions and their behaviours. They are very well prepared for their lives outside and after school.

Of the eight fully ABA schools in the UK, six are rated **Outstanding** and two rated **Good** by Ofsted. Throughout these evaluations are repeated reference to pupils flourishing, to staff concerned that pupils should be equipped with skills needed to lead rewarding and purposeful lives, helping pupils towards less intense environments, helping students to be as independent as possible, working to help pupils develop communication skills to let their preferences be known, staff listening to and supporting parents, and consistently positive responses by parents to the level of care and personal consideration their loved ones receive from the ABA specialists who work with them. The reality for children and their families clearly contradicts claims that behaviour analysis is either harmful or inappropriate in these settings.

Another public body, the Care Inspectorate of Wales, recently inspected the **Behaviour Analysis Clinic** at the University of South Wales. The Inspectorate rated the clinic **Excellent** in the provision of “Wellbeing” and “Care and Development”.

- On Wellbeing their report states “Children experience highly individualised care where their preferences are highly valued. Children have excellent opportunities to develop their skills which are extremely well-suited to their precise stage of development. They are motivated and really enjoy their play”.
- On Care and Development: “The staff team are extremely knowledgeable about child development and behaviour management. They work very effectively to share their knowledge with each other to improve outcomes for children. Staff monitor children’s development extremely closely and use this information to plan in a high level of detail. They are very motivated and passionate about their roles and form excellent relationships with children and families. Staff follow robust procedures to keep children safe and healthy”.

Again, care is highly individualised with individual preferences highly valued. Children have excellent opportunities to develop skills, really enjoy their play, and staff make sure children are kept safe and healthy. If the setting was in any way harmful or inappropriate, the CIW would no doubt have reported on that.

The Care Quality Commission, also a public body, makes clear throughout its 2017 guidance document “policy on registration and variations to registration for providers supporting people with a learning disability and/or autism” that the provision of Positive Behaviour Support (PBS, a behaviour analysis approach used widely in autism and learning disability contexts) increases the likelihood that applications to register as service providers will be approved. Their inspection of an ABA organisation providing services in London, Manchester and the South West, BEAM ABA, resulted in an overall rating of **Outstanding** and included the following very positive observations (direct quotes):

- BEAM ABA is a specialist provider which aims to improve the lives of children and young people who have complex behavioural needs using the evidence-based practice of Applied Behaviour Analysis (ABA). They also provide support for family members and teachers within school to enable children and young people to take part in family life, school, and activities within the community. All the family members we spoke with said that Beam ABA Services involvement meant that the quality of life of their loved ones and the whole family had improved.

- Behavioural plans were prepared in collaboration with family members and were reviewed at intervals suitable for each person's needs. This helped people to become as independent as possible and participate in their family life more.
- Because of staff interventions people were able to do things that were often difficult to do for people with Autism, behavioural difficulties and other special educational needs. This included meeting developmental goals which were similar to their age group, accessing activities in the community, participating in lessons at school and meeting their basic self-care needs..... This helped people to be an integral part of the community they lived in.
- A further part of the service was supporting children and young people to express their views, so their voice was heard. Staff supported people to communicate their needs to teachers at school. Children and young people were supported to make their own decisions with the use of various electronic aids, and when possible to say what they wanted and how they wanted it. Family members thought staff were excellent in communicating with people and supporting people with development of their communications skills.
- Another key part of BEAM ABA's service was supporting families in developing relationships with their loved ones. This was achieved by the provision of specialist training for families on ABA techniques and through ongoing dialogue with family members. Families thought staff skills and experience played an important role in progress and development achieved by their relatives. One family member said, "It's very reassuring to me that many of the staff have degrees in autism and applied skills to work in the field. I've always been impressed with the calibre of the staff."

Here, the CQC observed services improving the quality of life not only of individuals but of their whole families, people helped to become integral parts of the community in which they live, becoming as independent as possible, participating more in family life and developing communication skills. "Harmful" or "inappropriate" are not terms that define the reality these service users and their families experience.

Behaviour Analysis and Lived Experience

The lived experience of recipients of behaviour analysis services consistently speaks against the accusations (again, on social media, unsupported by scientific or any other kind of evidence) that it is either harmful or inappropriate to the needs of autistic or learning disability communities. Here are some of those experiences.

Mia, aged 14, is autistic and has epilepsy and severe learning difficulties. Her parents share how ABA has helped - especially with her ability to communicate via sign and with a huge decrease in her self-injurious behaviour. READ HERE: https://bfaa8272-804a-4cbd-a009-7b665b2beeac.filesusr.com/ugd/5f8b9f_f2d28449422e4a13b008d0affab30e9b.pdf

Liam is a non-verbal 12 year old. He started ABA later in his childhood years. At his autism "special school", his parents were told he couldn't do the most basic activities and had no desire to communicate. After seeing dramatic success with ABA, his parents arranged for him to attend a specifically ABA school. As a result, Liam has now learnt to communicate. READ HERE: https://bfaa8272-804a-4cbd-a009-7b665b2beeac.filesusr.com/ugd/5f8b9f_fed24eca1c0341afaf32e7fcd7f78bb9.pdf

Aged 17, autistic and with a severe learning disability, Johnny has come such a long way since starting ABA at age 3. He learned many skills that improve both his quality of life and his health - from talking right through to doing his own daily injections for Type 1 Diabetes and not lashing out

aggressively or self injuriously when stressed. READ HERE: https://bfaa8272-804a-4cbd-a009-7b665b2beeac.filesusr.com/ugd/5f8b9f_76988c61e59941f1ade27878195bd9c7.pdf

Aged 27, Mr K achieved so much through ABA between the ages of 3 and 12. He now works both in his old secondary school as a classroom assistant and in a London theatre. READ HERE: https://bfaa8272-804a-4cbd-a009-7b665b2beeac.filesusr.com/ugd/5f8b9f_56179655d8b9456c941b288ed45b2efc.pdf

An autistic teen who prefers to remain anonymous, pictured here when much younger, was given a poor prognosis at age 3. Yet with light-touch ABA in mainstream school, he is now at one of the UK's top grammar schools with only minimal support. He aims to develop autism-friendly apps and maybe join Microsoft! READ HERE: https://bfaa8272-804a-4cbd-a009-7b665b2beeac.filesusr.com/ugd/fb6772_f01bf77ec43c4652a9c1b1e70cdd8bb5.pdf

These are the lived experiences, the realities, of people with autism and learning disabilities. These experiences and others like them are being lived today, throughout the world, wherever behaviour analysts are available.

In Summary

Organisations tasked with making recommendations for the health and social care of vulnerable populations, and who have no doubt painstakingly reviewed the scientific evidence, conclude and recommend that behaviour analysis is a positive and appropriate service for improving the wellbeing of vulnerable populations in areas such as autism and learning disability.

Organisations inspecting behaviour analysis in situ repeatedly report that what they observe are outstanding and excellent services, with behaviour analysts facilitating individuals to develop skills that improve the quality of their lives.

The voices of autistic individuals and their families speak to the reality of difficulties faced and successes achieved by their lived experience with behaviour analysis.

The objectors are loud on social media. But assertions that behaviour analysis causes harm or is otherwise inappropriate are neither evidenced by the objectors nor shared (as this document shows) by the many organisations whose remit is to evaluate, recommend and monitor service provision for vulnerable populations.

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