Accredited Register: UK Society for Behavioural Analysis (UK-SBA)

Type of Review: Initial application

Period under review: N/A

Date Approved for Panel: 7 October 2022



Introduction

Before we make a decision about accreditation, we undertake an impact assessment to understand likely effects of this decision on different groups, and the wider health system. We begin to gather the information required for the impact assessment when a Register first applies for accreditation. We consider any changes to impacts when we renew accreditation, and when taking other decisions that affect accreditation status such as imposing Conditions or suspension. The Accreditation decision for the UK-SBA is published on our <u>Accreditation Decisions</u> webpage.

A key part of the impact assessment is consideration of equalities. The Equality Act 2010 imposes a legal duty, the Public Sector Equality Duty on all public bodies to consider the equality impact of its policies and decision making. The duty is known as the Equality Duty and is requires a public authority, in the discharge of its function to consider the following three aspects which form the basis of the duty:

- Consider the impact and eliminate unlawful (direct or indirect) discrimination and any other conduct prohibited under the Equality Act 2010.
- Advance equality of opportunity between people with protected characteristics and those who do not share these characteristics
- Foster good relations between people with protected characteristics and those who do not share these characteristics.

This means that public bodies must consider equality impact on individuals protected under the Equality Act 2010 in carrying out their work. The Authority, therefore, needs to be always mindful of the public duty when carrying out its oversight role which includes the approving of registers. It needs to have 'due regard' to the needs to balance the three aspects which make up the Equality Duty when achieving its goals.

The Equality Impact Assessment is an important tool/mechanism for demonstrating 'due regard' through the consideration of evidence and analysis, actual and potential to identify positive and/or adverse impacts. The key groups we need to consider when making our decisions are, sex, age, ethnicity, disability, religion and belief, sexual orientation, gender reassignment, marriage and civil partnership, pregnancy, and maternity.

Equalities impacts – summary

There are polarised views on the practice of Behaviour Analysis (BA/ABA), and consequently it is important for UK-SBA to engage with different groups to understand their experience and views, and how they might be impacted by the work of its registrants. UK-SBA's *Code of Professional and Ethical Conduct* makes clear that discrimination based on protected characteristics is not acceptable. It has also published a diversity policy,

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and a statement of how its organisational values relate to equality and discrimination. Its website is in plain English. However, UK-SBA does not currently gather data about the diversity of its registrants, or service users. Its application highlighted the potential positive impacts of accreditation but did not identify any potential negative impacts.

To understand the impact of accreditation on different groups, we reviewed wider evidence including that gathered for Standard 1b, and through our Share Your Experience process. As with all therapies grounded in scientific research, there are limitations and gaps in the available research on BA/ABA currently. Supporters highlight the positive outcomes it can have for people with autism and learning disabilities; while some critics claim that BA/ABA seeks to 'treat' autism and is experienced as punitive and de-humanizing. Assessing impact is complicated by the fact that BA/ABA is an evolving field, and some reporting negative experiences of BA/ABA may be describing something different to that offered by UK-SBA registrants. We received a high number of supportive responses to our SYE, with approximately 5% being concerns about BA/ABA and/or the UK-SBA. Although we did not identify direct links between the concerns and the practice of UK-SBA registrants, we need to acknowledge that the concerns raised were of a serious nature concerning punishment and equalities issues. These need to be balanced against the benefits of accreditation providing clearer standards of ethics, professional behaviour and training which could address some of the concerns about BA/ABA being used in harmful way.

People receiving treatment from BA/ABA practitioners are likely to be vulnerable. The majority (97%) of UK-SBA's service users are autistic and/or have a learning disability. Many are children and young people. Whilst the capacity for consent of individuals will vary widely, many will be young children, and in some cases may be non-verbal. BA/ABA is often used as an intervention to support people with high needs. Specific impacts we have identified for different groups are summarised below.

Age – children and young people (0-18)

Accreditation may lead to positive impacts for this group, through greater consistency of standards of registered professionals who are trained to develop strategies for supporting children to develop skills.

At the same time, there is a risk of any treatment used for this group, being done so without proper checks on capacity to consent. The Care Quality Commission's guidance on <u>Capacity and competence to consent in under 18s</u> outlines how to consider the child's interests in cases where they may refuse treatment. It also highlights the considerations in sharing safeguarding concerns with others involved in care.

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UK-SBA's current approach refers to those receiving treatment, and their families, as 'consumers'. Although it produces guidance in easy-read format, it had not produced child-friendly documents about treatment and feedback is not routinely collected from children or young people. Without actions to address this, accreditation has potential for a negative effect on children and young people since families may infer that registrants will be subject to the same requirements on consent and capacity as those working within managed settings. UK-SBA confirmed during our assessment that there were challenges with collecting direct feedback, but that it would seek to do this and to engage with those who raise concerns about BA/ABA in a meaningful way.

Disability – people with ASC and/or learning disability

UK-SBA's registrants are likely to be working with people with ASC and/or learning disability, including many with high needs.

Government guidance Helping health and care services manage difficult patient behaviour¹ sets out that 'People with autistic spectrum conditions and people with learning disability may present with behaviour that challenges and are at higher risk of being subjected to restrictive interventions.' It also references concerns about the inappropriate use of restrictive interventions across health and care settings included Transforming Care: a national response to Winterbourne View Hospital (DH 2012), Mental Health Crisis Care: physical restraint in crisis in June 2013 by Mind.

The UK legislative framework on mental capacity places emphasis on the need for treatment and care to be the least restrictive option². We heard views from people who had experienced BA/ABA that it is restrictive and punitive. However, there is also evidence to suggest that use of BA/ABA, and particularly Positive Behavioural Support (PBS), may improve outcomes by reducing the incidence of restrictive practices. Government guidance includes recommendations for 'increased behavioural support planning and restrictive intervention reduction to be taught to their staff'. This indicates a potential positive impact.

¹ https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions

² The Mental Capacity Act (MCA), which applies to people aged 16 and over in England and Wales says that 'treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.' The Adults with Incapacity Act (Scotland) 2000 includes a 'least restrictive option' principle.

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Accreditation has the potential to enable a consistent approach to working with autistic people and those with a learning disability, but there needs to be greater clarity about how registrants work with people when situations arise that may be challenging to the practitioner, the service user, and/or the family involved. We also identified through our review of research the need for more research into the impacts of BA/ABA, and NICE have highlighted this in relation to whether PBS provided for children aged under 5 years with a learning disability reduce the risk of developing behaviour that challenges (2015)³.

Gender reassignment

A 2020 study⁴ by the University of Cambridge's Autism Research Centre found that 'transgender and gender-diverse adults are three to six times more likely as cisgender adults (individuals whose gender identity corresponds to their sex assigned at birth) to be diagnosed as autistic.' Both autistic individuals and transgender and gender-diverse individuals may experience discrimination. We did not see evidence of UK-SBA taking this into account and suggest that it should work to promote understanding amongst its registrants of gender diversity.

Race

A study by Roman-Urrestarazu, R et al. found that pupils of black and Chinese ethnicity were 26% and 38% more likely to be autistic respectively, and that autistic children were much more likely to face social disadvantage. Since as already noted the costs of private provision of BA/ABA are likely to be funded by a family, and is not widely funded by schools, children from these ethnicities may be less likely to have access to aspects of BA/ABA that may be supportive, such as PBS. It is unclear what impact accreditation might have on this, but the findings indicate it would be beneficial for UK-SBA to gather data on the ethnicity of registrants and service users. This could be used, for example, to inform understanding about how different groups are likely to access care. UK-SBA also intends to set up special interest groups for registrants based on specific protected characteristics, with the aim of providing support.

Sex

³ https://www.nice.org.uk/researchrecommendation/preventing-behaviour-that-challenges-from-developing-in-children-aged-under-5-years-with-a-learning-disability-can-positive-behaviour-support-provided-for-children-aged-under-5-years-with-a-learning-disability-reduce-the-risk-of-developing-behaviour-that-

⁴ https://www.cam.ac.uk/research/news/transgender-and-gender-diverse-individuals-are-more-likely-to-be-autistic-and-report-higher-autistic

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Reports⁵ have identified a potential diagnostic gender bias in children with ASC, with a higher ration of males diagnosed than females. This could mean that girls who meet criteria for autism are at a disproportionate risk of not receiving a clinical diagnosis. Although BA/ABA does not involve diagnosis of conditions, it is a factor that could affect service users and therefore one for UK-SBA and its registrants to be aware of.

Sexual orientation

Ivar Lovas has been referenced as developing the first EIBI strategies, although these have developed substantially since then. Lovas also participated in studies attempting to modify the behaviour of children to suppress homosexuality (now known as 'conversion therapy') in the early 1970s. In October 2020, the Journal of Applied Behaviour Analysis published an 'expression of concern'6 for an article authored by Lovas in 1974 concerning this study. This highlights the concerns raised about 'using reinforcement and punishment to reduce gender nonconforming behaviors.' We have not seen any evidence to suggest that UK-SBA practitioners are practising BA/ABA as a form of conversion therapy and their response to the SYE report strongly condemned this practice. The Authority does not accredit Registers which permit any form of conversion therapy and so accreditation should give confidence to users in this area. However, we did receive some concerns through our SYE experience about links of BA/ABA to conversion therapy and we expect that this is due to the origins of the approach despite it having evolved since then. We will continue to monitor UK-SBA once accredited for any indications contrary to this.

Further actions identified for potential adverse impacts

Age

7 190			
Group(s)	Description	Actions required	Timeframe
affected			
Children and	It is important that practitioners regularly	 Greater focus on child-friendly 	
young people	assess the ability of children and young people	information and feedback.	
(0-18)	to make the decisions about their care.		

⁵ See: https://pubmed.ncbi.nlm.nih.gov/28545751/

⁶ https://onlinelibrary.wiley.com/doi/10.1002/jaba.781

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		Update: The UK-SBA's 'Information for Parents/Carers and Service Users': https://uk-sba.org/about-behaviour-analysis/information-for-parents-carers-new-to-aba/ was developed with the assistance of its Advisory Group, who are BA/ABA consumers. (Such as the parents of service users).	
Disability			
Group(s) affected	Description	Actions required	Timeframe
People with Autistic Spectrum Condition (ASC), people with learning disability	Many of UK-SBA's registrants will work with autistic people and/or those with aearning disability, some of whom may have high needs and/or display behaviour that challenges since this is one of the contexts in which BA/ABA is used.	UK-SBA should introduce a clearer position on use of restrictive interventions and its definition of 'challenging behaviour'. Update: The UK-SBA has provided its response to 'Action 5: The UK-SBA should include a clear definition of 'challenging behaviour' within its guidance'.	
		 Greater engagement and feedback sought from people with ASC and learning disabilities to understand views on BA/ABA. Update: The UK-SBA has provided its response to 'Recommendation 4: The UK-SBA should 	

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		continue the implementation of Patient and Public Involvement (PPI) strategies to inform and involve the public and service users in what they do. As part of this, the UK-SBA should consider how it can meaningfully engage in discussion with groups who oppose behaviour analysis, to ensure it considers all perspectives.	
Gender reassig	gnment		
Group(s) affected	Description	Actions required	Date identified
Transgender and gender- diverse adults	A 2020 study ⁷ by the University of Cambridge's Autism Research Centre found that 'transgender and gender-diverse adults are three to six times more likely as cisgender adults (individuals whose gender identity corresponds to their sex assigned at birth) to be diagnosed as autistic.' Both autistic individuals and transgender and gender-diverse individuals may experience discrimination.	Promote greater understanding of gender diversity by registrants. Update: The UK-SBA published its position statement regarding conversion therapy at: https://uk-sba.org/wp-content/uploads/2022/04/Position-Statement-on-Conversion-Therapy Apr-2022.pdf confirming it will 'remove from our Register any member found to be engaging in conversion therapy' referring to 'attempts to change an individual's gender or sexuality'.	

 $^{^{7}\,\}underline{\text{https://www.cam.ac.uk/research/news/transgender-and-gender-diverse-individuals-are-more-likely-to-be-autistic-and-report-higher-autistic}$

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Race

Group(s)	Description	Actions required	Timeframe
affected			
Children of	A recent study has identified that pupils of black	1. UK-SBA to seek to gather data on the ethnicity	
black and	and Chinese ethnicity were 26% and 38% more	of registrants and service users.	
Chinese	likely to be autistic respectively, and that autistic		
ethnicity	children were much more likely to face	Update: The Authority is currently consulting on a	
	significant social disadvantage.	new EDI Standard for Accredited Registers and	
		this information is likely to form part of the new	
		requirements for later in 2023.	

Sex

Group(s) affected	Description	Actions required	Timeframe
Females	Reports ⁸ have identified a potential diagnostic gender bias in children.	UK-SBA to seek to gather data on the gender of registrants and service users. Update: The Authority is currently consulting on a new EDI Standard for Accredited Registers and this information is likely to form part of the new requirements for later in 2023.	

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⁸ See: https://pubmed.ncbi.nlm.nih.gov/28545751/

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Impacts

Cost and market impacts - summary

There appears to be little public funding for BA/ABA, and so it is likely to be a costly option for families accessing privately (see McPhilemy et al.
2013). Whilst UK-SBA is not currently intending to raise its fees for registrants if accredited, it acknowledges that they could be increased in the future, which could in turn be passed on to service users. It is also possible that accreditation could lead to a standardization in costs of BA/ABA however. UKSBA's Conduct places a requirement on registrants for open, honest and clear communications about fees and the terms for providing services. Accreditation provides opportunity for independent assurance of this.

<u>Parsons et al, 2011</u> found there was not enough strong evidence in support of BA/ABA for it to be funded widely. However, there are pilots involving aspects of BA/ABA underway within the NHS (e.g. Leicestershire Partnership NHS Trust (LPT)) which could enable an assessment of this in future. Accreditation is not expected to have a significant impact on costs for those receiving services privately, or through the NHS.

UK-SBA appears to be the only register for behaviour analysts in the UK, currently. We have not identified any adverse effects on the wider market of accreditation.

Social and environmental impacts - summary

In broad terms, accreditation is likely to raise the profile of the UK-SBA and further the professionalisation of BA/ABA. We do not expect accreditation to lead to any specific environmental impacts.

Decision

A key consideration in our assessment of the potential impact of accreditation were the views of people who had raised concerns through the SYE consultation about BA/ABA being used in a way that is discriminatory or otherwise harmful. As detailed in the section above, we sought to understand these views through further meetings with individuals and independent organisations such as the NAS.

At its first meeting in March 2022, the Accreditation Panel adjourned on the basis that the UK-SBA needed to strengthen its mitigations against its registrants using BA/ABA in a way that was potentially discriminatory or harmful. The Accreditation Panel also determined that it would be

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important for the UK-SBA to have more independent input from those who could represent the interests of its service users, into its decisions. The further Actions (page **Error! Bookmark not defined.**) required before accreditation could be granted were focused on these areas.

When the Accreditation Panel met again in November 2022, it determined that since these further Actions had been met, the potential adverse impacts of accreditation had been sufficiently mitigated. Although the Authority will need to remain vigilant of concerns about BA/ABA, the commitment by the UK-SBA to best practice in this field should overall, reduce the risk of BA/ABA being used in a way that is discriminatory or harmful. This could have particular benefit for those receiving BA/ABA in private homes.