<u>Functional Assessments with People with Intellectual Disabilities who Display Behaviour That</u>

<u>Challenges: Practical Considerations</u>

Introduction

This essay discusses functional assessments (FAs) in the context of Positive Behaviour Support (PBS). It will focus on its use with people with intellectual disabilities (ID) who display behaviour that challenges services. While acknowledging the value FAs can bring to PBS plans, this essay argues there is scope for a more holistic, multi-disciplinary approach towards behaviour that challenges & the development of evidence-based user-friendly methods.

Functional Assessment

How does FA fit into PBS?

Behaviour that challenges can have a significant impact on the quality of life (QOL) of individuals with intellectual disabilities (ID) and those around them (including carers and family members; 'stakeholders'). For example, individuals who display behaviour that challenges experience increased risk of restrictive and aversive practices and social exclusion (Emerson and Einfeld, 2011). Carers who work with people with ID who display physical aggression (one form of behaviour that challenges) are more likely to report struggling to cope than those who work with people with ID who do not (Tyrer et al. 2006). PBS' main aim is to improve QOL of the individual and stakeholders, with the secondary aim of reducing the occurrence of behaviour that challenges (Carr et al. 2002). Individual PBS plans address these aims through various interventions that consider environmental redesign, teaching new skills and increasing opportunities for positive behaviours to be displayed (Carr et al. 2002). Multiple studies have demonstrated the benefits of a multi-element approach to behaviour that challenges, with FAs consistently found as a central and critical component of interventions (MacDonald et al. 2010; Toogood et al. 2011). FA is the NICE (2015) recommended approach to understanding behaviour for healthcare professionals supporting someone with an ID who displays behaviour that challenges. FAs form a helpful and important part of PBS; interventions, with people with ID who display behaviour that challenges, informed by FAs can be doubly effective as interventions that have excluded FAs (Carr et al. 1999).

What does FA look like?

FA is rooted in Applied Behavioural Analysis (ABA), a discipline from which PBS has developed (Baker & Allen, 2012; Carr et al. 2002; Dunlap et al. 2008). ABA aims to uncover the reasons why a

behaviour happens. It does this by looking at antecedents (events that precede a behaviour) and consequences (things that happen immediately after a behaviour). ABA is an applied science influenced by the principle of operant conditioning (that behaviour is learned and reinforced) (Dunlap et al. 2008). FAs can consist of a range of data collection methods including direct (observations) and indirect (questionnaires, interviews, historic data gathering) (Madsen, Peck and Valdovinos, 2016). These uncover correlations which help form hypotheses and formulations about the function and reinforcing factors of behaviour (Madsen, Peck and Valdovinos, 2016). Hypotheses can be translated straight into interventions, or they can be tested using experimental functional analysis to determine causation. Experimental analysis controls independent variables (antecedents and consequences) to see the effect on behaviour (dependant variable) (Madsen, Peck and Valdovinos, 2016). However, experimental analyses are resource intensive, requiring time and skill of trained assessors who often have limited availability (Carr et al. 2002). There is also the ethical dilemma that experimental analyses purposely elicit behaviour that challenges to test hypotheses, putting individuals and those around them at potential risk (Matson & Minshawi, 2007). Therefore, a phased approach to behaviour that challenges is recommended, with more formal functional analysis used only where behaviour that challenges is 'severe' (NICE 2015; Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists 2007).

No formal data collection templates are offered for a FA by NICE (2015), however, some 'formal rating scales' are suggested, including the Functional Analysis Screening Tool (FAST) and the Motivational Assessment Scale (MAS) (p. 17). The FAST, as an example, was developed by Iwata et al. (2013) as a screening tool to help guide a FA. It is a 16-item questionnaire that categorises behaviours into 4 areas of reinforcement: social-attention, social-escape, automatic-sensory stimulation and automatic-pain attenuation (Iwata et al. 2013, p. 274). The FAST may help inform further data gathering (such as by guiding what questions to include in an open interview) but is not intended as a single tool of FA. An informant-based interview sometimes used by clinicians is O'Neil et al.'s (1997) Functional Analysis Interview (FAI). Qualitative measures such as the FAI, and observations, help provide an idiographic understanding of individuals functions of behaviours. Ultimately, the battery of tools used in a FA are at the clinician's discretion.

Do FA tools assess what they are supposed to?

Questions around the validity and reliability of FA tools have been raised. The FAST was found to have low reliability and validity by its creators (Iwata et al. 2013). An overview of literature has also

casted doubt on the reliability of different methods used, with inconsistent results between tools, and low interrater reliability of informant-based measures (Madsen et al. 2015). This is hardly surprising, given that behaviours that challenge are socially constructed (Emerson and Einfeld, 2011). As Tyrer et al. (2006) found, informant-based reports of behaviour are likely to be influenced by informant's values and emotions, as well as the setting in which behaviours are displayed. PBS extends beyond ABA's traditional view of expert scientists and experimental designs as the "gold standard", placing inclusion of stakeholders within assessments and interventions as one if its key values (Carr et al. 2002, p. 9; Gore et al. 2015). Therefore, the utility of evidence-based measures with informants is important. Person-focused training (PFT) is a potential way to address validity and reliability issues of including stakeholders in FAs. PFT, where staff are trained to deliver FAs and interventions, has been shown to reduce incidents of behaviour that challenges by 77% compared to a control group who had no behaviour support intervention (Grey and McLean, 2006). While this is promising, it does not compare the effectiveness of FAs delivered by staff who received training compared to staff who had no training or by 'specialists' (as the control group received no intervention at all). Therefore, it is hard to make inferences about the effectiveness of the training. However, it would be useful for future research to address this to gain a real understanding of the effectiveness of PFT, and also to consider what kind of training is helpful, to help improve the reliability and validity of informant-based tools.

Person-centered/user-friendly

PBS also develops on from ABA and its inclusion of aversive interventions, to a values-based, personcentred perspective (Allen et al. 2005; Carr et al. 2002). NICE (2015) guidelines state that individuals should be involved in all aspects of their care, including the assessment process. However, it is questionable whether FAs reflect this in practice. As Carr et al. (1999, p. 85) found, while FA methods can provide accurate data, they require improvements to become user-friendly and easier to apply in community settings. This puts FAs at risk of excluding some individuals from the process, as well as being a time-consuming and complicated process for informants. Many people with ID experience communication difficulties (Bradshaw, Gore & Darvell, 2018) so given the complexities FA can entail, extra consideration is needed to ensure people with ID are given the means and opportunities to be heard. Bradshaw, Gore & Darvell (2018) examined the use of Talking Mats (TM) for including individuals with ID and communication difficulties in FAs. They devised an interview using TM that were held with four children with ID who displayed 'challenging behaviour'. The children interviewed provided valuable information about the functions of their behaviour, not always captured by informant methods alone, that was incorporated in their support plans. While theirs was a small-scale study with child participants that did not go on to measure effectiveness of

using TM in terms of reduction of behaviours that challenge and QOL, their approach did help include individuals with communication difficulties in their own FA and support planning. TM will not be an appropriate solution for everyone, but there is scope for further thought as to how FA can be more inclusive of those it is supposed to be helping.

Other approaches and methods

In addition to developing FAs as more evidence-based and user-friendly, it is important to consider whether FA methods capture a holistic understanding of individuals' QOL and behaviour that challenges. Some factors to consider in an assessment of behaviour that challenges are outlined by NICE (2015, p. 16 - 17) including environmental factors, physical health, communication abilities, adaptive skills, sensory profile and history of trauma. This is reflective of PBS having extended beyond principles of ABA and operant conditioning, by also incorporating other concepts and methodologies into its approach, such as genetic and pharmacological principles (Dunlap et al. 2008). However, as previously mentioned no tools are offered as a means for gathering such information (besides the functional FAST and MAS tools) and the process taken is likely to depend on available resources and experience. Considering the use of alternative or complimentary approaches to assessments of behaviour is useful; evidence suggests behaviour that challenges cannot be explained purely by a functional understanding alone, but by various biopsychosocial factors (Koristas & Iacano, 2015). For example, interventions should address early trauma, which has been identified as a potential contributory factor to behaviour that challenges (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists 2007). FAs should therefore take a multi-disciplinary approach and include methods that do not focus solely on functions of behaviour and consider various factors, such as psychological diagnoses and trauma, as 'slow triggers' for behaviour.

FAs have also been criticised for excluding sensory dysfunction as a possible variable in challenging behaviour (Allen, 2009; Mc Gill and Breen, 2020). Mc Gill and Breen (2020) identified that interventions sometimes use sensory integration strategies with successful results (measured by a reduction in 'challenging behaviour'), that are often dismissed as 'behavioural approaches'. Mc Gill and Breen (2020) therefore argue sensory assessments should be conducted alongside FAs to assess behaviour that challenges. However, Leong et al. (2015), in a systematic review, found there is weak evidence to support to the use of sensory integration strategies in working with people with ID who display behaviour that challenges. This is an area that probably needs more research and is not likely to be suitable for every case. However, Mc Gill and Breen (2020) have highlighted how FAs can be useful for providing data that highlights factors which may benefit from further investigation (such

as by Occupational Therapy). For example, where noise or crowd escape is considered a function of a behaviour that challenges, offering a sensory assessment should be considered.

Despite evidence that community engagement can reduce behaviours that challenge, people with ID who display behaviours that challenge often experience isolation, segregation and are excluded from employment (West and Patton 2010). West and Patton (2010) utilised FAs and 'supported employment procedures' with four adults with ID who were reported as displaying 'challenging behaviours' by staff at their day centre. The FA resulted in PBS plans being implemented that included antecedent strategies, alternative taught skills, positive reinforcements, crisis management and long-term prevention strategies (including community integration). Support staff received training to implement the FA, PBS plans and employment procedures. Participants were offered jobs in relation to their motivation, skills and preferences. By the end of their workplace training participants were able to complete 100% of their work tasks independently. The perceived challenging behaviours (such as self-injury and 'yelling') did not happen when any of the participants were at work. West and Patton's study did not collect data regarding behavior change within the day service settings, and no measure was used to record outcomes regarding QOL. However, participants did move from being isolated to "active engagement" in meaningful employment which could be viewed as a QOL measure (p. 110). As the study included multiple approaches in the intervention, it is unclear how much of the change relates to the employment programme compared to other factors. However, it does provide support for a multi-element approach to behaviour that challenges including increasing meaningful activity, PFT as well as FA.

Conclusion

Multiple studies have demonstrated the benefits of a multi-element approach to behaviour that challenges, with FAs consistently recognised as a critical component to help understand behaviour and positively influence interventions (MacDonald et al. 2010; Toogood et al. 2011). Therefore, it may often be helpful to gather a functional understanding of behaviour. Each individual should be considered on a case by case basis with a 'phased' and multi-element approach taken based on their needs. However, work needs to be done to ensure those working with people with ID who display behaviour that challenges have access to the skills, knowledge and evidence-based tools required to perform an effective FA and intervention that results in improved QOL. More is also needed to realise the goal of person-centred care, for example by ensuring individuals can be involved in their own FAs and PBS interventions where possible.

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