Designing specialist community-based behavioural support teams

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Abstract

Background: Given concern over inpatient treatment models for individuals with intellectual disabilities and challenging behaviour, there has been increased interest in specialist community-based behavioural support teams in the UK.

Methods: We discuss the approaches, priorities and outcomes specialist community-based behavioural support teams should be focused on by examining research, outputs from the Positive Behavioural Support (PBS) Academy and drawing on professional experience.

Results: We propose that teams should adopt the PBS framework intervention model, targeting vulnerability/impact factors and maintaining processes, in a preventative, multi-disciplinary model. The use of standardised measures (baseline and post-input) supports service evaluation. Specialised community-based behavioural support teams should report outcomes of case work to commissioners of services including quality of life and social validity impacts.

Conclusions: We conclude that teams should additionally contribute to proactive service wide approaches that include developing capable environments, policy, training and screening. We discuss service capacity and qualification requirements, and consider the importance of practice leadership.

Key words: positive behavioural support; challenging behaviour; psychotropic medication; outcome measures; community-based teams

Introduction

Recent studies indicate a prevalence of challenging behaviour (CB) within intellectual disability populations (ID) of approximately one in five adults (Jones et al, 2008; Lundqvist, 2013; Bowring et al, 2017a). Many people with ID who display CB are placed a long way from home (Department of Health, 2007), thereby reducing contact with family and friends. Additionally, out-of-area assessment and treatment units are associated with poor outcomes and high placement costs (NICE, 2015), with a number implicated in recent abuse scandals, eg Whorlton Hall (Triggle, 2019), stimulating interest in alternative local community-based support models.

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In 2015, a national plan for England, 'Building the Right Support', was published which committed to developing specialist community-based behavioural support teams, to reduce the need for inpatient care (NHS England, 2015). Clinical guidance (NICE, 2015) indicated that the role of community-based behavioural support teams was to complete comprehensive assessments of the factors likely to contribute to CB, suggesting the need for a range of multi-disciplinary professionals contributing to this person-centred process. More recent service guidance (NICE, 2018) identified the need for local authorities to commission services from community-based assessment and behavioural support teams, to ensure people have local support that is preventative, intervenes early and promotes quality of life (QoL).

Given national recommendations towards the development of the community-based behavioural support team model, it is timely to consider the design and operation of such teams. This paper will be of interest to those who develop, design, commission and work in community-based behavioural support teams. We summarise themes from recent research, outputs from the PBS Academy (http://pbsacademy.org.uk/), and offer insights from applied clinical practice to discuss a number of factors community-based behavioural support teams could usefully include within their design and operational remit. Additionally, we describe areas we think are important for service users and providers, and ways to describe knowledge of service impact to inform considerations about the quality and effectiveness of such teams.

Although not exhaustive, we think the following list could form the basis of an agenda for developing the community team model in the UK: (1) utilising positive behavioural support (PBS) as the underlying framework model; (2) addressing factors that contribute to the causes of CB (Hastings et al, 2013); (3) utilising a multi-disciplinary professional approach; (4) employing standardised measures to assess CB, and reporting other PBS outcomes, including QoL and social validity; (5) contributing to proactive service developments including policy and screening those at risk of CB; (6) designing and delivering effective training models; (7) developing the capacity among team members to work intensively; and (8) ensuring appropriately qualified and experienced staff and practice leaders. These areas and their basis in the literature, as well as in our clinical practice, are described below.

1 PBS as a framework intervention model

There has been increased interest in the development of PBS as a framework intervention model for community-based behavioural support teams (Toogood et al, 2015, 2016; Kincaid et al, 2016). This has been reflected in components of PBS being mentioned in practice (NICE, 2015, 2018; Skills for Care, 2014) and government guidelines in the UK (Department of Health 2012a, 2012b, 2013, 2014; Local Government Association and NHS England, 2014; Transforming Care and Commissioning Steering Group, 2014).

Evidence from reviews suggests that PBS can lead to significant reductions in CB (Carr et al, 1999; LaVigna and Willis, 2012). There is a small, yet growing, number of studies that include elements of PBS, with successful CB outcomes, in community-based behavioural teams (McBrien, 1994; Allen and Lowe, 1995; Toogood et al, 1994a, b; Lowe et al, 1996; Forrest et al, 1996; Emerson et al, 1996; McGill, 2000; Allen et al, 2011). However, studies have been limited by small sample sizes, research designs that are not robust, measures which are not psychometrically sound, and a lack of clarity over whether PBS interventions are specifically utilised (Kincaid et al, 2002; Carr et al, 2002; McClean et al, 2005). Studies have also focused predominantly on behaviour change, often presented in terms of the percentage of people for whom reductions in levels of CB were apparent, but without any indication of how meaningful that change was. There has also been a lack of evaluation of the other aims of PBS, namely the impact on QoL and social validity outcomes (Kincaid et al, 2002; Carr et al, 2002; McLean et al, 2005).

Two recent studies have presented more robust evidence of the effectiveness of PBS applied by community-based behavioural support teams. Firstly, Hassiotis et al (2009) utilised a randomised, single-blind controlled trial to explore the impact of a community-based behavioural support team who operated using the multidimensional model of applied behaviour analysis (ABA) and PBS. One group of 31 adults with ID and CB received input from a multi-disciplinary community service featuring nursing and adaptive skill support, with a second group of 32 adults receiving additional input from the behavioural support team. This second group experienced greater reduction in CB at three and six months as measured by the Aberrant Behaviour Checklist (ABC) (Aman and Singh, 1986) and at a two-year follow up (Hassiotis et al, 2011). In a second study, Bowring et al (2019) evaluated outcomes from a community-based PBS team in Jersey. Jersey is an island measuring 118

square kilometres, 14 miles off the coast of Normandy, France. This study involved 85 participants with the features of the PBS assessment and intervention process clearly described, which were missing in the Hassiotis et al (2009) study. In the Bowring et al study, significant reductions in CB were evidenced in mean group scores on the Behaviour Problems Inventory (Rojahn et al, 2012a), decreasing from 37.74 (SD = 30.54) at baseline to 12.12 (SD = 12.24) at follow-up. In addition, significant improvements were found in QoL (measured by a tool adapted from Kincaid et al, 2002), and Health related QoL (measured using the EQ5D 3L and VAS; EuroQol, 1990). Social validity assessments indicated that stakeholders valued PBS input from the community-based behavioural support team. The Bowring et al (2019) study, albeit a single group pre-post-test design, contributed to a better understanding of PBS outcomes in practising community-based behavioural support teams.

Despite the promising evidence-base for PBS, less than half of community-based behavioural support services (47%) in the UK described themselves as being based on the principles and practices of PBS (Davison, 2015). Research suggests services and users might benefit from a PBS framework being more widely adopted. The PBS Academy has developed the PBS Competence Framework that community-based behavioural support teams can utilise (http://pbsacademy.org.uk/pbs-competence-framework/). This framework details aspects required when designing and delivering community-based behavioural support services based on high quality PBS input.

2 Strengthening teams' understanding of the causes of CB

In developing a model to explain why individuals with ID engage in CB, Hastings et al (2013) described the inter-relatedness of vulnerability, maintaining process, and impact factors. Vulnerability factors include biological (sensory causes, physical health issues, and genetics) and psychosocial factors (negative life events, lack of communication skills, impoverished social networks, lack of meaningful activity, and psychiatric or mood problems) (Hastings et al, 2013). CB is also maintained by the social consequences that follow its occurrence and are directly related, therefore, to the behaviour of others (Hastings et al, 2013; Gore et al, 2013). CB is functional as it changes the environment in ways which are important to the person (Iwata et al, 1994). CB is associated with a number of negative impacts for individuals including exclusion from local communities and harm to self or others (Emerson and Einfeld, 2011). These can have a cyclical impact by increasing the risk of vulnerability factors. It is therefore logical for community-based behavioural support teams to apply interventions that address vulnerability, maintaining processes and impact factors which all contribute to the presentation of CB.

A focus on vulnerability factors

In a 2017 population study (Bowring et al, 2017a), being non-verbal, having limited understanding of communication and having a severe-profound ID were found to be consistently correlated with higher levels of CB. Communication impairments and increased severity of ID (Emerson and Bromley, 1995; Emerson et al, 2001; Holden and Gitlesen, 2006; Jones et al, 2008) have been consistently identified as vulnerability factors for CB. In the Bowring et al (2017a) study, having no daytime engagement, living in paid or congregate care, the presence of an additional diagnosis of autism, the presence of another genetic syndrome, impaired vision, no clear speech, incontinence, the presence of seizures, epilepsy, and mobility problems were significantly associated with specific topographies of CB, such as aggression and destruction, self-injurious behaviour or stereotypic behaviour. Findings from Bowring et al (2017a) indicated that a multi-component response to CB is required that includes interventions that address vulnerabilities to presenting CB. In the current paper, interventions that target the promotion of communication and engagement levels are described below.

Promoting communication skills

CB may be less likely to occur when a person is understood by others (Allen et al, 2013). It is logical, therefore, to expect that services ensure that all individuals with ID have access to appropriate methods of communication. In the Bowring et al (2017a) study, 119 out of 265 participants had an impairment of expressive communication and 73 had limited receptive understanding of communication, yet only 32 had a means of augmentative alternative communication. Of these, 26 used Makaton, but it was not always clear if staff were proficient in its use. In order to prevent the occurrence of communication-related CB, services should ensure that staff/carers are highly trained in the preferred communication style of that person and that support for communication is seen across all areas of the individual's life (Allen et al, 2013). Communication strategies should be shared across environments,

informing partner agencies, for example, by using tools like the communication passport (Allen et al, 2013). The function of behaviour should be described in PBS plans, with strategies in place to support functionally equivalent behaviours which will often involve communication strategies. Towards these aims, it is advantageous for community-based behavioural support teams to work closely with speech and language therapists. The PBS Academy has additionally developed easy to read documents on behaviour, PBS and quality of life for people with ID (http://pbsacademy.org.uk/people-with-learning-disabilities/) which explain the role of community-based behavioural support teams.

Promoting engagement: Active Support

Bowring et al (2017a) found a strong association between a lack of daytime engagement and self-injurious behaviour and stereotypic behaviour. In this total-population study, 38.5% of adults with ID had no daytime engagement (Bowring et al, 2017a), similar to previous population estimates (Lowe et al, 2007). Even within residential homes, adults with ID spent less than 50% of their time engaged in any activity (Qian et al, 2015).

Community-based behavioural support teams can help to address this issue by promoting increasing levels of meaningful engagement for people with ID in and out of their home. In an earlier paper, Totsika et al (2008) described how Active Support could be used within a PBS framework model. Active Support is a model that promotes activity, including domestic, educational, vocational, leisure and social activities. Improving engagement levels is a key environmental intervention that community-based behavioural teams can target to address low levels of engagement. Active Support in residential homes may provide a context for increasing activity engagement for every resident with ID no matter how severe their disability (Totsika et al, 2008; Toogood et al, 2016). While current evidence is inconclusive regarding the effects of Active Support on existing CB levels (Flynn et al, 2018), some studies have suggested Active Support may alter environmental contexts (establishing operations) in ways that make CB less likely to occur (Totsika et al, 2010; Jones et al, 2013). One role for community-based behavioural support teams would be to lead on Active Support training and ensure opportunities for implementation by staff through coaching and data monitoring. Mansell and Beadle-Brown (2012) provide helpful suggestions for services tasked with the implementation of Active Support.

With only 6% of adults with ID in employment in the UK (HSCIC, 2015), efforts to promote opportunities for paid employment might also be advocated. Community-based behavioural teams can support vocational training providers in improving on-task behaviour (see Bowring and Toogood, 2019), and developing pre-employment vocational and social skills. Teams could additionally link with potential employers to develop supportive work environments that are conducive to productive outcomes for people with ID, and to advise on any issues that may arise during employment.

A focus on maintaining processes

Hastings et al (2013) describe how CB must be useful for individuals for it to continue to occur; it must serve an important function. For example, a staff member may remove a request for an individual to perform a difficult task, contingent on the individual becoming aggressive. At times of low staff attention, engaging in self-injurious behaviour may lead to increased levels of staff attention and engagement. An understanding of the functions or maintaining processes to CB is helpful when designing person centred PBS intervention plans. All participants in the Bowring et al (2019) study had a pre-intervention functional assessment of CB, which informed the development of a stakeholder informed multi-component PBS intervention plan. Functional behavioural assessments are an important process in developing effective PBS interventions (Iwata et al, 1994). Community-based behavioural support services following a PBS model depend on recruiting trained staff, and investing in training for existing staff, so they are competent in completing functional behavioural assessments (see NICE, 2015) to inform intervention plans. Community-based behavioural support teams should focus on reciprocal processes for pro-social behaviour, such as antecedent supports that occasion desired behaviour, followed by reinforcement to strengthen the future likelihood of such pro-social behaviour.

A focus on impact factors

Given how impact factors are interrelated with vulnerability factors in the CB causal model proposed by Hastings et al (2013), community-based behavioural teams must be capable of addressing multiple related factors on a case-by-case basis. This includes refraining from aversive and restrictive responses to CB that negatively affect an individual's QoL. The Bowring et al (2019) study showed a strong correlation between QoL improvement and CB reduction. Given this,

community-based behavioural support teams can prioritise QoL outcomes and target restrictive practices for removal, with the latter serving as both an intervention and an outcome. Given the high level of psychotropic medication prescribed for adults with ID who present CB, but have no specific diagnosis of a mental illness, this may be a key restrictive practice for community-based behavioural teams to target for removal.

Psychotropic medication

Psychotropic medication is commonly prescribed in a high proportion of adults with ID presenting CB (eg Sheehan et al, 2015: 49%; Henderson et al, 2015: 49.1%; Bowring et al, 2017b: 39.7%), despite little evidence of clinical benefit (Emerson and Baines, 2010; Tsiouris, 2010; Paton et al, 2011; Wilner, 2014). In the Bowring et al (2017b) study, individuals who presented CB were nearly twice as likely to be prescribed psychotropic medication compared to adults who did not present CB and were nearly three times more likely to be prescribed antipsychotic medication. Psychotropic medication can have a number of adverse side effects such as weight gain, somnolence, metabolic syndromes and behavioural impact (Deb and Unwin, 2007; Maher et al, 2011; Deb et al, 2014; Wilner, 2014; Sheehan et al, 2017). There is national guidance on appropriate prescribing (NICE, 2015; RCP, 2016) and information available from national campaign groups such as STOMP - 'Stopping the over-medication of people with a learning disability, autism or both' (https://www.vodg.org.uk/campaigns/stompcampaign/).

Improving access to community-based behavioural support services may assist the reduction in the use of psychotropic medication prescribed for CB as an alternative or complementary intervention. During assessment, community-based behavioural support teams could, for example, audit use of psychotropic medication which individuals are prescribed and the reason for prescribing. Contact could be made with prescribers, and joint working programmes on CB devised, with drug reduction included as a target in intervention plans. Community-based behavioural support teams are ideally positioned to support prescribers by providing behavioural data on the impact of psychotropic medication, in relation to new medication or to support drug withdrawal programmes. Having access to CB data can greatly facilitate improvements in the area of functioning, so that the effects of prescribed medication are documented and decisions to continue or discontinue the medication are based on evidence.

3 Multi-disciplinary approach

Research on correlates (factors associated with higher levels of CB) or vulnerabilities of CB (Bowring et al, 2017a) helps identify factors to address in an holistic intervention model. These are likely to require the input of several different professions who work with individuals with ID. Research by Bowring et al (2017a, 2017b; 2019) suggests behaviour specialists are needed for completing functional assessments; nurses and health professionals for completing health checks and addressing issues such as incontinence; speech and language therapists for working on communication skills; physiotherapists for addressing mobility issues; occupational therapists for promoting engagement, teaching independence skills and completing sensory profile assessments; psychologists for providing therapeutic interventions; and psychiatrists for monitoring mental health and medication. Addressing the vulnerability and maintaining processes and impact of CB requires a multi-disciplinary based approach. The PBS Academy has developed standards for community-teams and services detailing high quality support approaches for people with ID (http://pbsacademy.org.uk/standards-for-services/). These standards list the staple features community-based behavioural teams will need to effectively implement PBS.

4 Standardised measures to assess CB

The use of behaviour rating scales can help identify CBs to target for intervention and for reporting individual and group outcomes of intervention. Completing rating scales on CB at the point of referral, and again following community-team input can contribute to the delineation of target behaviour to change. Completing scales intermittently thereafter can help to measure progress and monitor the maintenance of behaviour change. One such tool is the Behavior Problems Inventory – Short Form (BPI-S) (Rojahn et al, 2012a).

The Behavior Problems Inventory – Short Form (Rojahn et al, 2012a)

The BPI-S is an informant-based rating scale used to assess the occurrence and severity of CB in individuals with ID. The BPI-S has good psychometric properties (Rojahn et al, 2012a, 2012b; Mascitelli et al, 2015; Bowring et al, 2017a) and is easy to administer. In a 2018 study, Bowring et al extended the use of this tool in research and clinical practice by providing population reference data, clinically significant cut-off

scores, and reliable change scores. Normative data could be useful to community-based behavioural support teams at screening to identify those who meet behavioural criteria for a service, or for prioritising case waiting. Clinical cut-off scores and reliable change scores, calculated using an approach described by Jacobson and Truax (1991), can enable services and practitioners to evaluate behaviour change in their work (for individuals, and for groups of individuals) utilising the BPI-S as a pre-and-post measure. This can help community-based behavioural support teams describe whether behaviour change is meaningful and interventions have been effective.

Results in the Bowring et al (2019) study indicate that the BPI-S was capable of detecting change in the referred population, and could identify and describe clinically significant and reliable change in CB, even though very few participants (10.6% of all participants) experienced total removal of the target CB.

Decisions regarding which behaviours to assess may be better made using behaviour rating scales, as compared with referral forms. The first may be subject to less bias than the latter, although referral forms may have a greater congruence with CB that is socially constructed based on stakeholder perceptions of problematic behaviour. Adding a rating scale to assessment procedures also may address the under-reporting of inner-directed behaviours, such as stereotypy (Bowring et al, 2019). Discussing CBs identified at the point of referral with stakeholders could be one way of clarifying target behaviours to improve QoL, to operationally define behaviour for functional assessment, and to establish a check for the social validity of behaviour change.

Standardised measures that assess behaviour change may also inform community-based behavioural support teams on suitable timings for teams to withdraw their input (such as once clinically significant behaviour change has been achieved), and to monitor maintenance periodically.

Reporting outcomes

It is highly desirable that commissioners of community-based behavioural support services are provided with data on behaviour change, QoL, health related QoL and social validity impacts, to monitor service impact and effectiveness (Inchley-Mort et al, 2014). Monitoring of outcome is not currently widespread, nor is it routinely required or specified in contractual arrangements (Denne et al, 2015). An indicator of good community-based behavioural support services could be the quality of the outcome data produced. There are a range of tools that are low cost, easy to administer, and available for services to use and/or for commissioners to request (Bowring et al, 2019), such as the BPI-S (Rojahn et al, 2012a) for measuring behaviour change.

5 Proactive service approaches

There are several ways for community-based behavioural support teams to support system-wide PBS. For example, specialist teams could: (a) aid the development of service-wide PBS policies; (b) support the development of QoL initiatives for individuals with ID such as engagement and vocational initiatives; (c) promote capable environments (McGill et al, 2010); (d) provide consultancy to other professionals (including prescribers); (e) contribute to the development of care plans/education plans/transition plans; (f) support the development of PBS competencies in provider services; (g) develop early intervention models; (h) support the development of community residential services; and (i) assist to promote support staff competencies via training and coaching.

Community-based behavioural support teams could also consider aspects of screening (eg Fuchs et al, 2003) to identify individuals who would benefit from specialised behavioural support team input (subject to consent and ethical approval). As part of annual health checks, adults with ID could be screened using the BPI-S (Rojahn et al, 2012a). The BPI-S may identify adults who require function-based behavioural support. Vulnerability and impact factors could be explored to identify individuals who would benefit from input from other multi-disciplinary professionals. Screening tools could identify adults who require support with adaptive or communicative skills and ensure the relevant professional support is in place. This may prompt referrals to other services (eg communication impairments prompt a referral to speech and language therapy). This would ensure that adults with ID have holistic, robust, multi-disciplinary support arrangements.

6 Training models

Community-based behavioural support teams may have a training role to support the development of knowledge and implementation of PBS in services. Training could include activities that address QoL and the values models that inform PBS, such as normalisation and inclusion (Carr et al, 2002). Carers and staff may need help to develop an understanding of the causal model of behaviour, skills teaching, reduction of restrictive practices, and development of PBS plans. All staff who work with individuals with ID and/or autism would benefit from having access to PBS training and regular development sessions and updates. Many service workers may have had training in physical intervention approaches and not PBS.

Given that services will support individuals with CB, some staff will require access to accredited de-escalation and (non-restrictive) disengagement training to manage risk. All de-escalation and disengagement skills should be listed in PBS plans and be specific to individuals and regularly reviewed.

Personalised physical intervention training may assist support staff in positive risk taking, such as in promoting community presence for individuals with CB, hence promoting QoL. This training should be considered only for specific staff who support specific individuals and may be identified through a multi-component function-based intervention plan, involving key stakeholders and service users. Having PBS practitioners (who know service users) involved in physical intervention training can be helpful for function informed proactive strategies to be promoted and for restrictive practices to be taught based on last resort approaches. Community-based PBS teams should monitor the application of restrictive physical interventions and complete assessments/update PBS plans accordingly to minimise the use of these approaches. PBS plans should include procedures to reduce the use of restrictive practices as the individual's behaviour improves. Restrictive practices should be removed from intervention plans as soon as can be achieved. The PBS Academy has developed standards for training (http://pbsacademy.org.uk/standards-for-training/) which can assist organisations responsible for in-house PBS training in the design, delivery and evaluation of training programmes.

7 Capacity of specialist community-based behavioural support teams

PBS services in the UK are currently provided by various organisations including NHS services, local authorities, third sector groups and private health providers (Toogood et al, 2015). Current provision lacks breadth and is small scale (Toogood et al, 2015). Accordingly, there needs to be more evidence to support investment into the further development of such teams.

Given that average case length was 45 weeks in the Bowring et al (2019) study, this indicates the need for teams to have the ability to provide intensive, prolonged input. In the Bowring et al (2019) study, the community-based behavioural support team completed data-informed functional behavioural assessments and developed collaborative PBS intervention plans. A behaviour advisor assistant supported families and staff teams in implementing interventions through coaching, modelling and the development of specific intervention tools (such as visual planners). For community-based behavioural support teams to be able to work intensively in this way, each practitioner should have a case list of no more than six to eight individuals at any one time in various stages of assessment, implementation and monitoring. Given potential high referral rates, monthly advisory clinics may be useful where families and staff can meet practitioners for advice. This may additionally assist screening and prioritising case work input for new referrals and ensure advice/signposting if some cases are placed on a waiting list. Community-based behavioural support practitioners should also have capacity for training delivery and time to contribute to proactive service developments.

8 Qualifications and experience of staff and role of practice leaders

The PBS Academy has recently produced standards for individual PBS practitioners (http://pbsacademy.org.uk/wp-content/uploads/2019/04/PBS-Standards-for-Individual-Practitioners.pdf). This details the type of qualifications and supervised practice required for direct contact staff, behaviour specialists and higher-level behaviour specialists who are responsible for implementation of PBS within services. It is important that community-based behavioural support teams have suitably qualified, experienced staff who have access to appropriate supervised practice and ongoing professional development to undertake accurate functional behavioural assessments and

data-monitored intervention plans. Research evidence suggests that when PBS is delivered by non-expert clinicians or after short training courses, then failures of implementation can occur (eg Hassiotis et al, 2018; Bosco et al, 2019). These studies did not show the positive impact on behavioural and QoL outcomes that other studies with more experienced PBS practitioners have demonstrated (eg Bowring et al, 2019).

Outcomes from community-based behavioural support services may be influenced by the quality of the services they support (Toogood, 2016). There is increased evidence of the benefit of practice leaders in referral environments (Beadle-Brown et al, 2015; Deveau and McGill, 2016). Practice leaders are frontline leaders who have knowledge of PBS, support the implementation of interventions, and coach/organise staff accordingly (United Response, 2018). Community-based behavioural support teams should invest time in developing practice leaders within key provider services to support the fidelity of implementation of advice.

Recommendations and conclusions

We have summarised the findings from recently published research, outputs from the PBS Academy, and insights from applied clinical practice to generate an account of factors likely to affect the quality and effectiveness of specialist community-based behavioural support services in the UK. Although not exhaustive, we think this review could form the basis of an agenda for developing the community team model. In summary, our review suggests:

- The adoption and deployment of a PBS framework for community-based behavioural teams that targets vulnerability factors, maintaining processes, and assesses impact factors for CB. Intervention should be person centred, function based, and address system-wide issues to promote stakeholder quality of life and the reduction of challenging behaviour.
- Community-based behavioural support teams should be part of a multi-disciplinary, multi-stakeholder group assembled around individuals to develop multi-component plans and organisational contexts to address system-wide issues that contribute to the causal model of CB.
- Behavioural rating scales, such as the BPI-S, may be used to help identify behavioural problems at the point of referral, to assess behaviour change as a function of intervention and to monitor the maintenance of change over time.
- Community-based behavioural support teams should report outcomes to commissioners of services and help build a database of evidence on model effectiveness and efficiency. Teams should utilise multiple measures that capture progress in terms of meaningful behaviour change, QoL and social validity, as well as reductions in the use of restrictive practices and psychotropic medication.
- Teams should contribute to proactive service-wide approaches that include developing capable environments, policy, training and screening.
- Teams require capacity to work intensively in case work. Practitioners should be suitably qualified and experienced. Practice leaders are important in provider services to achieve this level of team competency.

References

Allen, D and Lowe, K (1995) 'Providing intensive community support to people with learning disabilities and challenging behaviour: A preliminary analysis of outcomes and costs', *Journal of Intellectual Disability Research*, 39, 67–82.

Allen, D, Lowe, K, Baker, P, Dench, C, Hawkins, S, Jones, E and James, W (2011) 'Assessing the effectiveness of positive behavioural support: The P-CPO project', *International Journal of Positive Behavioural Support*, 1, 14–23.

Allen, D, McGill, P, Hastings, R P, Toogood, S, Baker, P, Gore, N J and Hughes, J C (2013) 'Implementing positive behavioural support: Changing social and organisational contexts', *International Journal of Positive Behavioural Support*, 3, 32–40.

Aman, M G and Singh, N N (1986) *The Aberrant Behavior Checklist*, New York: Slosson Educational Publications.

Beadle-Brown, J, Bigby, C and Bould, E (2015) 'Observing practice leadership in intellectual and developmental disability services', *Journal of Intellectual Disability Research*, 59, 1081–1093.

Bosco, A, Paulauskaite, L, Hall, I, Crabtree, J, Soni, S, Biswas, A, et al (2019) 'Process evaluation of a randomised controlled trial of PBS-based staff training for challenging behaviour in adults with intellectual disability', *PLoS ONE*, 14(8). e0221507. doi:10.1371/journal.pone.0221507

Bowring, D L and Toogood, S (2019) 'The use of 'Positive Greetings at the Door' to increase on-task behaviour in a vocational training centre', *International Journal of Positive Behavioural Support*, 9, 38–46.

Bowring, D L, Totsika, V, Hastings, R P and Toogood, S (2018) 'Towards data based clinical decision making for adults with challenging behaviour using the Behaviour Problems Inventory – Short Form (BPI-S)', *Tizard Learning Disability Review*, 23, 103–110.

Bowring, D L, Totsika, V, Hastings, R P, and Toogood, S (2019) 'Outcomes from a community-based Positive Behavioural Support team for children and adults with developmental disabilities', *Journal of Applied Research in Intellectual Disabilities*, 1–11.

Bowring, D L, Totsika, V, Hastings, R P, Toogood, S and Griffiths, G M (2017a) 'Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices', *British Journal of Clinical Psychology*, 56, 16–32.

Bowring, D L, Totsika, V, Hastings, R P, Toogood, S and McMahon, M (2017b) 'Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability: A total population study', *Journal of Intellectual Disability Research*, 61, 604–617.

Carr, E, Horner, R, Turnbull, A, Marquis, J, Magito-McLaughlin, D, McAtee, M, et al (1999) *Positive Behavior Support For People With Developmental Disabilities: A Research Synthesis.* Washington, DC: American Association on Mental Retardation.

Carr, E G, Dunlap, G, Horner, R H, Koegel, R L, Turnbull, A P, Sailor, W, et al. (2002) 'Positive behavior support: Evolution of an applied science', *Journal of Positive Behavior Interventions*, 4, 4–16.

Davison, S, McGill, P, Baker, P, and Allen, D (2015) 'A national UK survey of peripatetic support teams for children and adults with intellectual and developmental disability who display challenging behaviour', *International Journal of Positive Behaviour Support*, 3, 25–33.

Deb, S and Unwin, G L (2007) 'Psychotropic medication for behavior problems in people with intellectual disability: A review of the current literature', *Current Opinion in Psychiatry*, 20, 461–466.

Deb, S, Unwin, G and Deb, T (2014) 'Characteristics and the trajectory of psychotropic medication use in general and antipsychotics in particular among adults with ID who exhibit CB', *Journal of Intellectual Disability Research*, 59, 11–25.

Denne, L, Jones, E, Lowe, K, Jackson Brown, F and Hughes, C J (2015) 'Putting positive behavioural support into practice: The challenges of workforce training and development', *International Journal of Positive Behavioural Support*, 5, 43–54.

Department of Health (2007) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* (Mansell Report – revised edition), London: HMSO.

Department of Health (2012a) *Transforming Care: A National Response to Winterbourne View Hospital*. London: Department of Health.

Department of Health (2012b) *Winterbourne View Review. Concordat: Programme of Action*. London: Department of Health.

Department of Health (2013) *Winterbourne View Review: Transforming Care One Year On*. London: Department of Health.

Department of Health (2014) *Positive and Proactive Care: Reducing the Need for Restrictive Interventions*. London: Department of Health.

Deveau, R and McGill, P (2016) 'Impact of practice leadership management style on staff experience in services for people with intellectual disability and challenging behaviour: A further examination and partial replication', *Research in Developmental Disabilities*, 56, 160–164.

Emerson, E and Baines, S (2010) *Health Inequalities and People with Learning Disabilities in the UK: 2010*. Durham: Improving Health & Lives: Learning Disabilities Observatory.

Emerson, E and Bromley, J (1995) 'The form and function of challenging behaviours', *Journal of Intellectual Disability Research*, 39, 388–398.

Emerson, E and Einfeld, S L (2011) *Challenging Behaviour* (3rd Edition). Cambridge: Cambridge University Press.

Emerson, E, Forrest, J, Cambridge, P and Mansell, J (1996) 'Community support teams for people with learning disabilities and challenging behaviours: Results of a national survey', *Journal of Mental Health*, 5, 395–406.

Emerson, E, Kiernan, C, Alborz, A, Reeves, D, Mason, H, Swarbrick, R, Mason, L and Hatton, C (2001) 'The prevalence of challenging behaviors: A total population study', *Research in Developmental Disabilities*, 22, 77–93.

EuroQol Group (1990) 'EuroQol– A new facility for the measurement of health related quality of life', *Health Policy* (Amsterdam, Netherlands),16(3), 199–208.

Flynn, S, Totsika, V, Hastings, R P, Hood, K, Toogood, S and Felce, D (2018) 'Effectiveness of Active Support for adults with intellectual disabilities in residential settings: Systematic review and meta-analysis', *Journal of Applied Research in Intellectual Disabilities*, 31, 983–998.

Forrest, J, Cambridge, P, Emerson, E, Mansell, J, Asbury, M and Beecham, J (1996) 'Community support teams for people with learning disabilities and challenging behaviour', in Gale, E (ed.) *Challenging Behaviour: What We Know*. London: Mental Health Foundation.

Fuchs, D, Mock, D, Morgan, P L and Young, C L (2003) 'Responsiveness-to-intervention: Definitions, evidence, and implications for the learning disabilities construct', *Learning Disabilities Research and Practice*, 18, 157–171.

Gore, N J, McGill, P, Toogood, S, Allen, D, Hughes, J C and Baker, P (2013) 'Definition and scope for positive behavioural support', *International Journal of Positive Behavioural Support*, 3, 4–23.

Hassiotis, A, Canagasabey, A, Robotham, D, Marston, L, Romeo, R, and King, M, (2011) 'Applied behaviour analysis and standard treatment in intellectual disability: 2-year outcomes', *British Journal of Psychiatry*, 198, 490–491.

Hassiotis, A, Poppe, M, Strydom, A, Vickerstaff, V, Hall, I, Crabtree, J, Crawford, M et al (2018) 'Clinical outcomes of staff training in positive behaviour support to reduce challenging behaviour in adults with intellectual disability: Cluster randomised controlled trial', *The British Journal of Psychiatry*, 212, 161–168.

Hassiotis, A, Robotham, D, Canagasabey, A, Romeo, R, Langridge, D, Blizard, R, et al (2009) 'Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities', *American Journal of Psychiatry*, 166, 1278–1285.

Hastings, R P, Allen, D, Baker, P, Gore, N J, Hughes, J C, McGill, P et al (2013) 'A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities', *International Journal of Positive Behavioural Support*, 3, 5–13.

Henderson, A, Kinnear, D, Morrison, J, Allen, L and Cooper, S-A (2015) 'Psychotropic drug prescribing in a cohort of adults with intellectual disabilities in Scotland'. Presented at the Seattle Club Conference, Cardiff,11 December 2015.

Holden, B and Gitlesen, J P (2006) 'A total population study of challenging behaviour in the county of Hedmark, Norway: Prevalence and risk markers', *Research in Developmental Disabilities*, 27, 456–465.

HSCIC (2015) *Measures from the Adult Social Care Outcomes Framework: England 2014-15, Final Release*. Available at: http://bit.ly/36zupfX (accessed 5 November 2019).

Inchley-Mort, S, Rantell, K, Wahlich, C and Hassiotis, A (2014) 'Complex behaviour service: Enhanced model for challenging behaviour', *Advances in Mental Health and Intellectual Disabilities*, 8, 219–227.

Iwata, B, Pace, G, Dorsey, M F, Zarcone, J R, Vollmer, T R et al (1994) 'The functions of self-injurious behaviour: an experimental-epidemiological analysis', *Journal of Applied Behavior Analysis*, 27, 215–240.

Jacobson, N S and Truax, P (1991) 'Clinical significance: A statistical approach to defining meaningful change in psychotherapy research', *Journal of Consulting and Clinical Psychology*, 59, 12–19.

Jones, E, Lowe, K, Brown, S, Albert L, Saunders, C, Haake, N et al (2013) 'Active Support as a primary prevention strategy for challenging behaviour', *International Journal of Positive Behavioural Support*, 3, 16–30.

Jones, S, Cooper, S-A, Smiley, E, Allen, L, Williamson, A and Morrison J (2008) 'Prevalence of, and factors associated with, problem behaviors in adults with intellectual disabilities', *The Journal of Nervous and Mental Disease*, 196, 678–686.

Kincaid, D, Dunlap, G, Kern, L, Lane, K L, Bambara, L M, Brown, F et al (2016) 'Positive behavior support. A proposal for updating and refining the definition', *Journal of Positive Behavior Interventions*, 18, 69–73.

Kincaid, D, Knoster, T, Harrower, J K, Shannon, P and Bustamante, S (2002) 'Measuring the impact of positive behaviour support', *Journal of Positive Behavior Interventions*, 4, 109–117.

LaVigna, G W and Willis, T J (2012) 'The efficacy of positive behavioural support with the most challenging behaviour: the evidence and its implications', *Journal of Intellectual and Developmental Disability*, 37, 185–195.

Local Government Association and NHS England (2014) *Ensuring Quality Services. Core Principles for the Commissioning of Services for Children, Young People, Adults and Older People with Learning Disabilities and/or Autism who Display or are at Risk of Displaying Behaviour that Challenges.* London: Local Government Association.

Lowe, K, Allen, D, Jones, E, Brophy, S, Moore, K and Jones, W (2007) 'Challenging behaviours: Prevalence and topographies', *Journal of Intellectual Disability Research*, 51, 625–636.

Lowe, K, Felce, D and Blackman, D (1996) 'People with learning disabilities and challenging behaviour: the characteristics of those referred and not referred to specialist teams', *Psychological Medic*ine, 25, 595–603.

Lundqvist, L (2013) 'Prevalence and risk markers of behaviour problems among adults with intellectual disabilities. A total population study in Orebro County, Sweden', *Research in Developmental Disabilities*, 34, 1346–1356.

Maher, A R, Maglione, M, Bagley, S, Suttorp, M, Hu J H, Ewing, B et al (2011) 'Efficacy and comparative effectiveness of atypical antipsychotic medications for off-label uses in adults: a systematic review and meta-analysis', *Journal of the American Medical Association*, 306, 1359–69.

Mansell, J and Beadle-Brown, J (2012) *Active Support: Enabling and Empowering People with Intellectual Disabilities.* London: Jessica Kingsley.

Mascitelli, A N, Rojahn, J, Nicolaides, V, Moore, L, Hastings, R P and Christian-Jones, C (2015) 'The Behavior Problems Inventory – Short Form (BPI-S): Reliability and factorial validity in adults with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, 28, 561–71.

McBrien, J (1994) 'Behavioural services team for people with learning disabilities', in E Emerson, P McGill and J Mansell (eds) *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*. London: Chapman and Hall.

McClean, B, Dench, C, Grey, I M, Shanahan, S, Fitzsimmons, E M, Hendler, J and Corrigan, M (2005) 'Person focused training: a model for delivering positive behavioural supports to people with challenging behaviours', *Journal of Intellectual Disability Research*, 49, 340–52.

McGill, P (2000) 'Ten years of providing intensive support services for people with learning disabilities and challenging behaviour', *Tizard Learning Disability Review*, 5, 23–25.

McGill, P, Bradshaw, J, Smyth, G, Hurman, M and Roy, A (2010) 'Capable environments'. In R Banks and A Bush (eds) *Challenging Behaviour: A Unified Approach*. London: Royal College of Psychiatrists.

NHS England (2015) *Building the Right Support: A National Plan to Develop Community Services and Close Inpatient Facilities for People with a Learning Disability and/or Autism who Display Behaviour that Challenges, Including Those with a Mental Health Condition*. London: NHS England.

NICE (2015) *Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities whose Behaviour Challenges* (NG11) London: NICE.

NICE (2018) *Learning Disabilities and Behaviour that Challenges: Service Design and Delivery* (NG93). London: NICE.

Paton, C, Flynn, A, Shingleton-Smith, A, Mcintyre, S, Bhaumik, S, Rasmussen, J et al (2011) 'Nature and quality of antipsychotic prescribing practice in UK psychiatry of intellectual disability services', *Journal of Intellectual Disability Research*, 55, 665–674.

Qian, X, Ticha, R, Larson, S A, Stancliffe, R J and Wuorio, A (2015) 'The impact of individual and organisational factors on engagement of individuals with intellectual disability living in community group homes: a multilevel model', *Journal of Intellectual Disability Research*, 59, 493–505.

Rojahn, J, Rowe, E W, Sharber, A C, Hastings, R, Matson, J L, Didden, R et al (2012a) 'The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part I: development and provisional clinical reference data', *Journal of Intellectual Disability Research*, 56, 527–545.

Rojahn, J, Rowe, E W, Sharber, A C, Hastings, R, Matson, J L, Didden, R et al (2012b) 'The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part II: reliability and validity', *Journal of Intellectual Disability Research*, 56, 546–565.

Royal College of Psychiatrists (RCP) (2016) *Psychotropic Drug Prescribing for People with Intellectual Disability, Mental Health Problems and/or Behaviours that Challenge: Practice Guidelines*. Faculty report FR/ID/09. Available at: http://bit.ly/2NKGlmq

Sheehan, R, Hassiotis, A, Walters, K, Osborn, D, Strydom, A and Horsfall, C (2015) 'Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study', *British Medical Journal*, 351, 1–9.

Sheehan, R, Horsfall, L, Strydom, A, Osborn, D, Walters, K and Hassiotis, A (2017) 'Movement side effects of antipsychotic drugs in adults with and without intellectual disability: UK population cohort', *British Medical Journal*, 7 (8), e017406.

Skills for Care and Skills for Health (2014) A Positive and Proactive Workforce. A Guide to Workforce Development for Commissioners and Employers Seeking to Minimise the Use of Restrictive Practices in Social Care and Health. Available at: http://bit.ly/2JQxVZS (accessed 5 November 2019).

Toogood, S (2016) 'Commentary on "reflection on culture, structure and function of an intensive support service centred on positive behavioural support"', *Tizard Learning Disability Review*, 21, 212–219

Toogood, S, Bell, A, Jaques, H, Lewis, S and Sinclair, C (1994a) 'Meeting the challenge in Clwyd: the intensive support team: Part 1', *British Journal of Learning Disabilities*, 22, 18–24.

Toogood, S, Bell, A, Jaques, H, Lewis, S and Sinclair, C (1994b) 'Meeting the challenge in Clwyd: the intensive support team: Part 2', *British Journal of Learning Disabilities*, 22, 46–52.

Toogood, S, Saville, M, McLennan, K, McWade, P, Morgan, G, Welch, C and Nicholson, M (2015) 'Providing positive behavioural support services: specialist challenging behaviour support teams', *International Journal of Positive Behavioural Support*, 5, 1–15.

Toogood, S, Totsika, V, Jones, E and Lowe, K (2016) 'Active Support'. In N Singh (ed.) *Handbook of Evidence-Based Practices in intellectual and Developmental Disabilities*, 537–560.

Totsika, V, Toogood, S and Hastings, R P (2008) 'Active Support: Development, evidence base, and future directions'. In L M Glidden (ed.) *International Review of Research in Mental Retardation*, 35, 205–250.

Totsika, V, Toogood, S, Hastings, R P and McCarthy, J (2010) 'The effect of active support interactive training on the daily lives of adults with an intellectual disability', *Journal of Applied Research in Intellectual Disabilities*, 23, 112–121.

Transforming Care and Commissioning Steering Group (2014) *Winterbourne View – Time for a Change: Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism* (Chairman S. Bubb). Available at: http://bit.ly/2NjanyJ (accessed 5 November 2019).

Triggle, N (2019) *Whorlton Hall: Hospital abused 'vulnerable' adults*. BBC News online, 22 May. Available at: https://www.bbc.co.uk/news/health-48367071 (accessed 5 November 2019).

Tsiouris, J A (2010) 'Pharmacotherapy for aggressive behaviours in persons with intellectual disabilities: treatment or mistreatment?', *Journal of Intellectual Disabilities Research*, 54, 1–16.

United Response (2018) *Practice Leadership*. Available at: http://bit.ly/2Cdk63c (accessed 5 November 2019).

Wilner, P (2014) 'The neurobiology of aggression: implications for the pharmacotherapy of aggressive CB by people with ID', *Journal of Intellectual Disability Research*, 59, 82–92.