Positive behavioural support for adults with intellectual disabilities and behaviours that challenge

by Valentina lemmi and Martin Knapp

Positive behavioural support (PBS) may be a potentially interesting service for adults with intellectual disabilities and behaviours that challenge, improving outcomes and lowering the cost of care in the longer term. This is the main finding of our initial look at the economic case in collaboration with a small local authority in England, with funding from the National Institute for Health Research School for Social Care Research (NIHR SSCR).

Why PBS for people with intellectual disabilities and behaviours that challenge?

In 2011, a Panorama documentary exposed staff abuse of people with intellectual disabilities at Winterbourne View. The political commitment was immediate, pledging to support people with intellectual disabilities within the community, and reserving residential care for only the most severe cases. The challenge of discharging people with intellectual disabilities and supporting them in the community followed. Among available interventions, PBS has been recognised as a potentially effective approach.



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PBS in a small local authority in England

PBS is a person-centred service aiming to support people with intellectual disabilities and behaviour that challenges to live in the community and to provide additional support to the carers and professionals working with them. The service offers different types of support depending on the severity of need at the point of referral: early intervention for high-risk groups; crisis prevention and management, technical support for the most complex cases; and placement development. First piloted in 2010, the service is provided in a small local authority in England by a team of

behaviour analysts, assistant behaviour analysts, and support workers. Further details on the service can be found in the recent NICE guideline.

What is the impact of PBS?

The small evaluation we carried out involved five adults with intellectual disabilities and behaviour that challenges referred to the PBS service between 2010 and 2013. The evaluation focused on services provided to the most complex cases, adults at risk of harm or placement breakdown and in need of assessment, intensive multi-level intervention, and maintenance. Data were collected before and after the provision of PBS, and included frequency and severity of behaviours that challenge, activity engagement, and community participation.

Results showed that all outcomes generally improved after provision of the PBS service. Yet the absence of a control group means we cannot be sure that improvement was a result of the PBS service only and the small sample asks for caution.

At what cost?

Our small evaluation was followed by an analysis of service use and costs. Data on service use were collected retrospectively over the first six months of PBS for three of the five adults. The economic analysis adopted a public service perspective, including health and social care services and criminal justice services. The total cost of services was estimated at £2,296 per week.

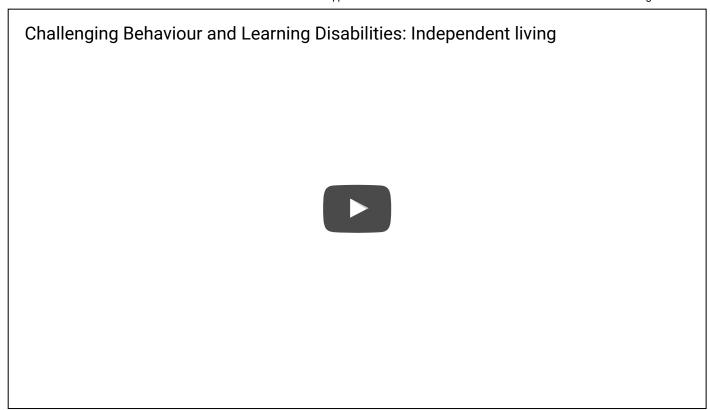
Due to the lack of a control group, we conducted a Delphi exercise to estimate the costs of current support packages in England, both in the community (£9 to £164 per week) and residential accommodation (£1,213 to £3,696 per week). All five adults initially at risk of harm or placement breakdown evaluated in this small study remained living in their original setting, four in the community and one in a nursing home, avoiding more expensive packages of care. By maintaining individuals with less severe needs in the community and those with more severe needs in less service-intensive residential care, PBS may potentially reduce public services cost in the longer term.

Time to provide!

Policy-makers are recognising the need to transform care for people with intellectual disabilities and behaviour that challenges, emphasising a shift toward provision within the community. Effective interventions are available.

Our small study suggests that PBS may improve the lives of adults with intellectual disabilities and behaviours that challenge, and potentially reduce public service costs in the longer term.

People with intellectual disabilities and behaviours that challenge can live within their local communities; providing the right support is paramount.



Further information

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NICE (2015) Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities Whose Behaviour Challenges (NICE Guideline 11), National Institute for Health and Care Excellence, London.

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

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