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# Positive behavioural support for adults with intellectual disabilities and behaviour that challenges: an initial exploration of the economic case

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## Abstract

**Background:** Since the closure of long-stay hospitals, positive behavioural support and person centred approaches have been recognised and encouraged to support people with intellectual disabilities in the community.

**Method and materials:** A small before-after study was conducted to explore the economic case for a positive behavioural support service for five adults with intellectual disabilities and behaviour that challenges in a small local authority in England. Evidence from a Delphi exercise was used as comparator.

**Results:** The service was effective in improving the outcomes (behaviours that challenge, activity engagement, community participation) at a total cost of services of £2,296 per week. By maintaining persons with less severe challenges in the community (£9 to £164 per week) and those with more severe behavioural needs in less service-intensive residential accommodations (£1,213 to £3,696 per week), the service may potentially reduce public services cost in the long term.

**Conclusions:** The positive behavioural support service may have the potential to improve outcomes and lower cost of care in the long term.

**Keywords:** Intellectual disabilities, behaviours that challenge, positive behavioural support, community, adults, economic evaluation

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## Introduction

Following the closure of long-stay hospitals since the 1980s (DH, 2012a, b), people with intellectual disabilities in England have increasingly been supported within the community. Positive behavioural support has been recognised as a potentially effective approach for supporting people with intellectual disabilities and behaviour that challenges (British Psychological Society, 2004; LGA and NHS England, 2014; Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

While the use of residential-based services has decreased, the lack of community-based alternatives in some localities may lead to high and perhaps avoidable expenditure. In England, it is estimated that 908,000 adults aged over 18 have intellectual disabilities (Emerson et al, 2013). Ten per cent of people with intellectual disabilities are exhibiting behaviours that challenge, at different types and levels of severity (Lowe et al, 2007). Overall, 40,270 adults with intellectual disabilities receive residential-based care, but practice

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varies widely across local authorities (Emerson et al, 2013). The annual cost of residential placement has been estimated to be as high as £185,127 for some placements, with a broad variation in cost explained by the variation in needs and circumstances of individuals (McGill and Poynter, 2012).

While the evidence on positive behavioural support is growing (Allen et al, 2013; Denne et al, 2013; Gore et al, 2013), evidence on cost-effectiveness remains scarce.

This small study aims to explore the clinical and economic case for a Positive Behavioural Support Service (PBSS) for adults with intellectual disabilities and behaviour that challenges in Halton, a small local authority in England.

**Method**

A small before-after study assessing the impact of PBSS on outcomes was followed by an evaluation of service use and costs. This was further informed by findings on the costs of different packages of care obtained from a Delphi exercise that asked participants about support that would be received by two adults with intellectual disabilities and behaviour that challenges described in vignettes, and then estimated the costs of those support packages.

**Participants**

Five adults with intellectual disabilities and behaviour that challenges referred to the PBSS in a small local authority in England between 2010 and 2013 were included in the study.

**Intervention**

PBSS is a flexible service that aims to maintain people with intellectual disabilities and behaviour that challenges in the community and to increase the ability to cope of carers and professionals working with them. First piloted in 2010, this local service is jointly funded and provided by three local authorities and the NHS clinical commissioning groups through a management team (operational director, clinical supervisor, and principal manager), and an operational team (behaviour analysts, assistant behaviour analysts, and support workers). The service supports children and adolescents (3–17 years old) and adults (18 years old and over), in four areas of practice: early intervention for high-risk groups (eg training workshops for carers and professionals working with people with intellectual

disabilities and behaviour that challenges), crisis prevention and management (eg early identification of behaviours that may lead to placement breakdowns), technical support for the most complex cases (eg intensive behavioural intervention), placement development (eg returning people in out-of-area placements to their ‘home’ borough).

As described in the companion paper by Toogood et al, in this volume, the service offers a variety of types of support depending on the severity of presenting need at referral. This study focused on adults and on services provided to individuals with the most severe level of need (ie those posing a meaningful risk of harm or placement breakdown and in need of assessment, intensive multi-level intervention, and maintenance).

**Measures**

*Behaviours that challenge*

‘Challenging behaviour’ has been defined as behaviour ‘of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion’ (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007, p 14). For this study, behaviours that challenge were determined by two dimensions: frequency and severity. Definitions of frequency and severity were finalised through discussions between authors and external experts. Each dimension was assessed as occurring on one of three levels: low, medium, and high. The complete definitions are provided in *Tables 1 and 2*.

**Table 1:** Behaviours that challenge: frequency

<b>High</b>	Behaviour(s) that challenge(s) occur(s) every 1–2 days.
<b>Medium</b>	Behaviour(s) that challenge(s) occur(s) more than every 2 days but less than a week.
<b>Low</b>	Behaviour(s) that challenge(s) occur(s) weekly or less.

**Table 2:** Behaviours that challenge: severity

<b>High</b>	At least four of the following criteria: at least moderate injury (eg bruising, broken skin) to self or others; at least moderate damage to environment (eg items broken/require repair); continuous risk of placement breakdown in the absence of external support; regular informal physical intervention (eg redirected to a safe physical environment) typically used in response to behaviours; full formal regular physical restraint typically used in response to behaviours; 'pro re nata' medication at least weekly.
<b>Medium</b>	At least four of the following criteria: at least minor (non-temporary) injury (eg minor bruising, broken skin) to self or others; minor damage to environment (eg items broken/require minor repair); intermittent risk of placement breakdown in the absence of external support; occasional informal physical intervention (as above) used in response to behaviours; full formal occasional physical restraint used in response to behaviours; 'pro re nata' medication at least twice a month used in response to behaviours. This may include some variability in intensity or impact from time to time (low to high) but does not meet criteria for high or low.
<b>Low</b>	At least four of the following criteria: no/minor temporary injury (redness of skin) to self or others; mild damage to property that does not require repair or replacement; no/low risk of placement breakdown in the absence of external support; no/rare isolated use of informal physical intervention (as above) used in response to behaviours; no/rare isolated use of full formal physical intervention used in response to behaviours; no regular use of 'pro re nata' medication (some rare isolated use) used in response to behaviours.

**Activity engagement**

Mansell and Beadle-Brown (2012, p40) defined engagement in meaningful activity in three ways: '(1) doing something constructive with materials (such as washing the dishes, cutting the grass, putting items in the trolley in the supermarket); (2) interacting with people (talking with people, listening to other people talking or attending while they show something); or (3) joining in group activities such as watching the ball and running after it in football'. Similarly to the definition of behaviours that challenge, the definition of activity engagement was finalised through discussions between authors and external experts, and a system of rating was agreed to classify activity engagement levels as low, medium, or high. Complete definitions are provided in *Table 3*.

**Community participation**

In the context of the present study community participation described the extent to which persons were present and engaged in meaningful activities outside their accommodation. For example, going to local shops and leisure centres would have provided opportunities for meaningful activity outside a person's house, whereas going to the city in a car without getting out would not. The definition of community participation was also finalised through discussions between

**Table 3:** Activity engagement

<b>High</b>	Frequency of meaningful activity engagement is high (above 60% of the day) and activities vary in type (eg leisure, personal care, social activity, education and learning, hobbies, interests) and time (eg day of the week).
<b>Medium</b>	Frequency of meaningful activity engagement is medium (25%–59% of the day) and activities sometimes vary in type (eg leisure, personal care, social activity, education and learning, hobbies, interests) and time (eg same activities every day but there is opportunity for novel activity at least once per day).
<b>Low</b>	Frequency of meaningful activity engagement is low (below 25% of the day) and activities do not vary in type (eg leisure, personal care, social activity, education and learning, hobbies, interests) and time (eg same activities every day).

**Table 4:** Community participation

<b>High</b>	Frequency of activities with community participation is high (above 30% of all activities) and activities with community participation vary in type (eg several different activities), location (eg several different locations) and time (eg several days a week).
<b>Medium</b>	Frequency of activities with community participation is medium (10%–30% of all activities) and activities with community participation sometimes vary in type (eg more than 2 different activities), location (eg more than 2 different locations) and time (eg more than once a week).
<b>Low</b>	Frequency of activities with community participation is low (less than 10% of all activities) and activities with community participation do not vary in type (eg same activity), location (eg in a day centre) and time (eg only once a week).

authors and external experts, and a system of rating was devised to classify community participation as low, medium, or high. Complete definitions are provided in *Table 4*.

#### *Client Service Receipt Inventory*

The Client Service Receipt Inventory (CSRI) (Beecham and Knapp, 2001) was adapted for adults with intellectual disabilities and behaviour that challenges and used to assess service use. The following data were collected: age, gender, ethnicity, marital status, educational level, living status, employment status, clinical characteristics, and use of health, social care, and criminal justice services. Health and social care services included in this questionnaire residential care, inpatient services, accident and emergency, outpatient services, psychiatrist, psychologist, nurse, occupational worker, social worker, care worker, day care centre, and other services paid through direct payments.

Data on behaviours that challenge, activity engagement, and community participation were collected by a clinician in the PBSS (MS), while data on service use for the CSRI were collected by two PBSS clinicians (MS, KML). Data on behaviours that challenge, activity engagement and community participation were collected before and after the PBSS from clinical files. Data on service use were collected using the CSRI retrospectively over the first six months of PBSS involvement and retrieved from routinely collected administrative data using the software CareFirst6 and clinical files.

#### **Costs**

The cost of the intervention was estimated to be £14,625 per adult for the length of the intervention (15 months). This figure was calculated by costing a representative high intensity case. The figure included staff costs (behaviour analyst, assistant behaviour analyst, support worker), overheads (IT, telephone, photocopy, training, human resources costs, accommodation costs, meetings, analysis and report formulation), travel costs, and clinical supervision.

Unit costs for health and social care services were taken from Curtis (2013), and NHS reference costs (DH, 2013) (*Table 5*). Costs are at 2012–13 price levels, and inflated if necessary using the Hospital and Community Health Services Pay and Prices Index (Curtis, 2013).

#### **Statistical analysis**

Socio-demographic and clinical characteristics were presented. Behaviours that challenge, activity engagement, and community participation were described before and after the PBSS intervention. Due to the difficulty in accessing information, data were only available for five individuals.

#### **Costs of alternative support**

In the absence of data on a local comparison group we used information coming from a Delphi exercise that asked a group of experts to describe what support would be provided to individuals described in two 'case vignettes' in their own localities. The two 'case vignettes' were provided by a PBSS clinician (MS) and were drawn from her clinical practice, with names and small details changed to preserve anonymity. The vignettes described the clinical characteristics of two individuals with severe level of need before referral to the PBSS, with no reference to the support received.

**Table 5:** Unit costs (£, 2012–13)

	<b>£ (2012–13)</b>	<b>Source</b>
<b>Health and Social Care</b>		
Inpatient service (Psychiatric ward)	£342 per day	Curtis 2013
Accident and emergency	£115 per contact	DH 2013
Outpatient service	£135 per contact	Curtis 2013
Psychiatrist	£261 per contact	Curtis 2013
Nurse	£50 per hour	Curtis 2013
Occupational therapist	£41 per hour	Curtis 2013
Social worker	£159 per hour	Curtis 2013
Care worker	£24 per hour	Curtis 2013
Other services (paid through direct payments)	£64 per contact	CSRI
Day care centre	£57 per day	Curtis 2013
Residential homes	£1,411 per week	Curtis 2013
Supported housing	£915 per week	Curtis 2013

We took the weighted cost of the support arrangements reported by the Delphi participants (the proportion of times that each support package was chosen multiplied by its cost) (Iemmi et al, 2015a).

**Cost elements**

The economic analysis adopted a public service perspective, including health and social care services and criminal justice services. Total cost was presented by group (residential care, inpatient care, outpatient care, community-based care and day care). Total cost of services per week and per year, including PBSS, were estimated. Annual total cost of services was calculated for an individual benefitting from PBSS for an average length of time and having a constant use of health, social care and criminal justice services. Weekly costs were compared with the cost of different packages of care estimated through the Delphi exercise (Iemmi et al, 2015a). Analyses were performed in STATA 13 and MS Excel 2010.

**Ethical approval**

Ethical approval was obtained for the overarching study from the Social Care Research Ethics Committee (12/IEC08/0026).

**Results**

**Participants**

Five adult white males with mean age 34 (SD=10, range=18–43) were included in the evaluation. Their highest education level was primary education or lower. None was earning a salary, three were unable to work and receiving benefits, and one was in an employment service with possibility to move to paid work in the future. All five were single. One lived alone, two with parents, one in supported housing, and one in a nursing home. Three were diagnosed with intellectual disability and one or more conditions, one with intellectual disability and autism, and one with intellectual disability and cerebral palsy. Two adults presented with only one, two

with two, and one with three behaviours that challenge. The mean length of the PBSS was 12 months (SD=4, range 7–18).

**Outcomes**

Behaviours that challenge, activity engagement, and community participation levels before and after PBSS involvement are summarised in *Table 6*: all four outcomes generally improved after PBSS. At the individual level, outcomes on all four measures either improved or remained unchanged while none worsened, suggesting PBSS involvement had been beneficial.

**Table 6:** Behaviours that challenge, activity engagement, and community participation before and after PBSS (N=5)

	Before PBSS	After PBSS
<b>Behaviours that challenge (frequency)</b>		
Low	1	3
Medium	1	2
High	3	0
<b>Behaviours that challenge (severity)</b>		
Low	2	5
Medium	1	0
High	2	0
<b>Activity engagement</b>		
Low	3	0
Medium	2	4
High	0	1
<b>Community participation</b>		
Low	2	0
Medium	3	3
High	0	2
N	5	5

Notes: PBSS = Positive Behaviour Support Service.

**Service use**

*Table 7* summarises service use by the three adults over the first six months of the PBSS involvement. Data were not available for two adults because we were not able to gain access to their full case records

Two adults lived in the community and one in supported housing over the entire six months. One of them used respite care for 35.5 days.

None of them used inpatient and outpatient services.

All three adults were supported by the allocated social worker and had regular visits with a nurse. Two adults had two visits with a psychiatrist. One adult received the support of a care worker 24 hours per day over the six months while another individual attended day care all day three times a week. Two adults received other services paid through direct payments three times a week. None of them had consultations with a psychologist.

None of the individuals had contact with the criminal justice services.

**Service cost**

*Table 7* reports the weekly cost of services for the three adults over the first six months that they received additional support from PBSS.

Total cost of health and social care services was £2,071 per week: 78 per cent (£1,618) was for community-based care, mainly care worker support (£1,344), followed by other services paid through direct payments (£128), social worker (£125), psychiatrist (£13) and nurse (£7). Nineteen per cent (£397) of the total cost was accounted for by residential care, with three-quarters (£305) for supported housing and a quarter (£92) for respite care. The remaining 3 per cent (£57) was for day care services. There were no inpatient and outpatient costs for these individuals.

After inclusion of the PBSS cost, total cost was £2,296 per week. Assuming constant use of services over one year and an average duration of PBSS, annual cost would be £119,408.

During the Delphi exercise the different packages of care were identified and their weekly cost estimated to vary widely, from £9 to £164 for support received within the community (without any support, with social care,

**Table 7:** Service use and cost for adults over the first 6 months of PBSS (N=3)

	<b>No. using</b>	<b>Number of contacts Mean (SD)</b>	<b>Length of contact in hours Mean (SD)</b>	<b>Weekly cost (£, 2012–13) Mean (SD)</b>
<b>Health and Social Care</b>				
<b>Residential care</b>				
Supported housing (days)	1	182 (.)	.	305 (528.3)
Residential home (days)	0	.	.	0 (.)
Other than residential home (days)	1	35.5 (.)	.	91.7 (158.9)
TOTAL Residential care				396.7 (469.4)
<b>Inpatient care</b>				
Inpatient service (Psychiatric ward) (days)	0	.	.	0 (.)
TOTAL Inpatient care				0 (.)
<b>Outpatient care</b>				
Accident and emergency	0	.	.	0 (.)
Outpatient service	0	.	.	0 (.)
TOTAL Outpatient care				0 (.)
<b>Community-based care</b>				
Psychiatrist	2	2 (0)	0.9 (0.2)	13.4 (11.6)
Psychologist	0	.	.	0 (.)
Nurse	3	5 (2.6)	0.8 (0.1)	7.4 (3.9)
Occupational therapist	0	.	.	0 (.)
Social worker	3	48.3 (17.2)	0.4 (0)	124.9 (53.9)
Care worker	1	182 (.)	24 (.)	1344.0 (2327.9)
Other services (paid through direct payments)	2	78 (0)	.	128.0 (110.8)
TOTAL Community-based care				1617.6 (2193.5)
<b>Day care</b>				
Day care centre	1	78 (.)	6 (.)	57.0 (98.7)
TOTAL Day care				57.0 (98.7)
TOTAL Health and Social Care				2071.3 (2597.6)
<b>Criminal Justice</b>				
Contacts with criminal justice	0	.	.	0 (.)
TOTAL Criminal Justice				0 (.)
TOTAL Health and Social Care and Criminal Justice				2071.3 (2597.6)
<b>PBSS</b>				
TOTAL Health and Social Care and Criminal Justice with PBSS				225
				2296.3 (2597.6)

Note: PBSS = Positive Behavioural Support Service.



with social and mental health care, or in supported accommodation), to £1,213 to £3,696 for residential-based care (residential placement, psychiatric hospital, and secure unit). When asked about the care likely to be received by the two adults with intellectual disabilities and behaviour that challenges described in the vignettes, more than a half of the participants in the Delphi exercise indicated that they were likely to be supported in residential-based care (Iemmi et al, 2015a). After weighting the cost of different packages of care by the probabilities (from the answers provided by Delphi participants), the estimated weekly cost was £1,567 for one vignette and £1,823 for the other, equivalent to annual costs of £81,478 and £94,799, respectively.

## Discussion

For this small sample of individuals, the PBSS was effective in both decreasing the frequency and severity of behaviours that challenge, and increasing the level of activity engagement and community participation of adults with intellectual disabilities and severe levels of behaviour that challenges. These improvements were associated with a total cost of services for adults in receipt of additional support from PBSS of £2,296 per week (or £119,408 per year).

Two of the three adults were living in the community and one in supported housing. Each was supported by a social worker and a nurse, and two had regular visits with a psychiatrist. Two adults received other services paid through direct payments. One received respite care. None used inpatient and outpatient services. Services used corresponded to individuals' needs and circumstances, as illustrated by the daily support of a care worker for one adult and the use of a day care centre by another one.

All costs were for health and social care services and none for criminal justice services. Three-quarters of the costs were for community-based care, but the figure was largely driven by the support of a care worker for one individual 24 hours per day over the six months, followed by other services paid through direct payments, and social workers. One fifth of the total cost was for residential care, mainly respite care received by one adult. The heterogeneity of the population, in both needs and circumstances, and the small sample size may explain the variation in costs.

The results suggest that during the length of the PBSS – about a year – the cost of supporting adults would be comparable to the cost of residential-based care. However, after receiving support from PBSS all five adults evaluated in this small study remained living in their original setting, four in the community and one in the nursing home, avoiding more costly packages of care. This suggests that adults already living within the community would be likely to remain in the community at a lower cost and adults living in residential accommodation would be likely to reintegrate into the community or to avoid more costly forms of residential-based care.

PBSS may be successful in helping to maintain persons with less severe levels of behaviour that challenges within the community, and persons with more severe levels in less service-intensive residential accommodation, and in doing so, potentially decreasing public service cost in the long term. Residential-based care has been estimated to represent 85 per cent of the total costs of supporting adults with learning disabilities and behaviour that challenges (Knapp et al, 2005), so that avoiding residential placements would potentially reduce them.

Positive behavioural support for children and adolescents with intellectual disabilities and behaviour that challenges was also found to improve outcomes at similar cost. Other small studies evaluated the weekly cost of supporting children and adolescents living within the community with positive behaviour support delivered at home at £1,454 for individuals with low-level needs and £1,402 for individuals with high-level needs (Iemmi et al, 2015b), and with positive behavioural support delivered at schools at £1,909 (Iemmi et al, 2015c). The findings suggest an increase in the cost of supporting people with learning disabilities and behaviour that challenges with positive behaviour support in adulthood.

## Strengths and limitations

To our knowledge, this small study is the first to look at the economic implications of positive behaviour support for adults with intellectual disabilities and behaviour that challenges in England.

The study has some limitations. First, while PBSS has four levels of response according to referral complexity, this small study focused on the most severe clinical contexts only, which is the most service-intensive level of response. Second, the small sample limits the

generalisability of the findings. Third, the difference in sample sizes between outcomes and service use may have introduced selection bias due to the differences in the characteristics of the two samples. Fourth, the definitions of different outcome levels may reflect the views of the authors and external experts who designed them. In particular, the absence of validity and reliability of information for data on behaviours that challenge, activity engagement and community participation, may have led to potential bias. Fifth, the lack of follow-up data on service use did not allow us to catch a possible change in services use and costs after PBSS. Sixth, the lack of data on unpaid care may have led to underestimation of the total costs. A recent London study by Barron et al (2013) found that three-fifths of the total societal cost of supporting young people with intellectual disabilities and behaviour that challenges was due to unpaid care. Finally, the absence of a directly observed comparison group did not allow us to attribute the results to the PBSS only. Searches of comparable data in similar localities and in the literature were unsuccessful, and so the Delphi exercise was performed with experts in the field, and used to identify the most likely packages of care.

### Implications for practice and for research

The Winterbourne View report marked the political commitment in England to support people with intellectual disabilities within the community, reserving residential care for respite for only the most severe cases (DH, 2012a, b; DH, 2013). While the value of person centred approaches and positive behaviour support has been recognised and encouraged (DH, 2014; LGA and NHS England, 2014), social and organisational challenges (Allen et al, 2013; Denne et al, 2013) and the scarcity of evidence on impact may have undermined their implementation. This small study suggests that PBSS may be a potentially interesting service, improving outcomes and lowering the cost of care in the long term.

While these preliminary results from a small exercise are promising, more robust evidence is required, with stronger study design, a larger sample, and including evaluation of impacts on carers.

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### Conflict of interest

None to declare.

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