Personalised approaches to learning disabilities and behaviour that challenges: new economic evidence

Valentina Iemmi & Martin Knapp

Personal Social Services Research Unit
London School of Economics & Political Science
Disclaimer

The preparation of this presentation was made possible by a grant from the National Institute for Health Research (NIHR) School for Social Care Research.

The views expressed in this presentation are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR.

Findings are in preparation; please don’t quote yet
1. Context
2. The intervention group(s) - 3 studies
3. The comparison group - 1 study
4. Results
5. Conclusions
1. Context
People with learning disabilities and behaviour that challenges in England

Learning disabilities:
1.14 million people with LD
(236,000 children; 908,000 adults)

Challenging behaviours:
CB - such as aggression and self-injury - are presented in 10-15% of people with LD, with prevalence peaking for 20-49-year olds

Emerson et al. 2013a, b
What services are provided?

Since the Winterbourne View report: shift of focus of care from residential-based to community-based models

Person-centred approaches and **positive behaviour support** have been recommended to support people with LD living within the community.
With what cost implications?

Opportunity to **reduce expenditure** on high-cost residential settings:
> £178,000 for children
> £185,000 for adults

...but future costs may increase (e.g. additional staff training and supervision)

McGill 2008; McGill & Poynter 2012
Positive Behaviour Support

**Person-centred** flexible model of care aiming to maintain people with LD and behaviour that challenges *in the community* (or in less-service intensive residential accommodation) and to increase carers’ ability to cope

- Assessment
- Intensive therapy
- Maintenance/closing case
- *(Short breaks)*
Our research question

Is there an economic case for PBS to meet the needs and respond to the preferences of people with LD and behaviour that challenges?
2. The intervention group(s)
What we did

3 small economic analyses

- **Ealing**
  - PBS for children (c. 14 months)

- **Bristol**
  - PBS for children (c. 22 months)

- **Halton**
  - PBS for adults (c. 12 months)

**Methods:**

1. **Outcomes** evaluation before-after PBS
2. **Cost** of the intervention (case studies, budget)
3. **Service use** during PBS (HSC, Educ, CJS)
4. **Service cost** during PBS (HSC, Educ, CJS)

*at risk of imminent residential placement*
<table>
<thead>
<tr>
<th>Location</th>
<th>Outcomes</th>
<th>PBS cost</th>
<th>Service cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ealing (N=10)</td>
<td>• Level of CB (+)</td>
<td>£200</td>
<td>£1,500 (HSC, Educ)</td>
</tr>
<tr>
<td></td>
<td>• Carer ability to cope (+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[Reid et al. (2013)]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bristol (N=12)</td>
<td>• Number of CB (+)</td>
<td>£700</td>
<td>£2,000 (HSC, Educ)</td>
</tr>
<tr>
<td></td>
<td>• Social and communication skills (+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Halton (N=5*)</td>
<td>• Frequency of CB (+)</td>
<td>£250</td>
<td>£2,300 (HSC, CJS)</td>
</tr>
<tr>
<td></td>
<td>• Severity of CB (+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Activity engagement (+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Community participation (+)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(£/week, 2012-13) *Only 3 people were included in the evaluation of service costs.

Iemmi et al 2015a, b, c
What to compare with

- No comparison group in the **localities evaluated**
- No comparison group in **similar localities**
- No comparison group in the **literature**

?
3. The comparison group
Our comparison group

Delphi exercise

Our research question:
What is standard care for people with LD and behaviour that challenges in England and what does it cost?

Methods:

Round 1 (N=30)
Focus group + paper questionnaire

• Different packages of care
• Their cost

Round 2 (N=118)
online questionnaire

• Likely support for the 6 vignettes (4 children, 2 adults)
• Their weighted* cost

*Iemmi et al 2015d* Cost of package of care * probability of use package of care*
Round 1: What packages of care...

**Residential-based settings:**
- secure unit
- psychiatric hospital
- 52-week residential (school) placement
- 38-week residential (school) placement

**Community-based settings:**
- supported accommodation
- at home with community-based social and mental health care and PBS
- at home with community-based social and mental health care
- at home with community-based social care
- at home without any support
...and their cost

<table>
<thead>
<tr>
<th></th>
<th>Residential-based settings</th>
<th>Community-based settings*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children</strong></td>
<td>c. £2,000-9,000</td>
<td>&lt;£200</td>
</tr>
<tr>
<td><strong>Adults</strong></td>
<td>c. £1,200-3,700</td>
<td>&lt;£200</td>
</tr>
</tbody>
</table>

(£/week, 2012-13)

*Excluding PBS
Round 2: What are the likely packages of care across vignettes and their cost

<table>
<thead>
<tr>
<th></th>
<th>Likely packages of care (residential care)</th>
<th>Estimated cost (£/week, 2012-13)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children</strong></td>
<td>Up to 40%</td>
<td>&lt;£1,500</td>
</tr>
<tr>
<td><strong>Adults</strong></td>
<td>Up to 66%</td>
<td>&lt;£2,000</td>
</tr>
</tbody>
</table>
4. Results
# PBS vs Comparison group

<table>
<thead>
<tr>
<th></th>
<th>Residential-based settings</th>
<th>Standard care</th>
<th>Community-based setting with PBS</th>
<th>Community-based settings*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children</strong></td>
<td>c. £2,000-9,000</td>
<td>&lt;£1,500&lt;£2,000 (14m)&lt;£2,300 (12m)</td>
<td>&lt;£1,500 (14m)&lt;£2,000 (22m)</td>
<td>&lt;£200</td>
</tr>
<tr>
<td><strong>Adults</strong></td>
<td>c. £1,200-3,700</td>
<td>&lt;£2,000 &lt;£200</td>
<td>&lt;£2,300 (12m)</td>
<td>&lt;£200</td>
</tr>
</tbody>
</table>

(£/week, 2012-13)

*Excluding PBS
Results: children

Outcomes
• Better clinical outcomes
• At the end of PBS, all children were living in the community, except 2 transferred to specialist residential schools

Costs
• Cost of services during PBS: <£2,000
• Cost of services for ‘standard care’: <£1,500
• After an increase in cost during the PBS support period (14-22 months), avoiding residential school placements (c. £2,000-£9,000) may potentially decrease the cost of care over the long term.
Results: adults

Outcomes
• Better clinical outcomes
• At the end of PBS, all adults remained living in their original settings, four in the community and one in a nursing home.

Costs
• Cost of services during PBS: <£2,300
• Cost of services for ‘standard care’: <£2,000
• After an increase in cost during the PBS support period (12 months), avoiding residential placements or transfer to more expensive residential care (c. £1,200-£3,700) may potentially decrease the cost of care over the long term.
5. Conclusions
What to take home

The three studies suggested that PBS may be a potentially valuable service, *improving outcomes* and *lowering the cost* of care in the long term.
Thank you
m.knapp@lse.ac.uk
v.iemmi@lse.ac.uk