Outcomes and costs of skilled support for people with severe or profound intellectual disability and complex needs

Beckie Whelton, Julie Beadle-Brown, Lisa Richardson, Jennifer Leigh, Jennifer Beecham, Theresa Baumker

Funded by NIHR School For Social Care Research, UK

Background

Following the closure of long stay hospitals and institutions, people with intellectual disabilities and complex needs are now supported in community settings. In recent years there has been a focus in social care towards providing personalised support for all, including those with the most complex needs. It has been found that person-centred support results in better outcomes. In order to provide person-centred support, staff need to be skilled in supporting people to make the most of the opportunities available, recognizing the difficulties that people have in achieving a good quality of life and providing the right level of help to compensate for people’s disabilities.

The project aims

To explore
• If skilled staff support associated with higher quality of life for people with complex needs
• Which domains of quality of life, if any, are influenced by skilled support
• Does providing skilled support, and the resulting better outcomes, cost more money
• How do aspects of organisation and management relate to the provision of skilled support
• To consider implications, for service organisation and management, of providing skilled support

Participants

• 35 services providing residential or supported living arrangements for people with severe or profound ID AND Physical disabilities OR Autism OR challenging behaviour.
• 25 services were nominated by their organisations as providing good support, and 10 services chosen randomly from lists of registered organisations as providing good support, and 10 services chosen randomly from lists of registered services.
• Services ranged from 1 to 8 places, with 33% for one person. The homes were generally very homelike (Mean 1.56 out of 5, range 1 – 2.8; NB 1 = very homelike).
• Data on quality of life and quality of service was collected for 110 people.

Summary of whole sample participants:

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>46 years (range 20–82)</td>
</tr>
<tr>
<td>Adaptive Behaviour (ABS)</td>
<td>113 (27 – 248)</td>
</tr>
<tr>
<td>% ABS &lt; 151 (severe ID)</td>
<td>73%</td>
</tr>
<tr>
<td>Challenging behaviour (ABC)</td>
<td>41 (0 – 37)</td>
</tr>
<tr>
<td>% male</td>
<td>51.5%</td>
</tr>
<tr>
<td>% white British</td>
<td>83%</td>
</tr>
<tr>
<td>% physical disability</td>
<td>53%</td>
</tr>
<tr>
<td>% autism</td>
<td>42%</td>
</tr>
<tr>
<td>% social impairment</td>
<td>78%</td>
</tr>
<tr>
<td>% non-verbal</td>
<td>60%</td>
</tr>
<tr>
<td>Incontinent</td>
<td>35%/25%</td>
</tr>
<tr>
<td>Required hoisting or manual handling for personal care</td>
<td>35%</td>
</tr>
</tbody>
</table>

Methods

The study utilised a mixed methods approach. •questionnaires collecting information on 1) the service users’ needs and abilities, participation and involvement and other services used, 2) staffing and costs of running the service and 3) staff characteristics, knowledge and experience. •2 hour structured observation of engagement in activity (EMACR) and quality of staff support (Active Support Measure)
•Interview with the manager
•Review of the records and plans
Observers then rated the support observed in terms of active support, total communication, positive behaviour support and the SPELL framework

Results

•Being a nominated services did not always predict skilled support. Good active support was the best predictor of outcomes. Good implementation of active support was only found in 38% of nominated services and 12% of CQC services.
•All services that provided good Active support, were also good at providing appropriate communication, demonstrating autism friendly practises and providing good PBS where this was needed.
•Across the a smaller sample controlling for level of ability, only one third received consistently good active (with a score of higher than 66%). Those that did had better outcomes in terms of participation in daily life, contact with friends, interacting with people in the community. They were better supported to make a range of choices, and their communication was effective in gaining attention and a response from staff.
•Although care packages were slightly more expensive in the skilled support group the difference was not statistically significant, despite more of these people living in supported living and individualised settings.
•Staff were found to be used more effectively in the skilled support group. Only 4 minutes per hour less observed contact time than funded support time – compared to 25 minutes less in the less skilled group.

Conclusions

Despite the current focus on person centred approaches, it appears that services find it difficult to implement these approaches to improve outcomes for the people they support especially for those with complex needs.

Implications
• Providing skilled support was statistically no more expensive than unskilled but the benefits for quality of life are immense and results in better outcomes.
• Commissioners need a better understanding of how support is provided within the services they commission in order to obtain better outcomes for individuals and consequently get value for money.
• There is a lot of focus on policy for person centred practices, but little guidance on how to put this into action. It has been shown that Active support is key in providing skilled support, but the use of this approach is not widespread.
• Government policy needs to specify the approaches needed (for example active support, SPELL, PBS, Alternative communication) that need to be used in order to provide skilled support.
• In order to get a true measure of the level of support being provided, inspectors need to observe what is really happening in services.
• The inspectors need to know what good support looks like, and what can be achieved if people are given the right support and the right opportunities.

For more information contact: j.d.beadle-brown@kent.ac.uk