

Quality of life and quality of support for people with severe Intellectual disabilities and Autism.

Introduction and Methods

To **main aims** of the wider study (Beadle-Brown et al, in preparation), were to explore:

- Whether skilled staff support is associated with higher quality of life for people with complex needs
- Which domains of quality of life, if any, are influenced by skilled support
- Whether providing skilled support, and the resulting better outcomes, costs more money
- How aspects of organisation and management relate to the provision of skilled support
- The possible implications, for service organisation and management, of providing skilled support

This poster explores the **quality of support** (QoS) and **quality of life** (QoL) provided by accommodation services supporting people with severe intellectual disabilities (ID) and **autism**.

The **mixed methods** approach included:

- A questionnaire on service users' needs and abilities, participation and involvement and other services used
- 2 hour structured observation of engagement in activity (EMAC-r) 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 person-centred approaches: Active Support, Total communication, Positive Behaviour Support and the NAS SPELL framework (for good autism practices).

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 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**.
- Nominated services did not always provide skilled support in terms of active support – **38% of people supported by nominated services received good active support**; only 12% of those from registered lists.
- Active support was found to be the best indicator of skilled support and so the sample was divided into those receiving consistently good active support overall and those who were receiving mixed/weak active support and outcomes compared.
- Ability was higher in good services so had to take a smaller sample to match – selected only those with more severe disabilities (ABS scores under 151) – reduced sample size to 64, of which **27 people were reported to have autism**.

Results

Characteristics

- Those with autism had significantly higher ($p<0.01$) ABS scores ($z=3.171$), more challenging behaviour ($z=3.806$) and were observed to spend more time in self-stimulatory behaviour ($z=2.655$). This remained true for the more severely disabled sample.
- They were less like to be reported as having speech impairments ($X^2=5.91$ $p<0.05$), or physical disabilities ($X^2=11.24$, $p<0.01$).
- There was also a trend for those with autism to live in smaller services ($z=2.225$ $p<0.05$; less able group $p=0.096$)

Characteristics:

	With autism (ABS<151)	Without autism (ABS <151)
Mean Age	44(20-82)	49 (26-82)
Mean Adaptive Behaviour (ABS score)	95 (34 –142)	75 (27 –147)
Mean Challenging behaviour (ABC score)	57 (18 –133)	31 (1-88)
%male	52	44
Size of service (mean no. places)	4	5
%time engaged (any)	34 (0-75)	41 (0 – 95)
%time using gas/electrical equipment	1 (0-11)	0.16 (0-7)
% time in self-stimulatory behaviour	18 (0 – 83)	12 (0-76)
Participation in daily tasks (mean)	32 (0 – 87)	25 (0-92)
Active support score (mean)	55 (14 – 95)	57 (17-92)
% time any contact from staff	21 (0 – 78)	27 (0 – 85)
% receiving consistently good AS	22	32
% communication consistently good	23	42

Quality of life: People with autism were more likely to live in a service where people were active at least some of the time ($X^2=7.21$, $p<0.01$)* and to be engaged in complex household tasks requiring equipment for more of the time ($z=2.16$, $p<0.05$)* (*also significant for ABS <151) Also reported to participate more in daily living tasks ($z=2.57$, $p<0.01$).

Quality of service: There were no differences in the QoS provided to those with or without autism in terms of Active Support, appropriate use of AAC, Intensive Interaction, support for choice making, Positive Behaviour Support or implementation of autism friendly practices (SPELL framework).

Of the 27 people with autism with an ABS<151 only 5 were receiving skilled support in terms of good Active Support (none of which were specialist autism settings; 4 were nominated services).

No correlation between ability and engagement or Active Support.

SPELL Framework. Percentage of people with autism where principle was in place at least most of the time for:

	With autism (ABS<151)	Without autism (ABS <151)
Structure	31	51
Positive Approaches and expectations	41	42
Empathy	31	44
Low arousal	22	24
Links (primarily due presence of PCP)	59	69

Where facets of the SPELL framework were not in place, the principle was usually misunderstood or only partially implemented.

Conclusions

Unlike other studies of engagement and Active Support (especially where implementation is mixed), no relationship was found between ABS and engagement or Active Support. Previous studies have shown that more able people were likely to be more engaged. The absence of this relationship in this study suggests that even where people with autism were more able, staff find it difficult to know how to present activities and to support engagement. Very few people with autism in the current sample were receiving skilled support despite the need for more specialist support due to CB for example. The absence of skilled support, in the form of person-centred approaches, can further disable people with autism. Organisations nominated many of these services as supporting at least one person with autism and severe ID. The fact that there were higher abilities (ABS) amongst those with autism suggests that providers may confuse the disabling effects of autism with lack of ability.