



What do quality services look like and do they cost more?

Findings from the UK

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Outline

- Background - What we know from previous research
- What determines better quality of life outcomes for people?
- What do we know about quality of life outcomes and quality of support?
- The Skilled Support study (UK)
 - Active support as the key indicator of skilled support
 - What are the costs and outcomes of skilled support?

What we know from previous research

- Just moving people into smaller houses in community was necessary but not sufficient for ensuring better quality of life outcomes.
- Institutional practices can exist in small community-based settings, even in one-person or supported living services

Quality of life

- Basic needs met plus life “enrichers” such as choice and control, personal development etc (Schalock and Verduga, 2002).
- Services can both facilitate and impede the quality of life of people with intellectual disabilities.
- Domains
 - Social inclusion
 - Personal development
 - Physical well-being
 - Emotional well-being
 - Material well-being
 - Choice and Autonomy/self-determination
 - Interpersonal relationships
 - Rights

Engagement in meaningful activities and relationships is key

Engagement is both:

- An indicator of quality of life (especially important for those with more severe disabilities)
- A means to achieving quality of life

It is not the only indicator, of course, but it is one that is relatively easily measured and it is associated with other measures of outcome too.

Providing services that promote quality of life

- Person-centred planning – important for co-ordination and development over time
- Person-centred thinking – Helps to promote the right attitudes – puts the person at the centre of their own lives and of staff activity
- Person-centred funding – can improve control over who supports them, how and in what activities.

But.....

Just having the funding person-centred, the support individualised and a plan in the file is not sufficient to ensure better outcomes for people with more severe cognitive disabilities (although these help to make it easier to do).

- Research across almost 4 decades tells us that the most critical thing (apart from the level of ability of the individual themselves) is how staff support people, minute by minute, day by day – in particular person-centred active support.

Person-centred active support – the enabling relationship

- Providing enough help to enable people to engage successfully in a range of meaningful activities and relationships
- So that the experience real choice and control, grow in independence and become a more valued member of their community
- Irrespective of the degree of intellectual disability or the presence of additional needs and difficulties.

Active support – the evidence base

- Increases engagement
- Increases independence
- Increases choice and control
- Increases social and community activities
- Reduces challenging behaviour

See Stancliffe et al., 2008; Mansell and Beadle-Brown (2012) for a review
Beadle-Brown et al. (submitted)

Quality of support for people with intellectual disability in the UK

- Average levels of engagement in group homes and residential services were around 40% of the time - engagement largely dependent on person's own skills and motivation.
- Levels of assistance to be engaged is on average 3% (Netten et al. 2010) – even lower for those with more severe disabilities.
- Almost two thirds of people received no assistance.
- Other forms of contact from staff – 12% of the time.
- Not compensated for by contact with other service users.
- So overall, people spent over 52 minutes in every hour without any contact from anyone.

What about in Australia?

Mansell, Beadle-Brown and Bigby (2013)

- 6 organisations, people generally much more able than in the UK samples.
- Engagement 51% (0 to 100)
- On average 19 percent received good active support but varied from 0 to 100 across 6 organisations)
- People received assistance 3% of the time (0 – 74); 72% received no assistance at all.
- People received other forms of contact from staff 10% (0-74); 36% received no contact at all

More recent data from 9 organisations in Australia

	Living the good life Year 2		
	Whole sample	<151 ABS	> 151 ABS
ABS	148	94	199
Engagement	49	33	65
<i>Social activity</i>	13	8	18
<i>Non-social activity</i>	38	26	49
Active support (% score)	58	48	67
Assistance	4	5	4
Contact	15	14	16
Assistance + Contact	19	19	20



Recent UK study

COSTS AND OUTCOMES OF SKILLED SUPPORT



Active support as the key indicator of skilled staff support

Criticism that research only focused on engagement and active support and not really on other elements of person-centred approaches. However,

- Active support makes the most logical sense as key indicator as without it other approaches cannot be successfully implemented
- Limited evidence:
 - That person-centred thinking makes a difference to outcomes
 - That person-centred planning makes a difference on most QoL domains, especially for those with more complex needs
 - That Positive Behaviour Support improves QoL other than presence of challenging behaviour.
 - That training in the SPELL framework results in improvements in quality of life more generally

Costs and Outcomes of skilled support (Beadle-Brown et al., 2015)

Settings

- 25 settings that had been nominated by their organisation as providing skilled support for those with severe or profound disabilities AND multiple physical/sensory disabilities, autism or challenging behaviour.
- 10 settings randomly sampled from registration lists.
- 20 different organisations
- $\frac{3}{4}$ of settings were supported living settings
- $\frac{1}{3}$ were services for just one person (range 1-8)

Measure

- Observational measures of active support, communication support, SPELL, PBS, also PCP etc. Engagement main measure but other measures of QoL included.

Active support as key indicator of skilled support

- Only 38% of the nominated services showed consistently high levels of active support and only 12% of the CQC sampled services.
- Similar findings around communication, autism friendly practices and PBS – nominated services were not necessarily better.
- Where active support was better – other elements of support were also better and outcomes were significantly better.

Predicting outcomes

- Stepwise linear regression of the quality of support variables on the percentage of time people spent engaged in any meaningful activity or interaction:
 - active support explained 31% of the variance in engagement, with adaptive behaviour explaining a further 4%.
 - Service level ratings for implementation of PBS, the SPELL framework and good support for communication did not emerge as significant.

Did skilled support make a difference?

	Overall sample (n=64)	Skilled support (n=18)	Less skilled support (n=46)
Outcome measures			
% time social activity	10.5 (0 – 64)	21 (0 – 64)	6 (0 – 39)
% time any non-social activity	28 (0 – 90)	39 (0 – 81)	24 (0-90)
% time non-social activity involving electrical or gas equipment	0.53 (0 – 11)	1.14 (0-7)	0.3 (0-11)
% time any engagement	36 (0 – 93)	53 (17 – 93)	29 (0 – 90)
Mean score Participation in activities of daily life (IPDL)	26 (0 – 92)	33 (11.5 – 50)	23 (0 – 92)
Has contact with friends	42%	72%	31%
Community involvement in past 2 weeks – person interacts with people other than staff and service users (True/not true or only somewhat true) n = 51	47%	100%	31%
% supported well to make a range of choices during the observation	21%	66.67%	4.5%
% where their communication was effective in gaining staff attention/response most of all of the time	59%	94.4%	42%

Was active support score a good indicator of skilled support?

Other measures of skilled support			
	Overall sample (n=64)	Skilled support (n=18)	Less skilled support (n=46)
% time receiving assistance to be engaged	3.8 (0 – 24)	9.6 (0 – 40)	5.4 (0-40)
% time receiving any contact from staff	36 (0 – 93)	52.9 (17 – 93)	29.4 (0 – 90)
% score on SPELL framework	75.7 (40 – 100)	94.6 (87 – 100)	68.5 (40 – 100)
% receiving appropriate communication from staff most of all of the time	65%	100%	50%
% living in services where support for communication was good and appropriate most of the time	34%	81%	0.9%

Did skilled support cost more?

Over 3 months		Skilled support (n=18 of 50)	Less skilled support (n=32 of 50)
Accommodation and support cost adjusted for reported per person staff hours	Mean	£21,640	£16,580
	Range	£7,430 – £67,020	£7,430 – £29,950
Total care package cost per person, including external services	Mean	£22,420	£17,060
	Range	£7,430 – £67,640	£7,430 – £30,990

These differences are not significant; the £67,020 was an outlier.

Did skilled support cost more?

Are staff used more efficiently?

- No significant difference in costs between those receiving skilled and less skilled support.
- No significant difference in the number of hours staff reported each person was meant to receive in terms of staff support (e.g. what their funding is based on) – Skilled support group were reported to receive 97 hours per week, less skilled group 85 hours.
- Calculated number of minutes per hour reported and number of minutes per hour any contact received from staff.
- No association between these two figures for support
- BUT discrepancy between the two significantly different.
 - Skilled support group received 4 minutes less observed contact than reported support
 - Less skilled group received 25 minutes less observed contact than reported support.

Conclusions from research

- Active support is the best indicator of skilled support for those with severe and profound disabilities
- When active support is better, outcomes for people (on a range of domains are better)
- Where active support is better, other person-centred approaches are also better implemented
- Good services are not significantly more expensive than those providing mixed to weak active support. Lots of money being spent on not very good support.
- It is not the number of staff (once you have the required number to meet people's physical needs and keep them safe) but what they do that is important
- Good services are more cost effective
- Observation key to monitoring especially for people with more severe and profound disabilities.

For further information...

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