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

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Abstract

Background: With increasing reductions in funding for social care across many countries, the need to ensure that resources are used to best effect is becoming increasingly important, in particular for those with severe and complex needs.

Methods: In order to explore the outcomes and costs of skilled support for this group of people, quality of life was assessed for 110 people in 35 services in England. Information on costs was also collected.

Results: People who received consistently good active support experienced better outcomes in terms of several quality of life domains. Good support did not require significantly more staff time, and there was no evidence of higher total costs for those receiving good support.

Conclusions: The inclusion of active support in government guidance and local commissioning practices related to people with severe intellectual disabilities is likely to improve user outcomes. Observation should be an important element in measuring service quality.

KEYWORDS

complex needs, costs, outcomes, quality of life, severe and profound intellectual disability, skilled support

1 | INTRODUCTION

In many parts of the world, services and support for people with intellectual and developmental disabilities are in a time of flux—on the one hand, many countries are trying to respond to the challenge set by the UN Convention on the Rights of Persons with a Disability (2006) to transform services from institutional to community based. On the other hand, other countries are moving further and further down the road to independent living for at least some people with

disabilities, while at the same time fighting against re-institutionalization, particularly for those with more severe disabilities and those with complex needs such as profound intellectual and multiple disabilities, autism or behaviour considered challenging (Šiška, Beadle-Brown, Káňová, & Jan Tøssebro, 2017; Tøssebro et al., 2012).

The challenge of transforming services has been exacerbated by the continuing financial crisis in many parts of the world, including in the UK, where cuts to local authority budgets have been impacting on the support available to people with disabilities and

We dedicate this paper to the memory of Prof Jim Mansell who passed away during the final months of the project. We thank all the organisations, managers, staff and the people they support for letting us observe and talk to them. Thanks also to Dr Jill Bradshaw for comments on an earlier version of the manuscript.

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their families (Carter, 2015). There has been a trend in England for small services, which were generally of better quality, to be the worst hit by cuts (CQC, 2016). This means that finding ways to use the resources available to maximum effect becomes increasingly more important.

In the UK, the other element that has been important is the Transforming Care agenda (Department of Health, 2012a; ADASS, CQC, Department of Health, HEE, LGA, NHS England, 2015). Following the revelations of abuse in an assessment and treatment unit (Winterbourne View, British Broadcasting Corporation, 2011), and a number of subsequent reviews and additional scandals which indicated that Winterbourne View was not an isolated incident (Department of Health, 2012b; Emerson, 2012; Flynn, 2012), the UK government made clear that a sustained effort was needed to move people out of such hospital settings and into community-based services (Department of Health, 2012c; Transforming Care and Commissioning Steering Group, 2014).

Although reliable data are hard to come by, recent analysis has indicated that change in terms of the numbers of people in these hospitals has been slow (Hatton, 2016, 2017; Health & Social Care Information Centre, 2016; National Audit Office, 2015). Many reasons have been suggested for this—one core element identified has been the lack of high-quality services in the community, where staff are able to provide the skilled support needed to prevent challenging behaviour developing and to reduce challenging behaviour where it already exists. In 2015, new emphasis was put on this in “Building the Right Support” (NHS England, Local Government Association, & the Association of Directors of Adult Social Services, 2015a, 2015b).

Over many years, research has shown that one of the key determinants of quality of life, and in particular whether people spend their time meaningfully engaged (apart from severity of disability), is whether the support they receive is enabling and empowering—helping people to do as much as possible themselves and then, when support is needed, doing *with* people rather than doing *for* or *to* people (see Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008 for a review). This approach is usually referred to as “active support” (see Beadle-Brown et al., 2016; Bigby & Beadle-Brown, 2018; Mansell & Beadle-Brown, 2012; Stancliffe, Jones, Mansell, Lowe, 2008). Core to the slightly different approaches to active support that exist is the fact that those who provide support are enabling and empowering those they support to successfully participate in a range of meaningful activities and relationships with the aim of improving quality of life. Mansell and Beadle-Brown (2012) describe active support as an enabling relationship by which staff and other carers provide graded assistance to ensure success—assistance that is tailored to the needs, pace and preferences of the individual delivered in a person-centred, warm and respectful way and making the most of all the opportunities available at home, in school, in the community and at work.

Although active support has been recognized as key to improving levels of engagement in meaningful activities and relationships, there has been little research on other forms of person-centred

support that are viewed as good practice for people with intellectual and developmental disabilities. In an earlier paper from this study, Beadle-Brown et al. (2016) explored quality of life and quality of support using a range of different indicators related to support for communication, autism-friendly practices and positive behaviour support. They found that scores on the active support measure (ASM) were very closely correlated with scores on other measures of support and that active support was the best predictor of engagement in meaningful activities and interactions. Engagement in meaningful activity and relationships is considered a particularly important outcome in that it is the vehicle by which many aspects of quality of life¹ are realized (Bellamy, Newton, LeBaron, & Horner, 1990; Mansell & Beadle-Brown, 2012; Mansell et al., 2008; Mansell, Felce, Jenkins, de Kock, & Toogood, 1987; Risley, 1996; Saunders & Spradlin, 1991).

The bulk of the research to date has focused on the impact of active support on engagement in meaningful activity and relationships, with research on other quality of life domains limited. A small number of studies have found a positive impact on: the range of different activities people get involved in (Beadle-Brown, Hutchinson, & Whelton, 2012; Jones et al., 2001; Stancliffe, Harman, Toogood, & McVilly, 2007); involvement in social and community activities (Jones et al., 2001; Stancliffe et al., 2007); opportunities for choice making (Beadle-Brown et al., 2012); adaptive behaviour and the development of skills (Beadle-brown et al., 2012; Felce, de Kock, Thomas, & Saxby, 1986; Mansell et al., 2002b; Mansell, McGill, & Emerson, 2001; Stancliffe, McVilly, Radler, Mountford, & Tomaszewski, 2010); challenging behaviour (Beadle-Brown et al., 2012; Koritsas, Iacono, Hamilton, & Leighton, 2008; Stancliffe et al., 2010); and mental health in terms of symptoms of depression (Stancliffe et al., 2010). However, there is a need for further evidence of the impact of implementing active support on a wider range of quality of life domains and on the costs of provision. Such evidence would enable service users (and their advocates), service providers and commissioners to identify and promote high-quality support that improves quality of life outcomes and to achieve value for money in the provision of services.

This paper provides a step in that direction and draws on the same data reported in Beadle-Brown et al. (2016) but extends the analysis to address some of the gaps in the existing literature by evaluating (a) the impact of active support on the lives of people with severe and profound intellectual disability and complex needs (autism, challenging behaviour or multiple disabilities including physical disabilities) and (b) the implications in terms of costs. Specifically, this paper explores.

- whether strong implementation of active support is associated with higher quality of life for people with severe intellectual disabilities and complex needs;

¹We used the domains suggested by the international consensus on quality of life (Schalock et al., 2002): Emotional well-being, Physical well-being, material well-being, personal development, social inclusion, interpersonal relationships, self-determination and rights.

- which domains of quality of life, if any, are influenced by active support;
- whether the provision of active support influences the costs of support for people with complex needs.

2 | METHODS

2.1 | Design

This study is a between-group comparison of the outcomes and costs of active support for people living in small registered services or in supported living settings.

2.2 | Sampling and participants

Participating services were recruited to the service in one of two ways as detailed in Beadle-Brown et al. (2016): (a) they were nominated by their organization as providing what they perceived as good person-centred support for the target group (people with severe intellectual disability AND either severe physical disabilities or autism or showing behaviour considered challenging); or (b) they were randomly selected from the Care Quality Commission lists of registered services. Settings could be either a small² registered residential care home or a supported living setting. The aim of the nominated sample was an attempt to ensure enough good services were included to allow the research questions to be explored—previous research had found that only approximately a quarter of people in registered services received good active support (Netten et al., 2010). The aim was not to produce findings that were necessarily representative of all services but to ensure a range of scores in terms of the quality of services and outcomes for those supported.

Organizations were chosen to represent a range of different types of services, sectors and specialisms and included organizations the research team had worked with previously. Each organization could nominate up to 10 services but most nominated 5 or fewer. From the list of 120 nominated services, 30 services were randomly selected and stratified to include different geographical locations, different sectors, different organizational sizes and each of the three participant groups on which the study was focusing. These services were contacted and invited to take part. If a service refused for any reason, then the next service on the random list of 120 was contacted.

The same process was followed in terms of selecting the sample from the lists of registered services—the purposive random sample aimed to include a range of services in different sectors, from different types of organizations across the three target groups and across the geographical areas. Although we had attempted to recruit at least 30 services via these methods, this proved to be impossible at

the time we were trying to do so.³ The final sample included 25 nominated settings and 10 settings selected from CQC lists.

2.3 | Measures

Measures were selected to ensure comparability with previous studies. Some information was collected by questionnaire and some by direct observation and interview during a visit to each service.

2.3.1 | Characteristics of people receiving support

Previous research had found that in addition to whether or not staff provided support consistent with active support, the only other factor reliably identified as predicting levels of engagement is the level of ability of the people being supported. As such, in order to compare the sample to other samples and control for level of ability in the analysis comparing outcomes, the Service User Questionnaire (SUQ) was completed in advance of the research visit for each participant by their key worker or a member of staff who knew them well. The SUQ included the following:

- The short form of the Adaptive Behaviour Scale (SABS) Part 1 (Hatton et al., 2001; Nihira, Leland, & Lambert, 1993), the Quality of Social Impairment question from the Schedule of Handicaps Behaviours and Skills (Wing & Gould, 1978) and the Aberrant behaviour Checklist (ABC; Aman, Singh, Stewart, & Field, 1985). The reliability and validity of the ABS (from which the SABS was drawn), ABC and the HBS have been studied and reported as acceptable by their authors. Internal consistency of the Short Adaptive Behaviour Scale was assessed and was found to be high (Cronbach's alpha 0.934) as was the ABC full-scale score (Cronbach's alpha 0.947). A full-scale score for Part 1 of the Adaptive Behaviour Scale was estimated from the Short Adaptive Behaviour Scale using the formula provided in Hatton et al. (2001).
- A revised version of the Client Service Receipt Inventory (CSRI; Beecham, 1995; Beecham and Knapp, 1992) was used to record information on accommodation arrangements and use of hospital- and community-based services and day activities over the previous 3 months.

2.3.2 | Quality of support—active support

Although the study used a wide range of measures of care processes and the quality of support, Beadle-Brown et al. (2016) explored the respective role different approaches played in predicting quality of

²Defined in this study as for six or fewer people.

³Recruitment was occurring almost immediately after the release of the BBC programme on the situation at Winterbourne View and as the care quality commission announced a wave of inspections. Service managers were not surprisingly wary of people coming in to spend time in the service observing. Secondly, we lost a number of services from this group due to the riots that occurred during this year.

life outcomes. It was identified that the best indicator of skilled support (i.e. support that promoted better quality of life outcomes) was whether staff were providing active support. As such, this paper will explore the impact of active support on quality of life outcomes.

The extent and consistency with which active support was provided was measured using the ASM (Mansell & Elliott, 1996; Mansell, Elliott, & Beadle-Brown, 2005). The ASM was completed for each individual at the end of the structured observational period, during which the measure of engagement was completed (see below for more information). The observer took detailed notes of everything that happened during the 2-h observation and then used that information to complete the ASM. The measure included 15 items focusing on the opportunities for involvement and the skills with which staff provided and supported those opportunities. Each item was scored on a scale of 0 (*poor, inconsistent support/performance*) to 3 (*good, consistent support/performance*). The maximum possible score was 45, and for each person, a percentage of the maximum score was calculated. Cronbach's alpha was high for the 15-item scale (0.925). The measure and reliability is described in greater detail in Beadle-Brown et al. (2016).

The active support measure scores were recoded into scores above 66.6% representing consistently good active support and scores 66.6% and below representing mixed, weak or non-existent active support.

2.4 | Quality of life outcomes for people receiving support

2.4.1 | Engagement in meaningful activity and relationships

An observational measure of both service user engagement in meaningful activity, the contact and assistance provided by staff and occurrence of challenging behaviour (EMAC-R; Mansell & Beadle-Brown, 2005) was collected using momentary time sampling. Observations were carried out in each house usually over a two-hour period between 1,600 and 1,800 hr in the lead up to the evening meal, since this is a period with many opportunities for participation in activity and a period that has been found to be relatively representative across the day in terms of engagement and the frequency of assistance (Mansell & Beadle-Brown, 2011). A 1-min interval was used, and each service user present at the time of the observation was observed for 5 min in rotation. Observations were collected by a team of three observers all trained by the first author.

Observational categories included social activity, non-social activity, contact from staff (including assistance by staff for engagement) and challenging behaviour. Further detail can be found in Beadle-Brown et al., 2016, and definitions of observational categories can be requested from the first author. None of the categories were mutually exclusive because people could be observed doing more than one behaviour at a time, but the same behaviour could only be coded once. Personal care was not observed.

Percentage of time spent in each behavioural category was calculated taking account of missed observations. Percentage of time in which a missed observation was coded ranged from 0% to 100% of the time (mean 16%). The total number of valid minutes of observational data collected was 3,514 with the average length of time observed by each participant being 35 min (ranging from 5 to 105). Inter-observer reliability was generally satisfactory with an average kappa statistic of 0.6 (see Beadle-Brown et al., 2016, for more detail).

2.4.2 | Specific quality of life domains

In addition to the measure of engagement, which, as explained in Introduction, is generally considered to act as an indicator of quality of life, a series of other measures were used to explore specific quality of life domains. The Choice-making Scale (Conroy & Feinstein, 1986) was used to give an indication of self-determination; the Index of Participation in Daily Living (Raynes, Wright, Shiell, & Pettipher, 1994) allowed exploration of the range of different activities people got involved in at home, garden and outside of the home includes and thus provides an indication of personal development in the people have the opportunities to develop skills by being involved in things on a regular basis. An adapted form of the Index of Community Involvement (Raynes, Sumpton, & Pettipher, 1989) was used to assess indicators of the domain of Community Inclusion and Social Relationships through questions about access to community-based activities and facilities, contact with family, friends and neighbours, interactions with those other than staff, direct family and those they live with when out in the community. Finally, whether or not people had an advocate was included on this questionnaire. Internal consistency for the IPDL, CMS and ICI (original 15 items) was very high with Cronbach's alpha's values over 0.9 for all three scales. These measures were completed by the person's key worker as part of the SUQ.

As noted earlier above, the CSRI also asked questions about whether people had a job or work placement or attended college or other educational activities, thus providing potential insight into material well-being and personal development.

Finally, some of the observational measures of staff support also gave some insight into quality of life. In addition to the active support measure outlined above, the momentary time sampling data (EMAC-R) also gave some insight into whether people were interacting with others around them in their home, a first step in terms of interpersonal relationships. Observers also recorded and rated whether or not people received opportunity and effective support for choice, as well as whether there were appropriate and effective communication methods in use—both of these are important for self-determination. Material well-being in terms of the nature and quality of the home environment was assessed through the Homelikeness Scale of the Revised Residential Settings Service Questionnaire (Welsh Centre for Learning Disabilities, Institute for Health Research and Centre for the Economics of Mental Health, 2003). The presence of challenging behaviour during the

observations and whether the environment was predictable and low arousal (as per the NAS SPELL Framework; see Beadle-Brown et al., 2016, for further descriptions on this) were used as indicators of emotional well-being. Observations were also made on whether people were seen to be physically active in any way during the visit by researchers and whether meal options available during the visit appeared to be nutritional, allowing some comment on physical well-being.

Table 1 summarizes the indicators available for each quality of life domain.

2.5 | Procedure

Once a service agreed to take part, a letter was sent to the manager to confirm what had been discussed over the phone and consent and consultee advice forms and information sheets were sent, along with any measures to be completed in advance of the visit. This initial phone call also talked the service manager through the process for gaining informed consent and consultee advice, and they were able to ask for advice at any point.

Researchers contacted each setting to arrange the visit and to check again that people met the eligibility criteria with the manager. Follow-up calls were made to confirm the visit, and to answer any queries, with each service receiving on average at least three phone calls before the visit. During the visit, researchers collected and checked the SUQs for completeness, clarified any questions regarding communication and challenging behaviour and met each individual briefly before starting the structured MTS observation.

The active support measure was completed immediately after the end of the 2-hr structured observation period. Before leaving, the researchers, if appropriate, spent some more time interacting with individuals, looking at their person-centred plans with them or talking to them. The researchers then completed the remaining individual and service-level quality ratings based on all the data collected during the visit.

All the measures collected were produced in machine readable form and following an observational visit were scanned and processed in Formic and cleaned in Excel, and then, the data files were transferred into SPSS for analysis.

2.6 | Ethical and research governance approval

Ethical approval was gained from the Social Care Research Ethics Committee, and local authority research governance approval was gained initially from Kent; evidence of approval was sent to all local authorities where services were likely to be included. In some cases, additional approval had to be gained from individual local authorities.

2.7 | Data Analysis

Group comparisons were conducted between those who were observed to receive consistently good active support (hereafter, the good active support group) and those who observed to receive mixed, weak or non-existent active support (hereafter, the weak/mixed active support group). In order to account for the effect of

TABLE 1 Quality of life domains and indicators explored (in addition to engagement in meaningful activities and relationships)

Quality of life domain	Indicator explored and measure used
Emotional well-being	<ul style="list-style-type: none"> • Level of challenging behaviour • Score on the SPELL framework elements in particular whether the environment contains structure to make it predictable and it is low arousal
Physical well-being	<ul style="list-style-type: none"> • Whether or not people engaged in any physical activity during the visit • Was the available meal relatively balanced nutritionally
Material well-being	<ul style="list-style-type: none"> • Whether or not people had a paid job • Was the accommodation well kept and homely
Personal development	<ul style="list-style-type: none"> • Whether the person attends college or work placements • Whether people are participating in a range of activities at home and in the community and therefore experiencing opportunities to develop (IPDL and ICI)
Social relationships	<ul style="list-style-type: none"> • Whether or not people receive contact from staff and others they live with • Whether they are in contact with their family • Whether they have friends and how often they see them • Whether they have contact with neighbours and are known by name by neighbours
Social inclusion	<ul style="list-style-type: none"> • Whether people have accessed community-based activities and facilities in the past month (ICI) • Whether people have interacted with others that are not staff and people they have lived with when out in the community
Self-determination	<ul style="list-style-type: none"> • Opportunities for choice (CMS) • Whether people are observed to make choices and have those choices respected • Whether people have an advocate • Whether people are able to effectively communicate
Rights	<ul style="list-style-type: none"> • Whether people encountered any barriers, or negative interactions or discrimination when out in the community

TABLE 2 Sample characteristics

Characteristic	Mean (range) or percent		
	Whole sample (n = 110)	ABS < 151 Sample	
		Weak/mixed active support group (n = 46)	Good active support group (n = 18)
Age	46 (20–82)	49 (20–82)	49 (25–82)
% male	52	43	39
% White British	83	85	82
Adaptive behaviour (ABS)	113 (27–248)	85 (27–147)	79 (31–135)
Per cent of sample with ABS < 151 (severe ID)	73		
Mean score on challenging behaviour measure (ABC)	40 (0–133)	45 (4–133)	29 (1–88)
% with more than five behaviours rated as severe on the ABC and at least some behaviours occurring on a daily basis.	10	15	11
% physical disability ^a	53	61	72
% autism	42	39	27
% coded as having profound and multiple disabilities ^b	22	24	39

^aAs recorded by staff on the user needs and characteristics questionnaire.

^bPIMD was coded if the person was recorded by staff as having a physical disability = 1, as being non-verbal as being incontinent of bowels, requiring a wheelchair and requiring hoisting or other manual handling for personal care.

adaptive behaviour, the key variable that has been shown to affect outcomes in other similar studies, analysis was only conducted for the sample that had a score below 151 on the Adaptive Behaviour Scales (ABS) as this is the point at which there was no significant difference in ABS scores between the two groups.

As the data did not meet parametric assumptions, this was primarily done using the Mann–Whitney U tests and chi-square analysis for nominal data. In order to account for the number of comparisons made, only results significant at 0.01 will be reported as significant. Effect size calculations ($r = z/\sqrt{N}$) are included for the Mann–Whitney tests along with η^2 to illustrate the proportion of variation explained by the independent variable. Effect sizes are interpreted using Cohen's criteria where r at .2 = small effect size; r at .5 = medium effect size and r at .8 = large effect size. Cramer's V is presented for the chi-squared analyses. Effect sizes are interpreted using the Cohen's 1988 guidelines where Cramer's V at 0.1 = small effect size; V at 0.3 = medium effect size; and V at 0.5 = large effect size.

2.7.1 | Cost estimation and analysis

The estimation of support package costs followed established methodologies and principles (Beecham, 1995). Unit costs for all services used by participants were sought that would represent a good

approximation of their long-run marginal opportunity cost values at 2010–2011 prices (Curtis, 2011; Drummond, O'Brien, Stoddart, & Torrance, 1997). The amount of each service used by each person was multiplied by the appropriate unit cost (per hour, per session, etc.). Total costs per person were calculated over the three months before the interview and include use of accommodation facilities, hospital services (inpatient stays, outpatient clinics and accident and emergency attendance) and contacts with primary care and specialist services, social care and day activities. The cost estimates therefore take a public sector perspective.

As a high proportion of the total support costs were likely to derive from the provision of accommodation and associated on-site staff support, particular care was taken with these estimates. Detailed information was requested in the Manager's Questionnaire on staff costs (care staff and others such as cleaning, catering, laundry), non-staff items (such as heat, light, maintenance, household equipment), overhead costs borne by the managing agency and the capital value of buildings, etc. These financial data were carefully checked and any queries resolved with other members of the research team. It was possible to estimate facility-specific annual costs for 27 of the 34 accommodation settings, and the average cost per place was calculated for each setting (total cost/number of places). We also calculated an accommodation cost in which the on-site care staff costs were adjusted in line with staff reports of the number of

person-hours each person received. This “adjusted” accommodation cost per person reflects the way resources within the accommodation unit are distributed. By adding this figure to the fixed (non-care staff) accommodation costs, and the costs of external services, we obtained a care package cost that is unique to each person and that reflects their share of available resource inputs both within and outside the accommodation setting.

The total costs of support are presented using simple descriptive statistics such as means and ranges. Where comparisons are made between groups, results are reported from a *t* test accompanied by 95% confidence intervals generated by the non-parametric bootstrap method (with 1,000 repetitions; Briggs, Wonderling, & Mooney, 1997; Mooney & Duval, 1993). We also report results from the non-parametric Mann–Whitney test.

3 | RESULTS

3.1 | Setting and participant characteristics

The average size of home was 3 places (range 1–8) with 33% of settings for just one person. Seventy-one per cent of settings were supported living settings. Eighty three per cent were from the voluntary sector. Average established staff–client ratio was 3.35 (range 0.86–9.33). Homes were in general very homelike (average homelikeness scale score was 1.5; range 1–2.8).

There were 110 people with intellectual and severe disabilities for whom consent or consultee agreement to take part was gained. Information on characteristics of participants is provided in Table 2.

Initial analysis indicated that those receiving good active support had significantly higher scores on the adaptive behaviour scale ($z = 2.836, p < .01, n = 35$, in the good active support group, 51 in the weak-to-mixed active support group; $r = .31$). The analysis was repeated just for the sample of people who were more severely disabled using an ABS cut-off point of 151, and there was now no significant difference between good active support group ($n = 18$) and the weak-to-mixed active support group ($n = 46$) in terms of scores on the adaptive behaviour scale ($z = 0.598, p > .05, r = 0.07$). There was a small difference in the total score on the ABC ($z = 2.138, p < .05, r = .27$) with those in the good active support group having lower scores and therefore less challenging behaviour (mean ABC score 29; range 1–88) than those in the weak/mixed active support group (mean ABC score = 45; range 4–133). However, as challenging behaviour has not in the past been shown to predict outcomes in terms of the main outcome variable (engagement), it was decided to tolerate this difference. This is likely to be an indication that in general people who show behaviour described as challenging are less likely to receive the support needed to promote better outcomes or indeed that challenging behaviour is more prevalent when support is less skilled and engagement is lower. The analysis presented below relates only to the sample of 64 people with ABS scores less than 151. Eighteen were receiving good active support. Table 2 also presents the main characteristics of the smaller sample of ABS less than 151.

The difference between the good active support group and the weak/mixed active support group is presented below for engagement in meaningful activity and engagement and for each of the quality of life domains and indicators outlined in Table 1.

3.2 | Engagement in meaningful activities and relationships

As can be seen from Table 3, those who were receiving active support more consistently were significantly more engaged in meaningful activities and relationships overall and also in social activity.

Table 3 also illustrates the significant results on each quality of life domain.

3.3 | Emotional well-being

There was no difference between the two groups in terms of the amount of time observed showing any form of challenging behaviour, although overall levels of challenging behaviour were generally very low, despite some of the settings being nominated as showing good support for those with challenging behaviour. The most common form of challenging behaviour in both groups was self-stimulatory and repetitive behaviour (observed for on average 9% of the time in good active support group and 17% of the time in the weak/mixed active support group). In terms of people having an environment that is conducive to reduced stress and anxiety, the two groups did significantly vary on the ratings of how well the SPELL framework was being implemented (see Table 3).

3.4 | Physical well-being

There was no difference between the two groups in terms of how balanced the evening meal was and whether or not people engaged in physical activity during the visit.

3.5 | Material well-being

No one in the sample had paid employment of any type, and there was no difference between the two groups in terms of the homelikeness of the setting.

3.6 | Personal development

Only 5 people across the whole sample had recently or were currently attending some form of educational programme. As illustrated in Table 3, those in the good active support group were more involved in a wider range of tasks of daily living (as measured by the IPDL); in particular, they were more likely to be involved in shopping

TABLE 3 Mean scores (with range, standard deviation [SD] and mean ranks [MR]) in terms of engagement in meaningful activities and relationships and challenging behaviour for those with severe or profound intellectual disabilities

Outcome measures	Overall sample (n = 64)	Good active support (n = 18)	Weak or mixed active support (n = 46)	Mann-Whitney U test z or χ^2 (effect size)
Engagement in meaningful activities and relationships—% time social activity	10.5 (0–64; 13.1)	21 (0–64; 15)	6 (0–39; 9.7)	$z = 4.282$ $p < .001$ ($r = .54$; $\eta^2 = 0.29$)
Engagement in meaningful activities and relationships—% time any engagement	36 (0–93; 24.7)	53 (17–93; 23)	29 (0–90; 22.3)	$z = 3.325$ $p = .001$ ($r = .42$; $\eta^2 = 0.18$)
Emotional well-being—% score on SPELL framework	75.7 (40–100; 16.8)	94.6 (87–100; 4.65)	68.5 (40–100; 13.9)	$z = 5.461$ $p < .001$ ($r = .55$; $\eta^2 = 0.44$)
Personal development—mean score participation in activities of daily life (IPDL)	26 (0–92; 21.2)	33 (11.5–50; 13.8)	23 (0–92; 23.0)	$z = 2.429$ $p = .015$ ($r = .30$; $\eta^2 = 0.15$)
Social relationships—% time receiving any contact from staff	36 (0–93; 24.7)	52.9 (17–93; 23)	29.4 (0–90; 22.3)	$z = 4.375$ $p < .001$ ($r = .55$; $\eta^2 = 0.29$)
Social relationships—has contact with friends	42%	72%	31%	$\chi^2 = 7.897$ $p = .005$ ($V = 0.34$)
Social inclusion—interaction with people other than staff and service users (true versus not true/only somewhat true) (n = 51)	47%	100%	31%	$\chi^2 = 17.65$ $p < .001$ ($V = 0.59$)
Self-determination—% of people receiving good support for choice making and having decisions respected	21%	57%	4%	$\chi^2 = 27.72$ $p < .001$ ($V = 0.64$)
Self-determination—% of people who have an advocate	54%	78%	42%	$\chi^2 = 6.563$ $p = .01$ ($V = 0.32$)
Self-determination—% of people for whom communication was effective in gaining staff attention most or all of the time	59%	94.4%	42%	$\chi^2 = 17.73$ $p < .001$ ($V = 0.53$)

for food ($\chi^2 = 4.636$ $p = .002$, $V = 0.44$), than those in the weak/mixed active support group.

3.7 | Social relationships

There were large differences in the amount of contact (of any type) that people were receiving from staff during observations (see Table 3). Almost no contact from other service users was observed in either group. There were no differences between the groups in terms of contact with families, but there were significant differences in terms of contact with friends. There were no difference in terms of relationships with neighbours although the numbers who did have contact with their neighbours were very small overall—15% of people were reported to have formal contact with staff and only 29% of people were reported to know any neighbours by name or be known by neighbours by name.

3.8 | Social inclusion

There was no difference on the Index of Community Involvement overall; however, those in the good active support group were more

likely to be reported as having interacted with people who were not staff or people they lived with, when out in the community.

3.9 | Self-determination

Although there were no differences in terms of overall scores on the Choice-making Scale (opportunities for choice as reported by staff), those in the good active support group were reported as having more opportunities for choice with regard to outings ($z = 3.078$ $p = .002$, $r = .38$, $r^2 = .14$) and also with regard to visiting friends ($z = 2.596$ $p = .009$, $r = .32$, $r^2 = .10$).

As illustrated in Table 3, those in the good active support group were more likely to be observed to be supported to make choices well and have those choices respected and were more likely to be using communication that was effective in gaining staff attention. They were also more likely to have an advocate.

3.10 | Rights

There were no reported differences in terms of whether people experienced barriers or negative interactions in the community.

TABLE 4 Quarterly costs by skilled and less skilled support for accommodation and support costs

Over 3 months	Skilled support (<i>n</i> = 18 of 50)	Less skilled support (<i>n</i> = 32 of 50)	<i>p</i> -value
Accommodation and support cost adjusted for reported per person staff hours			
Mean	£21,640	£16,580	<i>t</i> test, <i>p</i> = .020 95% CI (-12,825, 683)
Range	£7,430–£67,020	£7,430–£29,950	Mann–Whitney <i>z</i> = 1.518, <i>p</i> = .129
Total care package cost per person, including external services			
Mean	£22,420	£17,060	<i>t</i> test, <i>p</i> = .045 95% CI (-13,091, 451)
Range	£7,430–£67,640	£7,430–£30,990	Mann–Whitney <i>z</i> = 1.728, <i>p</i> = .084

3.11 | Effect size interpretation and the explanatory power of active support on outcomes

Analysis of effect sizes shows that differences were primarily small to medium effects but with some falling within the large effect size category. Whether or not people were receiving consistent active support explained between 7% and 29% of the variation in the dependent variables presented.

3.12 | Difference in estimated costs of support

The good active support indicator was available for 69 of the 78 participants for whom total support package costs (including on-site staff support, accommodation, and external services) could be estimated; 33 received good active support and 36 received weak/mixed active support. These participants form the “cost sample” and include 50 people who scored less than 151 on the Adaptive Behaviour Scale (the sample considered here), of whom 18 people were receiving consistent active support.

Table 4 summarizes the support costs over three months for the 50 people in the more severely disabled group, showing the “adjusted” accommodation cost and then total costs (adjusted accommodation costs plus external services). There was no significant difference between those receiving consistent active support (*n* = 18) and those receiving weak/mixed active support (*n* = 32) in terms of their adaptive behaviour.

The limited sample size, wide ranges of costs and data skew suggest that non-parametric confidence intervals and Mann–Whitney tests of between-group differences are the most appropriate ones to consider (Table 4, final column). So although the observed mean costs are higher for the good active support group, this is not a statistically significant difference for either the adjusted accommodation cost or the total care package cost. The higher mean cost can be attributed to one person who showed challenging behaviour and had a very expensive cost package in an individualized service. Neither is the between-group difference in the number of reported staff hours statistically significant. On average, the 10 people in the good active support group for whom these data were available were reported

to receive 97.4 hr (*SD* 42.1) and the average for the 32 people in the weak/mixed active support group was 85.3 hr (*SD* 43.7; *z* = 0.993, *p* = .321.)

The cost measures reported here have been adjusted to reflect the number of hours that on-site staff reported for each resident. Data are also available on the contact between staff and users during the two-hour structured observation period. Both the “reported” and “contact” data were converted to a number of minutes per hour. For the 69 residents for whom these data were available, no significant association was found between the two figures (Pearson's correlation, *p* = .972), but the observed discrepancy was lower for those in the good active support groups than for the weak/mixed active support group. On average, people in the good active support group received just 4 min less “contact” time than “reported funded” time, whereas the discrepancy for the weak/mixed active support group was 25 min.

4 | DISCUSSION

In this paper, we explore the impact of consistently good active support on a wider range of quality of life outcomes for people with severe intellectual disability and complex needs than had previously been explored. In addition, we wanted to look at, for the first time, whether working in this way was likely to require more resources than not doing so.

4.1 | Does active support make a difference in terms of quality of life outcomes

Although the study had a number of limitations (see below), the research found significant differences in terms of quality of life outcomes between those who were receiving consistently good active support and those were receiving mixed, weak or non-existent active support, even when there was no significant difference between the two groups on level of ability (the only other factor that has been found to consistently predict levels of engagement in other studies).

Specifically, those in the good active support group experienced better outcomes in terms of overall engagement in meaningful

activities and relationships and in terms of emotional well-being and personal development, interpersonal relationships, social inclusion and self-determination. This, for the most part, replicates the findings from earlier studies using slightly different measures, with a greater focus on people's lived experience rather than solely relying on staff-reported outcomes.

4.2 | Does active support require more resources

Although observed figures suggest that accommodation and on-site support costs for people with severe and complex disabilities are slightly higher for those receiving skilled support, the mean difference was just less than £1,700 per month and the between-group difference was not statistically significant. This may be partly explained by the fact that there were proportionally more people in the skilled support group in supported living and individualized settings where it is more difficult to share staff hours between residents than in more traditional shared/group settings. A similar pattern could be seen when looking at the number of staff-reported support hours per person per week; mean staff-reported hours were slightly higher for those receiving skilled support, but the difference was not significant.

Of course, these comparisons do not as yet take into account the potential impact on costs of the participants' characteristics and needs. Although the two groups (good and weak/mixed active support) were not significantly different in terms of level of adaptive behaviour, the sample for those with an ABS score of less than 151 was too small to allow us to control for other characteristics in the cost analysis. Staff reported a range of on-site person-hours across the sample. These allowed the accommodation costs to be adjusted and so some association with people's needs should be expected. For example, in the full costs sample of 78 people it was found that costs were higher for those with autism (who were also more likely to be living in supported living/individualized services) compared with those without autism, and also for those of White British origin. Interestingly, the mean total support package cost for the group of 50 more severely disabled people was not significantly different from those with an ABS score of 151 or above. This may be partially explained by the fact that those with ABS over 151 were more likely to have autism.

4.3 | Adequacy of the data

The key limitation to this study was the small numbers of those with more severe intellectual disabilities and complex needs who were receiving good active support. Out of a total of 110 people, only 18 people had ABS scores in the lower half of possible ABS scores AND were receiving consistently good support. Though the use of the ABS < 151 cut-off is not in itself a measure of severe intellectual disability, this was the cut-off point that has been used in other research. Using this cut-off eliminated significant group differences in

terms of level of adaptive behaviour, which had been shown in previous research to be a key determinant of engagement in meaningful activities and relationships, as well as other measures of quality of life. To have taken a lower cut-off point would have reduced the sample size further.

As discussed in Beadle-Brown et al. (2016) a number of other factors had combined to reduce the sample size overall, despite a substantial extension on the project—a climate of uncertainty and distrust of people coming into services to observe, due to the aftermath of the Winterbourne View scandal; riots in London and Bristol; and a lack of awareness from managers about what might constitute good support. It is also interesting to note that relying on staff/managers in these settings to identify individuals who met the inclusion criteria was not necessarily an accurate measure—some individuals and some settings had to be eliminated from the data because it was clear from the beginning of the visit that the individuals did not have a severe or profound intellectual disability. This may have been because managers had focused on other requirements and had missed the requirement for severe or profound intellectual disabilities. Alternatively, managers may have underestimated levels of ability. Anecdotal evidence suggested that both of these played a role in this case.

Although the number of people receiving good active support was very small in spite of having positively recruited for "good" services, this sample is still receiving better support overall than has been found in other randomly selected samples (Mansell & Beadle-Brown, 2012; Netten et al., 2010) and as such may not be representative of services more generally. Moreover, the study required managers to report financial data but despite demands for greater evidence on costs and cost-effectiveness, this proved to be one of the major barriers to participation in the study.

While having used observable indicators of quality of life is, on the one hand, a strength, it can introduce some confounding factors in that something that is observed might both indicate good processes/support and good outcomes. For example, one of the indicators of emotional well-being, the score on the SPELL framework (representing an environment (including interactions) that is predictable, positive and low arousal) can be used both an indicator of good support and as an output of good support, which ultimately will lead to the outcome that people express low levels of anxiety/stress and high levels of satisfaction/happiness. Similarly, most QoL indicators can be divided into outputs and outcomes and sometimes the outputs are difficult to extricate from processes. When working with people with severe and complex needs, it is often necessary to rely more heavily on such observable output indicators than on more subjective measures (Mansell, 2011). In addition, quality of life domains are interconnected and inter-related, with outcomes on one domain often impacting on other domains—this means that often one indicator can be related to more than one domain.

One of the commonly cited problems with collecting service use data on a questionnaire is that it is subject to recall errors. In some cases, staff just did not know information around the costs of someone's accommodation and support package, and although they were

encouraged to ask other people who might know, there was a substantial amount of missing data. The second, and again very common, challenge faced in cost-related research is that of skewed data. Careful attention to the selection and interpretation of statistical tests (parametric and non-parametric) is key in this respect. However, even when considering the more conservative non-parametric results the small sample size means caution is advised when interpreting the findings.

The issues with recruitment and the fact that some people lived in individualized settings also meant that we did not have enough data to use more stringent methods of analysis to, for example, take account of potential cluster effects at service or organizational level. Although the group comparison design was useful for exploring potential differences in outcomes and whether there might be differences in terms of costs, future research in this field should seek to employ a longitudinal design and multi-level or hierarchical modelling approaches to explore implementation of active support over time and the impact of any clustering effects. Findings currently emerging from Australia and work planned in the UK seek to respond to these limitations, building on the findings of the current study.

4.4 | Implication for policy and practice

Despite the limitations outlined above, this study does provide some important findings that have relevance for policy and practice. Data collected for this study indicated that local authorities are continuing to pay a fee for accommodation and on-site support services based mainly on the gross expenditure figure—which in turn is mainly accounted for by the staffing establishment (total staff hours). These fees did not differ significantly between the two groups so local authorities are paying a similar fee for people receiving less enabling and empowering support as those receiving support that is promoting better quality of life outcomes; they are paying for a specified amount of inputs rather than support that will achieve better outcomes. Understanding better what happens within the accommodation and support arrangements that they currently commission—and what it is possible to achieve by using existing staff better—may help improve services for people with severe disabilities, regardless of whether they are organized as supported living environments or in a manner more akin to small residential care homes. The preliminary findings reported here are encouraging and suggest that any cost difference is unlikely to be large when set against the experience of residents in the houses where consistent active support is provided. In particular, it is essential that local authorities should understand the extent to which the employed staff are engaging and interacting with those they support, using person-centred and positive practices, which have been shown in previous studies to promote better outcomes for those supported and for the staff employed.

The measure of “contact” with supported people from the observational data may be key in this respect. It provides a slightly different measure of staff input from the reported person-hours. It is a measure of staff *engagement* or *interaction* with residents, rather than time spent in a range of resident-related activities (sorting

money, filling in daily monitoring, cooking for them, etc.). The contact variable includes assistance for engagement in meaningful activity, social contact and care-related activities such as helping people be mobile, dressing people and feeding people. From a cost perspective, therefore, the “contact” variable identifies resource inputs (time spent) but also may say something about the *quality* of staff time residents receive because it focuses more on active engagement, which in turn leads to better outcomes for people. Notably, the analysis reported here suggests that more of the staff-reported hours per person are spent on “contact” time for those receiving consistently good active support than those receiving weak/mixed active support. Thus, it may well be that for the former group, the available time is used more efficiently because better outcomes are generated. It is possible that employing more staff in poor services may not improve outcomes for the people supported but helping staff to work differently might; it is only when a staff team is already providing skilled support such as active support and the culture is supportive of good practices that additional staffing is likely to make a difference.

This has potential implications for staff training and support. Currently, person-centred approaches such as active support, positive behaviour support, alternative and augmentative communication and the SPELL framework have been adopted by a number of organizations in the UK but as clearly indicated in this study (and in previous larger scale surveys such as Netten et al., 2010), they are by no means widespread. UK government policy specifies person-centred planning as a requirement for all people with an intellectual disability, and recent guidance related to the Transforming Care agenda (Local Government Association, Directors of Adult Social Services, & NHS England, 2015) refers to the importance of positive behaviour support. However, the latter is primarily in the context of people who show or are at risk of showing challenging behaviour. Government policy does not specify other approaches for supporting people day to day, unlike in some states in Australia where active support is named as the approach that will form the basis of how disability support services will operate. This would not guarantee higher quality services but would raise awareness that it was an essential approach. For active support and other similar approaches to be implemented, staff must have appropriate training and must believe that it is what is expected of them and valued most by their employers and those who lead staff must also be able to operate as practice leaders (Beadle-Brown, Bigby, & Bould, 2015; Beadle-Brown et al., 2014; Deveau & McGill, 2016; Mansell & Beadle-Brown, 2012).

There are also important implications for how the quality of services is measured, and in particular, the findings illustrate the importance of observation as a critical element in assessing service quality; the quality of the interactions between staff and the people they support is not something that can be captured in paper-based recording systems. Organizations themselves should ensure that observations of the day-to-day lived experiences of the people supported and the quality of the support they receive from staff are a key element of audit processes. Such data could usefully be used to inform commissioners about the quality of

services. Although structured observations that provide some sort of rating or score can be helpful, the qualitative and descriptive information that comes from such observations is also important. Finally, the findings from this study indicate the importance of inspection processes routinely including observations of staff practice and interactions with the people they support and of having a focus on whether staff are providing skilled support and whether managers can lead such practice. However, any observations need to be done by people with experience of what it is possible to achieve despite people's level of disability or the complexity of their needs—in other words, they need to know what “good” looks like.

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