QUALITY OF LIFE AND QUALITY OF SUPPORT FOR PEOPLE WITH SEVERE INTELLECTUAL DISABILITY AND COMPLEX NEEDS.

Short title: Quality of life and quality of support

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Abstract

Background

People with severe and profound intellectual disabilities often spend substantial time isolated and disengaged. The nature and quality of the support appears to be important in determining quality of life.

Methods

Structured observations and staff questionnaires were used to explore the quality of life and quality of support for 110 people with severe and profound disabilities and complex needs.

Results

On average people spent approximately 40% of their time engaged in meaningful activities, received contact from staff 25% of the time (6% in the form of assistance to be engaged). Just over one third received consistently good active support, which was associated with other measures of quality of support and emerged as the strongest predictor of outcomes.

Conclusions

Quality of life and quality of support was relatively poor, although with about one third of people receiving skilled support. Consistently good active support was the best predictor of outcome and proposed as a good indicator of skilled support.

Introduction

Following the move from larger congregate settings to smaller-scale services in the community, people with intellectual disabilities typically experience better outcomes across almost all quality of life domains (Emerson & Hatton, 1994);(Kozma, Mansell, & Beadle-Brown, 2009). These benefits are experienced most strongly by people with less severe disabilities. For these people, the provision of better material conditions in the community, together with relatively less sophisticated support that listens to what people want, is usually sufficient to enable people to lead a better life (Mansell & Beadle-Brown, 2012).

However, those with more complex needs, such as people with severe and profound intellectual disabilities, and in particular those with severe and profound disabilities whose behaviour presents a challenge, or who have multiple physical or sensory disabilities, or who have autistic spectrum conditions, often experience poorer outcomes (Mansell and Beadle-Brown, 2012). They are often unable to make full use of the opportunities presented by new service models because they depend on skilled support from staff to do so. Staff members play a central role in mediating use of opportunities by people with complex needs ((Landesman-Dwyer, Sackett, & Kleinman, 1980); (Mansell & Elliott, 2001); (Rice & Rosen, 1991). Through the provision of help and encouragement, staff mediate access to, and use of, the opportunities presented in the home and community. Staff may control access to materials and activities directly (for example, by opening or locking rooms) and indirectly (by setting out and preparing materials so that the people they support can take part in the activity). Through their ability to use alternative forms of communication, they enhance or diminish people's ability to exercise choice and take control over the course of their lives. They make it more or less likely that people will experience the rewards intrinsic to the task by the level of assistance and facilitation they provide. Through the disposition of their social interaction they reinforce either engagement in meaningful activity or passivity and inactivity. They shape the person's behaviour by the feedback and reinforcement they provide.

Improving outcomes for vulnerable people is central to international, national and local policy and decision-makers – in the UK this is a particular issue following a number of scandals in learning disability services culminating in the revelation of the abuse of people with autism and people with challenging behaviour at Winterbourne View (British Broadcasting Corporation, 2011) and its resulting review of service quality (Care Quality Commission, 2012). In the wave of inspections that followed the Winterbourne View media coverage, approximately half of the 145 assessment and treatment, secure and residential care services for people with intellectual disability were found to be not compliant with the essential standards on care and welfare and on safety of people using services. Services were generally not adhering to good person-centred practices in terms of supporting, in particular, people with challenging behaviour.

Research has also shown that the day-to-day experiences of people living in residential care services leave much to be desired. Although there is variability in outcomes, with the most able usually experiencing better outcomes, people with intellectual and developmental disabilities tend to spend a large proportion of their time disengaged and isolated (Netten et al., 2010); Mansell and Beadle-Brown, 2012, chapter 2; (Mansell, Beadle-Brown, & Bigby, 2013), despite relatively well resourced services.

Recognition of the importance of skilled staff support has led to attempts to codify and describe beneficial care practices such as, for example, active support (Stancliffe, Jones, & Mansell, 2008); Mansell and Beadle-Brown, 2012) augmentative and alternative communication (Wilkinson & Hennig, 2007), positive behaviour support (Koegel, Koegel, &

Dunlap, 1996) or the National Autistic Society 'SPELL[1]' framework (Beadle-Brown & Mills, 2010). Although the evidence base for the positive impact of active support on the quality of life of people with intellectual disabilities is strong at least in the UK and Australia (see Stancliffe *et al* ., 2008; Mansell and Beadle-Brown, 2012 for reviews), the evidence base for other person-centred approaches is more limited. Positive behaviour support has generally been found to result in a reduction in challenging behaviour rather than the impact on quality of life more broadly (Carr et al., 1999); (Allen, James, Evans, Hawkins, & Jenkins, 2005); (MacDonald & McGill, 2013). In the absence of firmer evidence, it is difficult for people using services, the organisations providing them or the commissioners and regulators of services to judge the potential benefits of these approaches.

In terms of how wide-spread the use of active support is, research in a random sample of services across 4 areas of England found that only 13% of the 336 people with intellectual disability were receiving consistently good active support, 71% received no assistance to be engaged in meaningful activities and relationships and 25% received no contact from staff at all during the time they were observed (Netten *et al* ., 2010). On average people received contact in any form (including negative contact) from staff or other service users for less than 9 minutes in every hour. This was only slightly more than found in much larger services for older adults (aged over 80 years of age on average). Mansell and Beadle-Brown (2012) review the literature on levels of engagement in meaningful activities and reported (page 48) that the average level of engagement was 39% (ranging from 17 to 70% across the 24 studies). There was of course substantial variation in engagement levels between and within studies, mainly related to level of ability of participants. However there was little variation across time. In most studies reviewed by Mansell and Beadle-Brown (2012, chapter 3) levels

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[1] The SPELL framework includes five elements: Structure, Positive Approaches and Expectations, Empathy, Low Arousal and Links.

of assistance before the implementation of active support usually fell below 8% of the time, sometimes as low as 2% when those with more profound and complex needs were included.

There are a number of gaps in the literature that this paper sets out to address. Firstly firmer evidence is needed on the nature of support provided to people with intellectual disabilities and the impact of this support on a range of quality of life outcomes experienced by people in settings that have sufficient resources and are facilitated by small group or even individualised environments. The Netten *et al* . study included only residential care, some of which were relative large – average size of services was 7 places but ranged from 2 – 21 places. Little research exists on outcomes for people in supported living arrangements, in particular on engagement in meaningful activities.

This paper is the first from a larger study looking at the costs and outcomes of skilled support for people with severe intellectual disability and complex needs – profound and multiple disabilities, autism or challenging behaviour. The study had aimed to compare services where the staff team were providing skilled support to those where support was weaker, on a variety of outcome variables as well as in terms of cost. The current paper focuses on people with severe intellectual disabilities and complex needs more generally. Further papers will explore in detail the situation of those in specific groups, such as those with autism, those with challenging behaviour, those with severe physical disabilities and those requiring support with communication. This paper has four main aims:

- To describe the quality of life across a range of domains of people with severe intellectual disabilities and complex needs living in small community based settings in the UK.
- To describe the quality of support that people receive from staff across a number of domains – active support, support for communication, autism friendly practices and positive behaviour support.

- To identify, if possible, the best variable to represent “skilled” support for this group of people.

Methods

Design

This study is a one point in time observational study.

Sampling and participants

There were two elements to the sampling strategy.

1. A range of service-providing organisations known to provide residential care and/or supported living for people in the target groups were contacted and invited to nominate up to 10 settings that they felt provided ‘good’ services for one of the target groups described above. These settings could be either a registered residential care home, ideally with fewer than 6 places but an absolute maximum of 8, or a supported living setting. From that list a ‘pot’ was generated of approximately 120 settings that were self-identified as ‘good’.

Thirty services were randomly selected from this pot and stratified to include each of the geographic areas (London, the South East, the South West and the North East/York and Humber), different sectors, different organisational sizes and each of the three groups on which the study was focusing. These services were approached initially by a phone call to tell them about the project and explain the commitment and this was followed by a letter inviting them to take part, informing them that they had been nominated by the organisation to take part and confirming what the next steps would be. If a service refused for any reason then the next service on the random list of 120 was contacted.

2. A purposeful random sample drawn from the lists of registered services provided by the Care Quality Commission was also generated. This sample aimed to include a range of services in different sectors, from different types of organisations across the three target groups and across the geographical areas. An initial telephone screening of each service randomly selected aimed to check that they provided for one or more of the target groups and gathered basic information on age, gender and ethnicity in order to stratify the sample to match the nominated good services as closely as possible.

The final sample included 25 nominated settings and 10 settings selected from CQC lists. The average size of home was 3 places (range 1-8) with 33% of settings for just one person. Table 1 summarises some of the other characteristics of the services recruited. As can be seen there were slightly more services in the North East and the majority of the settings were supported living arrangements.

Insert Table 1 about here

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.

Managers questionnaire and interview

A Manager's Questionnaire (MQ) was based on the Revised Residential Services Settings Questionnaire (RRSSQ: (Welsh Centre for Learning Disabilities, Institute for Health Research, & Centre for the Economics of Mental Health, 2003) and collecting information about the setting, staffing, person support hours provided, person-centred planning, planning resident activities, staff support for resident activities and distribution of support across residents. In addition, questions on the cost of running the services based on previous work by Knapp, Beecham and colleagues were included. The MQ took approximately an hour to complete and managers could consult senior managers if necessary for the cost information.

Interviews with managers lasted approximately 1 hour and covered the aims, ethos and approaches of the service, systems for performance management, for person-centred planning and for staff allocation, and the managers' views on skilled support.

Characteristics of people with intellectual disability receiving support

The Service User Questionnaire (SUQ), which brought together a range of existing measures, 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 Service User Questionnaire included:

a. The short form of the Adaptive Behaviour Scale (SABS) Part 1 (Nihira, Leland, & Lambert, 1993); (Hatton et al., 2001), 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).

b. A revised version of the Client Service Receipt Inventory (CSRI: (J. Beecham, 1995); (J. K. Beecham & Knapp, 1992)), used to record information on accommodation arrangements and use of hospital- and community-based services and day activities over the previous three months.

Outcomes for people receiving support

Engagement in meaningful activity and relationships

An observational measure of both service user engagement in meaningful activity and the contact and assistance provided by staff (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 1600 hours and 1800 hours in the lead up to the evening meal, since this is a period with many opportunities for participation in activity (Mansell & Beadle-Brown, 2011). A one minute interval was used and each service user present at the time of the observation was observed for 5 minutes in rotation. Observations were collected by a team of three observers all trained by the first author.

Observational categories are outlined in Table 2.

INSERT TABLE 2 about HERE

Detailed 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 3514 with the average length of time observed by each participant being 35 minutes (ranging from 5 to 105).

Inter-observer reliability was initially checked during several pilot observations and then two observers collected data in 20% of services involved in the study. Observational data was collected by 2 observers for 720 minutes which also amounted to 20% of observational sample. Reliability was generally satisfactory with an average Kappa statistic of 0.6 (range 0.444 to 0.782). Only three observational categories had Kappa values below 0.5 and these were categories where the behaviour was observed very infrequently.

Participation, opportunities for choice and community involvement

The Choice-making Scale (Conroy & Feinstein 1986), the Index of Participation in Daily Living (Raynes et al. 1994) and the Index of Community Involvement (Raynes & Sumpton 1989) were used to assess the opportunity for choices, participation in activities of daily life around the home and garden and access to community based activities and facilities and contact with family, friends, and neighbours. Internal consistency on each of the scales was very high with Cronbach Alpha's values over 0.9 for all three scales. These measures were completed by the person's keyworker as part of the Service user Questionnaire.

Quality of staff support

Active support

The extent and consistency with which active support was provided was measured using the Active Support Measure (ASM) (Mansell & Elliott, 1996); (Mansell, Elliott, & Beadle-Brown, 2005). The ASM was completed for each individual observed during the visit at the end of the observational period. The observer took detailed notes of everything that happened during the two hour 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 measure is described in greater detail other publications (Mansell and Beadle-Brown, 2012; (Beadle-Brown, Hutchinson, & Whelton, 2012). 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). In terms of inter-observer reliability, there was a strong positive correlation between the observers on overall score on the ASM (spearman's rank order correlation = 0.848; n=30). Kappa analysis was conducted for the grouping of ASM scores into weak (less than 33.33%), mixed (33.33 to 66.66%) and good (66.67% and above) active support, using each observers total scores. This was one of the key variables use to identify skilled support in this paper and the Kappa value was 0.668 (p<0.001 n = 30). Percentage agreement was 80%. Kappa scores for individual items varied and can be requested from the first author.

Contact from staff

The contact codes from the MTS observations described above were used to calculate the amount of time people actually spent receiving contact from staff, including the amount of time they received facilitative help to be engaged.

Other person-centred approaches

A measure was developed to rate the quality of other aspects of support that each individual was seen to receive during the visit. These were based around observations of Augmentative and Alternative Communication (AAC), Positive Behaviour Support (PBS) and the SPELL framework, and were completed by the researchers shortly after the visit based on the detailed notes that they had taken during the observation, the interview with the manager and a review of the records and plans for each individual. Categories included: the extent to which choice was offered; whether Intensive Interaction was used and how it was used; methods of communication used by and with the individual and their efficacy; the amount of visual structure the individual had access to; the quality of staff interactions; the level of empathy; the arousal level of the environment including interactions with the individual; the links that existed for the individual including Person Centred Planning; and the implementation of Positive Behaviour Support. Aspects were marked as being present or not, or were rated on a sliding scale from none of the time to most or all of the time.

In addition, researchers rated the service overall on the use of communication strategies; structure; positive approaches; empathy; low arousal; links and aspects of PBS. Most were rated as the principle being implemented well, misunderstood, or violated OR as being implemented most or all of the time/for all of the people supported, to none of the time/for none of the people supported. The numbers of people seen to be doing any form of exercise during the visit was noted, as well as things such as choice of menu, and nutrition. Aspects of the building design such as numbers of bedrooms, living areas and bathrooms were noted, along with how ‘home-like’ they were on a scale of 1-5 (with 1 – very home like, and 5 non-home like or institutional).

At service level, internal consistency for the 5 item scale for implementation of the SPELL framework was high (Cronbach’s alpha of 0.812 rated for 34 services). For the 6 item scale for the implementation of Positive Behaviour Support (PBS) also showed acceptable internal reliability (Cronbach’s alpha of 0.715 rated for 24 services). Further information on the nature and reliability of these scales can be requested from the first author.

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. 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 Service User Questionnaires for completeness, conducted the review of assessments and plans for each individual, and conducted an interview with the manager and checked the manager questionnaire. At the end of the interview they clarified any questions regarding communication and dealing with any challenging behaviour and met each individual briefly before starting the structured MTS observation. 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 ASM and the individual and service level quality ratings.

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

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 and 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.

The main ethical considerations were around gaining consent. Where possible informed consent was gained directly from the people being supported, using the easy read materials combined with appropriate alternative communication strategies to support the person to understand about the research and decide whether to take part. However for the majority of people it was not possible to gain informed consent in this way due to complexity of their needs and in particular their communication needs. In these cases the first recourse was to a personal consultee (as defined by the Mental Capacity Act, usually a family member or an advocate) who was asked to advise about whether the person would like to take part if they could communicate so. Where personal consultees were not available, managers of the services were asked to nominate a consultee who knew the person well to advise. In addition, individual assent was checked on the day of the visit and monitored throughout the observations. In the case that people appeared uncomfortable or upset with the presence of the observers, procedures were in place to stop the observations. However this was not found to be necessary.

Data Analysis

The analysis reported in this paper includes:

- Descriptive analysis of the needs and characteristics of people supported, the quality of staff support and the outcomes for those who received skilled support versus less skilled support.
- Relationships between active support and other measures of staff support (using Spearman’s rank order correlations and chi-square analysis)

Findings

Participant characteristics

At least some data was available for 110 people and the basic characteristics of the overall sample are presented in Table 3. As can be seen, even though some settings had already been dropped due to the high level of ability of all the individuals in the settings, there were still some people included in the overall sample who did not have severe or profound disabilities. In most of these cases, these individuals lived with people who were considered more severely disabled and so the setting was still included in the research. However some of the analyses reported below will only refer to those who had ABS scores below 151 (a rough cut off used to indicate more severe disabilities, Mansell et al, 2014).

Insert Table 3 about here

Quality of life

Observational data were available for 107 people.

Table 4 below summarises the percentage of time people spent in different types of activities. As illustrated, people in this sample spent on average 44% of their time (26 minutes in every hour) engaged in some sort of social or non-social activity. Some people were engaged as much as 95% of the time observed but others were not observed to be engaged at all during the 2 hour observation. Most of the non-social engagement was accounted for by self-care (eating and drinking), leisure and audio-visual activity, despite the period chosen for observations being one with opportunities for involvement in the activities around preparing the evening meal. People spent on average just under 15% of the time self-stimulating but again with a range from no time to 89% of the time.

Insert Table 4 here

Staff rated measures of participation in involvement were also quite low but with some variation. As illustrated in Table 4, scores on the Index of Participation in daily living, community living and opportunities for making choices were all relatively low. However given that this is on balance a sample with severe and profound disabilities, this is as might be expected.

When out and about in the community, one third of people only interacted with staff and other people they lived with. Almost 50% of people were not known by their neighbours or did not know their neighbours by name. However 80% of people were reported to be treated with dignity and respect by those in the community. The majority (86%) had contact with their family and for 62% their family were activity involved in their life. Just over one third of people were reported to have no friends outside their home and almost three quarters had less than 4 friends outside their home.

In terms of structured daytime activity outside their home, 4% had some form of work (paid or unpaid), 19% had an individualised day programme and less than 20% attended some form of day centre or externally organised day programme (mostly local authority or charity run).

Those who were more able generally experienced better outcomes. For example, they were more engaged (Spearmans' rho 0.305; $p<0.01$) and were rated by staff to participate more in activities of daily living (Spearmans' rho 0.694; $p<0.01$), in community activities (Spearmans' rho 0.312; $p<0.01$) and to have more opportunities for choice (Spearmans' rho 0.270; $p<0.01$). Table 4 also shows the levels of engagement and participation for those who had ABS scores below 151. As can be seen levels of engagement were slightly lower for the more severely disabled group (n=72).

Quality of Support

Table 5 summarises the quality of support received by individuals in terms of active support, communication, the SPELL framework and positive behaviour support. It brings together both the structured observations and the ratings made by researchers on the new measures developed to explore practice.

Insert Table 5 about here

As can be seen there was substantial variation in the quality of the support received by people in the overall sample. Just over 1/3 of people were receiving good consistent active support (a score of over 66.66% on the ASM). Just under half the sample received no assistance from staff to be engaged in any meaningful activity during the two hour structured observation. There was a weak but significant positive correlation between level of ability (score on the ABS) and assistance, indicating that those who were more able got more help from staff (rho = 0.221 $p<0.05$, n = 92), which is clearly contrary to the fact that those with the most severe disabilities need the most help to be able to be engaged.

In terms of communication, there was a lack of use of non-verbal forms of communication, despite staff rating 60% of people they support as not using verbal means to communicate and 18% as not understanding any verbal communication. However 82% of people were observed to only receive verbal communication from staff at least some of the time, showing inconsistency of approach. Seventy-eight percent of individuals whom staff rated as not understanding any verbal communication only received verbal communication from staff at least some of the time (See Bradshaw *et al* ., in preparation) for further analysis related to support for communication.

The majority of people (50%) lived in services where implementation of positive behaviour support (PBS) was mixed, with only 17% of people living in settings where PBS was well implemented. Review of paperwork indicated that staff appeared to have training and there were clear plans for what to do when an incident arose etc. However the main element which resulted in a mixed implementation rating was that there was a lack of support for activities so that people had something to do other than challenging behaviour and were having opportunities to learn new skills – i.e. the positive programming element of PBS was absent. Similar findings emerge if one looks at just the 24 people who were rated by staff as showing 5 or more severe behaviours on the ABC (good implementation 12%) and the 10 people showing five or more severe behaviours on the ABC and challenging behaviour on a daily basis (good implementation 20%). Richardson *et al* ., (in preparation) reports further findings and analysis related to support for people with challenging behaviour and the implementation of positive behaviour support.

Finally in terms of the SPELL framework there was variation in how well the elements of autism friendly practice were in place. The majority of people lived in settings where support in this area was of mixed quality. However some people were receiving good autism friendly support in this area and this was not just true for people with autism. For the

41 people whom staff had recorded as having autism, the overall score on the SPELL measure was almost exactly the same as for the overall sample (mean 75%, range 40 – 100) – as such those with a diagnosis of autism did not necessarily experience more autism friendly support from staff than the sample as a whole (See Richardson *et al* ., for a more in depth look at the experiences of people with autism).

Defining skilled support

Although it had been hoped that the nominated sample might have mapped relatively well on to those receiving skilled support, preliminary analysis showed that this was not the case. For example, only 38% of the nominated services showed consistent high levels of active support and only 12% of the CQC sampled services. As such it was necessary to identify another variable that could be used to group participants in terms of the quality of support they received.

As noted the main variable that has been used in previous research has been whether staff were providing active support and this measure has been found to both clearly distinguish groups of participants and to predict outcomes in terms of engagement in meaningful activities, choice and reduced challenging behaviour. An initial series of Spearman's rank order correlations showed that for this sample the variable with the best correlation with measures of outcome was the score on the active support measure which in turn was related to other measures of skilled support. Table 6 summarises the correlation matrix.

Insert table 6 about here

The correlation matrix illustrates that people receiving better active support also tended to be receiving better support in terms of the frequency of staff contact (and assistance in particular), support for communication, the implementation of positive behaviour support and autism friendly practices. In terms of outcomes, those receiving better active support had higher levels of engagement, more participation in activities around the home and in the community and more opportunities for choice (as rated by staff). Stepwise linear regression of the quality of support variables on the percentage of time people spent engaged in any meaningful activity or interaction, identified that active support explained 31% of the variance in engagement, with adaptive behaviour explaining a further 4% (main effect F=19.12 df 73,2 $p<0.001$ $R^2 = 0.347$). The service level ratings for implementation of PBS, the SPELL framework and good choice for communication did not emerge as significant. Due to the relatively small sample, a series of regression analyses including only the ASM percentage score, the ABS score and one other variable related to quality of support were conducted. None of the variables emerged from these analyses as significant – active support and level of ability remained the only variables predictive of engagement.

Discussion

This study explored the quality of support, the use of person-centred approaches and the quality of life of people with severe intellectual disability and complex needs. This paper highlights the generally low levels of support and the poor outcomes experienced even when living in small community based services. For many people in the sample outcomes were similar to those found in larger care homes and even in some of the older institutions. For the whole sample, only one third of people were receiving consistently good active support and on average people were still spending at least three quarters of their time with no contact from anyone. If one considers only the randomly selected services from CQC registration lists, only 12% of people received good active support consistently. The nature of activities people engaged in were those that required little support from staff – for example eating and drinking and audio-visual activities such as watching TV or listening to music. On average across the whole sample, people spent between 50 and 60% of their time disengaged but with variation - some people spent all of the observation disengaged while a very small number of people were engaged almost 95% of the time. As for previous studies, the variables which best explained variation in levels of engagement, were level of ability and whether staff were using active support consistently.

Although the participants in this sample were specifically recruited because of their levels of intellectual disability and the presence of complex needs, we know from other studies (reviewed and compiled in Mansell and Beadle-Brown, 2012) that it is possible to observe much higher levels of engagement even for those with the most severe needs. Of course, whilst levels of observed engagement aren't the only measure of quality of life, they have been shown to relate positively with other measures of quality of life and as such act as a good indicator of quality of life. As Mansell and Beadle-Brown (2012) among others, point out, engagement in activities and interactions is an essential route to achieving personal development, physical well-being, social relationships, social integration and other domains of quality of life. However engagement in meaningful activities and relationships is also a measure of quality of life, in particular emotional and physical well-being.

Staff ratios in these services were high – so lack of staff does not explain the poorer outcomes for people. This study supports the finding from previous research that it is what staff do and how they do it that is important for bringing about a better quality of life for those with severe intellectual disability and complex needs. It appears that if services get some core elements of support right then other elements of good support (such as better support for communication, better autism friendly practices and good implementation of positive behaviour support) will flow from this. We believe, based on both research and experience of working with many organisations to improve the quality of life of people they support, that this core variable is active support. A lack of such an enabling and empowering approach results in isolation, disengagement and potentially challenging behaviour for those with severe intellectual disabilities and complex needs. Although not necessarily easy to implement (Mansell and Beadle-brown, 2012), the resources needed to do so are less about the number of staff or the amount of money available and more about how the resources are used and the staff supported to work in this way. Beadle-Brown *et al* ., (submitted) found that providing this type of skilled support does not require more staff and does not cost significantly more money but results in significantly better outcomes.

There are a number of limitations that should be acknowledged, not least the relatively small sample size. The intention had been to recruit 200 people in 60 services, 30 randomly chosen from nominated services and 30 randomly selected in the same geographical area as nominated services. Unfortunately the study was recruiting just after the revelations about abuse in Winterbourne View and then the ensuing inspections by the Care Quality Commission. Services were understandably reticent in participating in a study where people would be spending time observing, looking at records etc. There was also a sense of distrust of people coming in from outside. Secondly, some of the services that were recruited, despite checking several times before the visit, turned out not to support people who met the study criteria – in general this was true for people with autism who were put forward as eligible but who did not have severe intellectual disabilities, therefore could not be included in the sample. Thirdly, data collection was hampered and some services lost to the study because of the riots in the summer of 2011 – visits in the areas of the riots had to be cancelled and some where just not possible to rearrange within the timescales of the funding. Finally, the other difficulty in recruitment came from the need to collect information on costs as part of the larger project – some services were particularly reticent to provide that type of information and therefore could not take part in the study.

Although most of the services were nominated by their organisations as providing good support for those with severe intellectual disability and autism, challenging behaviour or profound intellectual and multiple disabilities (and therefore not a random, or necessarily representative sample), the findings from this study confirm findings from previous studies both in the UK and in Australia in terms of the quality of support, relationship with outcomes, and levels of engagement. As such the paper appears to offer some valid insight into the experiences of people with intellectual disability and complex needs in community based settings in the England. There is no reason to believe that this would be any different in similar settings in other countries as the key factors highlighted are related to staff skills and client level of ability, rather than policy or resources.

As most of the research in the past has concentrated on just a small number of measures of staff support - primarily the frequency and quality of the assistance provided - it was necessary to design some new measures for this study to be able to rate the implementation of positive behaviour support, the SPELL framework and communication. As such this is the first study that these measures had been used and they will of course benefit from further development and testing. However one of the limitations of any measure of positive behaviour support is that it is hard to observe – if staff are implementing PBS really well then it should be almost invisible as what you should see is staff working calmly with people and people engaging in a range of activities and interactions, improving their quality of life. So in a skilled team, not seeing challenging behaviour does not necessarily mean that it does not exist. As such observations have to be combined with other forms of data in order to rate what is happening.

Active support as the key measure of skilled support

Identifying one core measure of skilled support is useful for a number of reasons. Firstly it allows one to look at the impact and costs of such skilled support and allows the exploration of the factors that might impact on the quality of support. It is also helpful in terms of describing more succinctly what good services look like for both service providers and for those that measure the quality of services in some way, in terms of identifying how support can be improved. This study explored a range of variables/measures of different aspects of person-centred support that have been identified in the research as related to better outcomes for people with complex needs or as generally good practice.

As noted above, we believe that this core indicator of skilled support is active support. The active support measure has the best relationship with outcomes, explains more of the variance in outcomes and is also positively correlated with other measures of person-centred support.

Active support is also logically or theoretically the most appropriate variable – Mansell and Beadle-Brown (2012) argue that active support is one of the building blocks which need to be in place no matter who is being supported. Providing good effective communication is an essential part of active support but the use of formal alternative and augmentative communication strategies, approaches such as positive behaviour support and autism friendly practices might be more or less relevant depending on the individuals being supported – however without the enabling and empowering approaches to support that have become known over the past 50 years as active support, it is extremely difficult if not impossible to achieve good practice in these other areas, especially for people with severe and profound intellectual disability. For example, research over many years indicates that active support should be a vital component in the support of people with challenging behaviour ((P. McGill & Toogood, 1994); (Jones et al., 2013) and implementation of active support is closely linked to the implementation of positive behaviour support (Ockenden, Ashman, & Beadle-Brown, 2014); (P McGill, 2013). Support for communication is much less useful and much harder to provide if people spend most of their time sitting staring at a wall or pacing up and down the corridor. It becomes much easier to interact with people when there is something concrete and meaningful to interact over, something to communicate about (Bradshaw et al., 2013). A critical element of support for people with autism is the use of positive approaches and expectations – this involves supporting people sensitively and positively to try new things, to grow in their skills (Beadle-Brown and Mills, 2010) – for this staff need to be able to support people to engage in a range of activities, new and familiar. Finally, for those that need the most support to be able to participate even in the smallest capacity, staff needs the greatest skills – for those with profound intellectual and multiple physical disabilities staff often have to be able to provide physical guidance and support – not only to facilitate participation but to provide opportunities for both occupational therapy and physiotherapy.

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Table 1: Characteristics of the services recruited

Characteristics		**Percentage (N)**	**Mean (range)**
Location	South West	20% (7)	
	London	23% (8)	
	South East	23% (8)	
	North East	34% (12)	
Service type	Supported living	71%	
	Residential care	29%	
Sector	Private for-profit	17%	
	Voluntary/not-for-profit	83%	
Established staff:client ratio			3.35 (0.86– 9.33)
Observed staff:client ratio			1.14 (0.44– 4.00)
Homelikeness (1 = very homelike; 5 = not homelike at all)			1.56 (1 – 2.80)

Table 2: Behavioural codes from the measure of Engagement in Meaningful Activities and Relationships (EMACR)

Activity	1. Social activity (SA) 2. Non-social activity (NSA): This category was further broken down into: *Self care*; *Household garden or work activity simple* (no gas or electrical equipment used); *Household garden or work activity using gas or electrical equipment*; *Audio visual*; and *Leisure/recreational/unstructured educational*. There was also a code *Unclear non-social activity* (UNSA) which was used to capture participation by people with profound and multiple disability where staff were providing hand-over-hand support to an individual to take part in an activity but where it was unclear whether the person was engaged.
Contact	1. assistance by staff to engage in a meaningful activity 2. other contact from staff that was not direct assistance. 3. contact from other service users.
Challenging Behaviour	1. self-stimulatory or repetitive behaviour; 2. self-injurious behaviour; 3. aggressive or destructive behaviour 4. other challenging behaviour, which could be used to record repetitive, inappropriate sounds , inappropriate social approaches etc.

Table 3 characteristics of the whole sample (n=110 at the maximum)

Characteristics	**Mean (range) or percentage**
Age	46 years (20 – 82)
Adaptive Behaviour (ABS)	113 (27 – 248)
Percent of sample with ABS < 151 (severe ID)	73%
Mean score on Challenging behaviour measure (ABC)	40 (0 – 133)
% with more than five behaviours rated as severe on the ABC and at least some behaviours occurring on a daily basis.	10%
% male	52%
% white British	83%
% physical disability[2]	53%
% autism	42%
% social impairment	78%
% non-verbal (expression)	60%
% not understanding any verbal communication	18%
% Incontinent (bladder/bowels)	35%/25%
% Required hoisting or manual handling for personal care	35%
% coded as having profound and multiple disabilities[3]	22%

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[2] As recorded by staff on the user needs and characteristics questionnaire.

[3] PIMD 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.

Table 4: Summary of findings on quality of life in terms of engagement in meaningful activities and relationship

Observed measures of quality of life	Percentage of time spent – whole sample (range)	Percentage of time spent – ABS < 151 (range)
Social activity	13% (0–64)	12% (0 – 64)
Any non-social activity	34% (0 – 90)	30% (0-90)
Non-social activity – self care	10% (0-64)	10 (0-64)
Non-social activity – simple household	6.6% (0 – 72)	4 (0 – 67)
Non-social activity – complex household	1.6% (0 – 36)	0.5 (0-11)
Non-social activity – audio visual	8.2% (0 – 79)	10 (0 – 79)
Non-social activity – leisure	8% (0 – 77)	6 (0 – 60)
Any engagement	44.1% (0 – 95)	39 (0 – 95)
Self-stimulatory behaviour	14.5% (0 – 89)	14 (0 – 83)
Other CB	5.4% (0 – 94)	6 (0-94)
Staff rated measures	Mean percentage score and range	
Index of participation in Daily Life	35 (0-100)	27 (0 – 92)
Index of Community Involvement	48 (19-81)	45 (19 – 81)
Choice making scale	55 (1-100)	52 (1 – 100)

Table 5: Quality of staff support

Element of skilled support	Mean (range) or % people
Active support	
Mean percentage of time receiving any contact from staff	24.5 (range 0 – 85)
Mean percentage of time receiving assistance	6.3 (range 0 – 69)
Percentage of people receiving no assistance	45%
Percentage receiving assistance >13% of the time[4]	15%
Percentage of people receiving no contact at all from staff	12%
Mean percentage score on the active support measure	59 (5 – 95)
Percentage receiving good consistent active support	37%
Percentage receiving good support for a wider range of choices	22%
Communication	
Percentage where staff only used verbal communication	82%
Percentage supported by a team where communication was rated as good and appropriate most or all of the time	36%
Percentage receiving intensive interaction	17%
Positive Behaviour Support	
Percentage of people living in services where PBS was rated as well implemented overall	17%

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[4] 14% was the lower level found in the pioneering Andover services set up specifically to provide high quality support (Felce, de Kock and Repp, 1986)

Element of skilled support	**Mean (range) or % people**
SPELL framework:	
Overall percentage score on the SPELL rating	75 (40 – 100)
Percentage living in a setting where the principle was clearly in practice	
Structure	40%
Positive approaches	44%
Empathy	37%
Low arousal	18%
Links	55%

Table 6. Summary of correlations between percentage score on the ASM and other variables describing the quality of the support received.

	Percentage score on the ASM	**Any contact from staff**	**Assistance from staff**	**Communication**	**PBS**	**SPELL**
Percentage score on the ASM		$.530^{**}$	$.513^{**}$	$.759^{**}$	$.282^{**}$	$.749^{**}$
Any engagement	$.498^{**}$	$.363^{**}$	$.205^{*}$	$.316^{**}$	.128	$.319^{**}$
Any contact from staff	$.530^{**}$		$.505^{**}$	$.422^{**}$	.082	$.436^{**}$
Assistance from staff	$.513^{**}$	$.505^{**}$		$.304^{**}$	.119	$.363^{**}$
Participation in tasks of daily living (IPDL)	$.486^{**}$	.134	$.421^{**}$	$.270^{*}$	-.154	$.247^{*}$
Opportunities for choice (CMS)	$.223^{*}$	.150	.204	.137	.020	.177
Index of community involvement (ICI)	$.318^{**}$	.104	$.274^{**}$	.166	-.126	.084
Communication rating	$.759^{**}$	$.422^{**}$	$.304^{**}$		$.234^{*}$	$.849^{**}$
PBS implementation	$.282^{**}$	.082	.119	$.234^{*}$		$.299^{**}$
SPELL implementation	$.749^{**}$	$.436^{**}$	$.363^{**}$	$.849^{**}$	$.299^{**}$	