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Citation for published version

Bradshaw, Jill and Beadle-Brown, Julie and Richardson, Lisa and Whelton, Beckie and Leigh, Jennifer S (2018) Managers' views of skilled support. Journal of Applied Research in Intellectual Disabilities. ISSN 1360-2322.

DOI

https://doi.org/10.1111/jar.12444

Link to record in KAR

http://kar.kent.ac.uk/66535/

Document Version

Author's Accepted Manuscript

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Introduction

Since the introduction of the UN Conventions on the Rights of Persons with a disability (2006), policy related to people with disabilities across many parts of the world has focused on promoting the inclusion of people with disabilities in society and on ensuring that they experience full participation and self-determination across all aspects of their lives.

However, research highlights that for many people the reality is very different, with many people still living in institutional settings and experience exclusion and a lack of choice and control (Mansell, Knapp, Beadle-Brown & Beecham, 2007; Šiška, Beadle-Brown, Káňová & Tössebro, 2017). This is particularly an issue for people with intellectual and developmental disabilities, especially those with more severe disabilities and complex needs (Šiška, Beadle-Brown, Káňová, & Tøssebro, , 2017 & Šiška, Beadle-Brown, Káňová & Kittlesea, 2017).

Although living in ordinary housing dispersed in the community is a necessary condition for improved quality of life (such as inclusion, independence, self-determination, wellbeing), it is not sufficient (Mansell, 2006). Apart from the severity of disability and the presence of complex needs, only one factor has emerged from the research as predicting quality of life of those with intellectual and developmental disabilities — whether those services are providing a facilitative style of support that focuses on enabling and empowering people with disabilities (See Bigby & Beadle-Brown, 2016 for a recent review). One approach for providing such support, and the one with the most research, is usually referred to as [person-centred] active support (Stancliffe, Jones, Mansell & Lowe, 2008; Mansell & Beadle-Brown, 2012). Other person-centred approaches, albeit less well researched, also focus on

promoting better quality of life. Positive Behaviour Support (PBS) defined by Gore *et al* (2013) as a framework for understanding challenging behaviour within the contexts in which it occurs and using this understanding to develop, implement and evaluate support which increases the person's quality of life. Support for communication is also key (Bradshaw *et al*, 2013). Total communication (Jones, 2000) is an inclusive approach where all approaches to communication (e.g. signed communication, objects of reference, speech, symbols) are valued and supported. Finally, the extent to which practice is autism friendly is also relevant with one approach for doing this being the National Autistic Society SPELL¹ Framework (Beadle-Brown & Mills, 2010). Beadle-Brown *et al*. (2016) explored all of these approaches and found measures of active support were the best predictors of quality of life and were also highly associated with the other measures (e.g. good support for communication and autism), as such they argued that active support can be taken as the core measure of skilled support.

However, research in the UK and Australia has found that good implementation of approaches such as active support is only found for between one quarter (*Netten et al.*, 2010) and one third of people with intellectual disabilities in small group homes (supporting six people or fewer) and supported living arrangements (Mansell, Beadle-Brown & Bigby, 2013; Beadle-Brown *et al.*, 2016). The factors that predict whether or not staff work in this way are less well researched (Bigby & Beadle-Brown, 2016).

The one thing we do know is that managers are critical to providing the support and motivation required to enable staff to work using enabling approaches (such as active

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¹ The acronym SPELL stands for Structure, Positive approaches and expectations, Empathy, Low arousal, Links

support) (Mansell & Beadle-Brown, 2012). Particularly important appears to be whether staff are receiving practice leadership, which involves managers leading by example, modelling, coaching, reviewing how support is being provided through supervision and team meetings and organising staff to deliver support when and how the people need and like it (Beadle-Brown, Mansell, Ashman, Ockenden, Iles and Whelton,, 2014; Beadle-Brown, Bigby & Bould, 2015; Deveau & McGill, 2016).

In the UK (as in many other countries), the current context in social care is one of austerity and cuts to funding. These cuts were presented as being necessary in order to reduce dependency on the state (Jensen, 2013). Runswick-Cole & Goodley (2015) describe how austerity has been 'constructed as a rationale antidote to irrational obsession with spending' (p.165). The impact of the cuts on people with intellectual and developmental disabilities is described in Sully & Bowen's (2012) report for the Learning Disability Collation, with Local Authorities reported as making cuts or efficiency savings and tightening eligibility criteria. Although Beadle-Brown, Beecham, Baumker, Leigh, Whelton, & Richardson (submitted) found staffing was no greater and cost of care packages no higher for those receiving good active support compared to those not receiving such good support, it is possible that the impact of the cuts is currently greatest in terms of the ability of managers to provide practice leadership.

This paper sets out to explore the views and experiences of managers in small community based residential services and supported living teams. In doing so we explore their views around the aim of their service, their understanding of active support and the challenges they are currently facing in fulfilling their role.

Method

This paper focuses on the managers' views gained at one point in time using qualitative interviews. Managers were recruited as part of the XXXX (2016) study.

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.

Participants and Settings

Interviews were conducted with 35 service managers (72% of whom were female). Of the 35 services included in this study, 71% were classed as supported living and the rest were small group residential care services with the majority run by voluntary/not for profit organisations (83%). Some managers were managing services in addition to those included in this study. The services were spread across the United Kingdom in London (23%), the South East (23%), South West (20%) as well as the North East (34%). The basic characteristics of the overall sample of service users are presented in XXXXX (2016). In summary, services users ranged from 20 – 82 years of age, 73% had an Adaptive Behaviour Scale (ABS) Score below 151 (a rough cut off used to indicate more severe disabilities, Mansell Beadle-Brown & Bigby, 2013), 42% were reported as having autism, 53% had a physical disability and 10% were reported as having more than five behaviours that challenge rated as severe (with at least some behaviours occurring on a daily basis).

Measures

Semi-structured interviews were conducted based on the interview guide in appendix 1. The interview guide was developed in consultation with advisory group members and piloted in a service before being finalised. Although the guide includes specific questions, a degree of flexibility and responsiveness was maintained within the interview and interviewers were free to ask follow-up questions. Interviews lasted around an hour, were audio-recorded and then transcribed.

Data Analysis

Thematic networks are 'web-like illustrations (networks) that summarize the main themes constituting a piece of text' (Attride-Stirling, 2001). Analysis involves the interpretation of written text. Attride-Stirling (2001) describes the stages involved as coding the material, identifying the key themes, constructing the thematic networks, describing and exploring these thematic networks, summarising the thematic networks and then interpreting the patterns. The thematic networks are presented illustratively, with links shown between the global themes (which consist of organising themes and basic themes). These are superordinate themes which capture the principle interpretations. Basic themes describe key issues that have emerged from the data (and are descriptive of coded text) were then grouped into the organising themes, which show related issues. In the thematic network, the basic themes are read clockwise, starting from the top.

Codes were developed during the process of transcription. The data were then coded using QSR NVIVO and key themes were agreed upon by the research team.

Results

This paper examines the two global themes which emerged from analysis: 'Individualised not contextualised' and 'Supporting to do'.

Figure 1 about here

1. Global theme - Individualised not contextualised

This network represents participants' views and experiences of the service aims and how these aims are realised. This can be seen in Figure 1 (Thematic networks analysis) as global theme 1, organising theme 1.1. Basic themes are in *italics* in the text. The participants are identified by their service number.

1.1 Organising theme – Multiple aims

This theme relates to participants' understandings of what the service aims are. Most managers agreed that the service aims included *increasing independence* e.g. "....so the aim is independence and the highest level that each of them can achieve in that..." (P5206). In terms of *skills development*, managers talked in general terms about the need to develop skills but made specific mention of daily living skills e.g. "....to support service users to enhance their skills, their daily living skills first of all and to become as independent as possible...." (5008).

They described daily living skills as being linked to people having increased independence. Participants acknowledged that diversity amongst the population of people supported meant that independence level was likely to be influenced by the level of need and hence, aims needed to be individualised and *person-centred* e.g. "....really the aims of the service

are to provide people with a person-centred support in the way that they want it built around their needs..." (5202).

Managers also discussed the need to support people to achieve the aim of participation as a valued member of local communities e.g. "...she gets 24 hour support due to the level of her needs and to continue to support her really to be part of her community as well as a valued member of the community..." (5011). Some, though not all managers, discussed the need to provide individuals with choice and control e.g. "...we are promoting choice, his control over choice and the impact that may have on his life..." (5201).

Maintaining and improving *health and wellbeing* was an aim for some managers. They discussed this in terms of keeping people safe and acknowledging vulnerabilities but also in terms of the people they supported being happy e.g. "...the health and wellbeing of the people we support and that is the kind of base that they are safe and they are happy and they are protected from anything that they may be vulnerable to and then we build on that..." (5206).

Finally, a small number of managers acknowledged that they were having to achieve what they could within the constraints imposed on them by *budgets* and described a service aim as being to provide a good service within an agreed budget e.g. "...is to provide better quality of life and so to work with him to provide high quality of service and to work within the agreed budgets..." (5009).

<u>Summary</u>

The managers' discussed a number of key aims for their services. They reported the need to involve people in their communities, to provide individualised support that enabled people

to achieve independence and to enable people to make choices and exert control. They reflected on the need to keep people safe and to ensure people were happy. Some managers were explicit in that they needed to achieve these aims whilst keeping within an agreed budget. How these aims had been decided upon will be discussed in the next organising theme.

1.2 Organising theme – creation of goals

Having had the opportunity to discuss the service aims, managers were asked to discuss where the service aims had come from and how the aims had been decided upon. They identified a number of key factors which had led to the development of service aims.

The *service users* who were being supported by the service were seen as having a role in deciding the service aims. This included asking users explicitly what they wanted from the service and gaining feedback on whether or not the service was meeting their needs. It was also described in terms of staff recognising service users' needs "...It kind of centres on us recognising what and for [name of service user] to tell us what it is that works for him..." (5004).

For some managers, this meant *not making assumptions* about what people might want from the services that were being provided "...don't just assume that you know what they want..." (5014).

The *organisation* was seen as influencing the aims of the service for a small number of managers. This was described as working together with the service user generated aims

"...ensuring that people get the support they want in the way they want it and that we are working in line and towards people's aims and the organisations aims and objectives..."

(5202).

Managers described these aims being embedded within training and mentioned in staff inductions in particular.

Family and friends were seen as having an influence on service aims, in addition to the organisation and the service user e.g. "...a) the organisation tells us and b) we have sort of had input from ... the guy's family and friends and ... sort of like using the best guess in places where we can't get information from them..." (5203).

Other professionals were also mentioned as having input into the service aims "...care managers and other professionals involved in her life..." (5601). Some managers also mentioned the regulatory bodies as having an influence on service aims "..it is from the outcomes of the Care Quality Commission and it is the standards that are all set for us to abide by..." (5402).

One manager also mentioned *legal obligations* such as having a duty of care and compliance with the terms of a tenancy agreement:

...there is still an element of a duty of care so we have to make sure that he is safe, he is protected and that he has the support he needs to maintain his tenancy and that his finances are managed in a way which is safe. And so there are legal obligations that we have as a provider but the more quality driven aims are driven by [name of service user] really... (5004)

<u>Summary</u>

The question about where the aims had come from was one which managers had some difficulty in answering. Most managers were focused on individual service users and made reference less often to organisational aims. How these aims were realised in practice will be discussed in the next organising theme.

1.3 Organising theme – internal analysis

In this organising theme, information about the ways in which managers achieved the service aims is presented. Managers were asked about challenges they faced in realising these aims and how they would know if they had achieved a particular aim. Participants, like in organising theme 1.2, continued to focus on individuals.

These *service user* items included a focus on the ways in which individuals could be supported to achieve the aims relating to independence, skills development, choice and control and participation. They included developing individual communication strategies to enable people to participate and make choices and using person-centred approaches to support people to become more involved "...develop them initially around the communication skills to live an independent life to be able to do ... no matter how small the task is as long as they can develop their independence..." (5010).

Feedback from service users was also seen as being important. The used measures included asking service users how they felt about the service they were receiving and observing service users in order to make judgements about how they were feeling "...Through various talks with (name of service user)..." (5208).

It also involved more *objective measures*, including levels of challenging behaviour " ...they have seen the changes in the levels of his behaviours..." (5004). These were seen as being important in that levels of challenging behaviour were described as a possible threat to tenancy agreements "which may potentially put his tenancy at risk" (5004).

Finally, feedback from external people was important in evaluating whether or not a service was meeting its aims. This included from funding authorities, from other professional and from family and friends "...we kind of take the feedback from other people [outside the service]...and they [the funders] have celebrated the successes that we have had..." (5004).

<u>Summary</u>

Participants, like in organising theme 1.2, continued to focus on individuals. Whilst it is encouraging that they valued feedback from service users, it was unclear how they had been able to gain user views, particularly given the communication needs of the people they supported. This individual approach to service evaluation lacks the means to compare service performance against other services and to problem-solve at more systemic levels.

Summary of global theme one: Individualised not contextualised

Managers shared many of their understandings of the ways in which service aims are developed and evaluated. Lack of reference to external or comparative data to determine quality is particularly relevant.

2. Global theme – Supporting to do

Participants' views and experiences of person-centred support were explored in this second global theme. Given Beadle-Brown *et al.*'s (2016) finding that active support was the best predictor of quality of life outcomes and closely associated with other person-centred approaches the analysis reported here focuses on managers' views and understanding of person centred approaches such as active support, as the best predictor we have of the presence of skilled support.

2.1 Organising theme – It's hard to define

Participants had difficulties defining active support. They described it as part of people's daily routines "Active support is just part of the daily routine with whatever they happen to be doing." (5206).

They discussed it in terms of *treating people the same as others* and providing care and support as they themselves would like it to be "You yourself treat people as how you would like to treated and if you were having support and care, you know, what would you like your care and support to be like." (5014).

With the staff role being to work out which parts of tasks people could be *engaged* in "To try and work when they are doing tasks, to try and involve people to do the parts that they can do and to try and keep them engaged." (5202).

For the majority of participants, there was an element of this support *achieving an action:* "Active support is something we do daily... actively engaging with them, supporting them to achieve tasks (5409).

Whereas for a smaller number of participants this was less of a focus and the importance of spending time with the individual received more emphasis "....whether that is just through interaction of talking to the person, saying what they are doing or sensory of letting people feel what they are doing and hand on hand and you know...." (5202).

Similarly, choice was identified as an important element by only a small number of the managers interviewed "So people are not left [on their own with nothing to do], people can make choices" (5011).

<u>Summary</u>

Managers found it difficult to describe skilled support other than by reference to using person-centred approaches such as person-centred active support. When asked to define these approaches, they able to describe the approaches with reference to what people might be doing if such approaches were followed. For most managers, active support was seen as task focused with an emphasis on the person being engaged in doing something to achieve an end 'result'.

2.2 Organising theme – It's just what you do

Participants described ways of implementing active support. For some services this was seen as a natural or *instinctive* way of working. Participants varied as to whether they saw this as being something natural, something that didn't need to be taught "...stuff probably happens but it happens because it is common sense..." (5206)

Or where they had been taught but the approach had now become *embedded* to the extent that conscious thought was no longer necessary "...is just sort of second nature to us now to include her in everything..." (5601).

Others perhaps implied that they had been using approaches for some time but that terminology had changed and that these were *old approaches with new names "I think we call it active something, active support at the moment"* (5208). The staff role in *enabling rather than caring for* was highlighted by participants "We try and step back and do less and let the people we support do more" (5206).

When questioned about monitoring of implementation, staff *record*ed implementation in a number of ways, including daily notes and files "...we have a working section in our daily notes where we can record things about what we have done, what we have tried and what we might have learnt from it and then that will be ... filled..." (5203).

Whereas others saw no need to *monitor* formally as it was happening "...there is no need because it happens..." (5009). Or because they were lone working "...they are not really monitored because you are lone working..." (5105).

For a small number of organisations, recorded information was *reviewed* "....we try to review things like at team meetings to just say like how it is going..." (5011).

<u>Summary</u>

Lack of clarity around what skilled support comprised of, together with comments that it was an instinctive way of working, or one that was so embedded that it was 'just what you did' made it difficult for managers to answer questions about how such approaches were monitored. Monitoring, where it took place, was more likely to be described as an informal

process. Given these issues, what were managers' views about how staff had gained the skills to work in person-centred ways?

2.3 Organising theme – Gaining skills in active support

Managers were asked about what training they and their staff had had in person-centred approaches as part of a topic around how they had become skilled in their work.

Managers reported a role for *training* but some implied that the theory alone was insufficient "Yes, there is a basic training in PCAS [person-centred active support] unfortunately it is now only the theory online, it used to be that people attended workshops in PCAS" (5008). Some managers reported *modelling* but this was again described informally and as ad hoc "...we also try to do things like modelling but probably not consciously" 5203. Whereas in other services, on the job training via *mentoring* was seen as key "They develop a lot on the job, experience, mentoring I am always there to mentor them on the floor" (5010).

Observing was also described as a possible strategy and for some, was an important part of the senior support workers role:

I like to think that the seniors are observing all the time because that is part of their role is to observe that practice is to standard and to what we were expecting people to be getting and so really when a senior is on shift they would be observing what was happening all the time and ...planning the shift (5202).

Whereas wider *organisational support* was rarely acknowledged "...but we do have a person centred sort of manager, she supports if you need any training around it, if she needs to

come in and see certain things" (5014).

<u>Summary</u>

It was difficult to gain information about the ways in which skills had been gained as many managers reported that this way of working was instinctive or just 'what they did'. Some people remember having had training previously, either carried out by externally or provided internally. Some elements of practice leadership models could be inferred though were not always explicit within their responses to questions.

2.4 Organising theme – Challenges and benefits

Managers were invited to discuss the challenges and benefits of working in a personcentred way. Clear benefits were seen in terms of *outcomes for the people* they were supporting:

Massive, confidence and pride, self-pride ...you will find they have more respect for their belongings, they try all sorts of new things so they have a greater worldly knowledge, they understand more how things work and the input they have to have to make things happen (5206).

However, the majority of managers interviewed focused on the challenges. These included difficulties around *challenging behaviours* "You know these are challenges at times you probably think you have done all you wanted to do why is she shouting why is she screaming but still and so we still deal with it" (5009).

Although difficult in the short-term, these were outweighed by the *long-term benefits*:

Active support as a means of developing we all know that we will get a lot more challenges the more that we try and push but all the staff as well are also aware that after these challenges, this becomes part of the routine (5203).

Participants also mentioned the challenges associated with supporting people as they aged:

Um well the obvious one is because people get older every day and I can observe that X like her mobility is really getting poor and um so in future all that is going to have an impact like deteriorate her mobility and health" (5011).

High staff *turnover* was problematic in some services. Managers reported that it was difficult to induct new staff into the approaches to know whether staff had the necessary skills.

That is where changes of staff have major impact because we can trust ourselves to step away and know that that person is safe in what they are doing and they are going to do a good job and they can understand any dangers, if somebody new comes in it is very difficult without knowing the person to know what they are capable of (5206).

This was in part due to their view that *knowing the service user* was of greatest importance "Again it is all about knowing the person..." (5206).

Offering choices for people with very severe and profound multiple intellectual *disabilities* was also seen as challenging.

I think that another area that can be quite challenging because we work in a PC [person-centred] way and we want to involve people and give them as much choice as possible and make it their life it is very challenging because of their level of disability

to do that and also sometimes to get staff to see that (5202).

Summary

Managers discussed a number of challenges and some benefits of person-centred approaches. They reflected on the skills and experiences gained by the people being supported. New staff were described as presenting challenges for implementation, based partly on their assumption that knowledge and skills were person-specific. The level of disability was also sees as creating some barriers, not least in the ability to offer choice to people who had very limited ways of expressing preferences. However, the biggest challenge reported centred around finances and this is presented as the next global theme.

2.5 Organising theme – Funding cuts

Participants expressed a number of concerns regarding the impact of current and future cuts to services. They described the impact in a number of ways. Lack of funding meant that some *training* had been reduced "to be supported to do other training, which actually with things like NVQ [National Vocational Qualifications which are work-based awards] and diploma are not as easy now (due to financial matters) to access than before" (5008). They were also reported to have had an impact on service user *recreational activities* such as holidays, activities and going out.

I think it is around money I think it worries everybody at the moment I think because [name of service user] is being threatened to have his... he goes to a craft group two afternoons a week and [name of funder] are wanting to cut his funding (5007).

Participants acknowledged that packages that had been agreed would not be funded under the current financial climate and that this would have meant a *deterioration in the quality of service placement* and sometimes, a different model:

"...and the costings and the panel was agreed two years ago before things got really, really tight. If we were going to panel now, he wouldn't get that...kind of getting into the realms of it being a care home under a different name really..." (5004).

They reported that *current funding was very much under threat* "We do have a very good relationship with care managers [term used within this organisation to describe managers whose roles focus on care packages] but it has become very clear when they have come here the past few times that they are under pressure to find a way of cutting anything" (5009).

Other services reported managing funding cuts by introducing *shared hours* "I wouldn't say that it's a lesser quality of support that they get in so much as the sharing of that time from that staff member and so they mightn't have as individual attention that they might have". (5202). Or increasing the use of *volunteers* in order to try to maintain current levels of activities and commented that to maintain this we need "input like getting volunteers who can come and do things with them" (5010).

Managers were also concerned about impact on *core spending* "It's things like the food budget" (5203).

The current management of cuts to funding seemed to have impacted on the *management* of services rather than on cuts to frontline staff "I would say yes but not to frontline staff's, not to frontline staff's maybe to management because I used to manage two Services up 'to

last year and it increased to four and this year it is now seven" (5011).

Though of course, having less managerial support was seen to eventually impact on the service quality.

I was saying we have to provide high quality of service, with low income, with low money, and so with the government cutting and cutting and cutting and so this cutting just continues to be on and on and this is going to affect her (5009).

<u>Summary</u>

Past, current and proposed cuts to services were all presenting with challenges to service quality. Some managers reported that creative use of resources had minimised the impact on the service users in the short term. The difficulties of managing remotely are dealt with in the final theme.

2.6 Organising theme – Multisite working

Many organisations had tried to limit the impact of funding cuts on frontline staff. One strategy employed was to increase the number of services that each person managed. Sixteen managers had experienced an increase in the number of settings they managed (range two to -seven settings). Two managers described reductions in their management hours in their single settings. The remaining 17 managers were not explicit. This final organising theme considers managers' views of the changes this way of working had necessitated. It had reduced the amount of *time* that managers spent in houses

"I remote manage for the majority of the time" (5004)

"...and I just wish Ii had time as well, even spending quality time with staff, rather than just "oh come on, let's do your supervision"... but it's always seems to be like "go go go"... and the second you are then taking on other service" (5409).

Managing remotely often led to a *delay* in responding to an issue "remote managing is quite challenging to be honest because very often you are dealing with information after a delay" (5004).

Often, the managers were getting *less support from the people above them*, who had also taken on more work "I am stretched and not only myself, my managers are also stretched because they are working across Boroughs" (5011).

Mentoring from a distance was also problematic in that managers did not always have *first-hand experience* of the issue. "My role is more mentoring the staff, I would say...Saying, telling people quite openly that I haven't got a clue but you seem to so let's go with it." (5201).

Less time also led to a *change in roles* from those managers had held previously.

"When I used to do the support, eight hours, one shift with the staff member a week, so much better than a weekly check where you can spend an hour or 2 in the service and I think you pick up different things when you are actually physically there to support and lead" (5202).

Managing more services meant that managers only had time to do *essential activities* with staff "and I just wish I had time as well, even spending quality time with staff, rather than just "oh come on, let's do your supervision"... but it's always seems to be like 'go, go, go"

(5409).

Finally, managers were concerned about the *Impact on Quality* from not being able to give enough attention to the service "...if you want a quality service, you got to have quality time..." (5409).

<u>Summary</u>

Having greater responsibilities impacted on the quality of support that the managers felt able to provide. They also reported feeling less support by their managers, due to similar constraints. Managers reported having to work in a more hands-off way and felt that this was problematic in not having direct experience of the issues and in the delay in responding that this often caused.

Summary of the global theme 2: Skilled support

Some participants viewed skilled support as instinctive. Others reported it as task-focused. Though participants were not always able to describe active support in any great detail, they were able to describe some ways in which active support as an approach was implemented and monitored. Services varied in terms of how formal their approaches to implementation and monitoring were. Training was seen as useful but the classroom-based aspects were described as needing to be reinforced by practical support, including mentoring and on-the-job training.

Providing person-centred support was reported to present with both challenges and

benefits. These were related to both individuals' support and to staff. However, the cuts to funding were seen as posing the greatest challenges to service quality. Despite trying to keep the cuts away from frontline staff, managers were aware that their reduced role in services (as a consequence of reduced funding) was causing some difficulties.

Comparing themes generated by mangers of services observed to provide better active support and those where active support was weak or mixed

Our initial intention had been to uncover any differences in managers' perceptions, according to the quality of support being provided (see XXXXX, 2016 for methodology used to determine support quality). As noted by XXXXX, services were rated as showing good active support if the average active support measure score was greater than 66.67%. However, no differences in themes or subthemes emerged between the two groups of managers.

Discussion

This paper has focused on describing the views and experiences of managers given the essential role they are thought to play in the shaping of staff skills and motivation, which in turn determine the quality of life of people receiving support.

As might be expected given UK legislation and major pieces of intellectual disability policy (Department of Health, 2001; 2009) over the last few decades, managers most commonly reported services aims as focused on being individualised, person-centred, and promoting independence and choice and control. Managers generally reported these as individual concepts rather than as part of the concept of quality of life (Schalock ., 2002) and more global concepts such as human rights did not feature in their descriptions.

Two of the quality of life domains which were, perhaps surprisingly, less frequently mentioned were physical and emotional wellbeing. For the few that did mention this, it was primarily focused on safety and protection and general happiness with little mention of other elements of wellbeing. At the point of data collection for this study, wellbeing was part of health and child/family related policy, less mentioned in social care related documentation and generally missing in learning disability specific policy in the UK. Given that the Care Act (2014) uses both wellbeing and quality of life as principles, awareness of these elements might change in coming years. This does, however, depend on senior managers translating government policy into organisation policy and objectives in a way that is easy for managers and staff to operationalise.

Managers did not mention the influence of general policy in terms of the origins of service aims nor did they often mention the overall aims of the organisation. Most of the aims they described were related to the people they supported specifically and managers described the importance of not making assumptions but recognising service user needs and what they wanted from the service. However, given that many of the people in the services included had severe and profound disability and communication difficulties, it was unclear how service user's views had been ascertained. It appeared to be primarily informal and carried the risk that staff were interpreting people's needs and wants based on their own views and experiences. More systematic approaches such as the "See what I mean" guidelines described by Grove, Bunning, Porter & Morgan (1999; 2000) would help services in this. In addition, it is argued (Bradshaw *et al.*, 2013) that skilled support in terms of active support is critical for staff to be able to communicate with people and also informs staff

about individual's preferences and needs, which in turn helps to identify potential longer term aims and objectives for individuals.

Family and friends were also seen as important sources of information about what individuals might want or need the service to provide and the importance of involving families has been highlighted elsewhere (e.g Morningstar, Turnbull & Turnbull, 1996).

However, we know that families are often excluded from decisions about their family member, especially where people are displaying behaviour that is seen as challenging. The lack of involvement of families was seen as a core factor in the Winterbourne View scandal, where families were not allowed to visit their family member on the ward (Flynn, 2012).

The Raising our Sights report (Mansell, 2010) also highlighted the issue of needing to listen to and work with families.

Although not mentioned consistently, other influences on service aims included: the organisation; external professionals involved in the life of the people supported; the regulatory body (The Care Quality Commission); and legislation and a general duty of care. These were presented more in terms of requirements that needed to be fulfilled rather than about improving the quality of life outcomes of the people they supported. In the UK there is no policy document that talks about skilled support in terms of active support - the focus has been on person-centred planning (DoH, 2001; Mansell & Beadle-Brown, 2004) and more recently on positive behaviour support (NHS England, Local Government Association & the Association for Directors of Adult Social Services (2015a).

Traditionally inspection and registration processes has not focused on assessing the lived experience of people with intellectual and developmental disabilities, other than through interviews with people who could talk. Whilst subjective measures are important primarily

providing credibility, objective measures are important for providing reliability (Brown, Hatton & Emerson, 2013). For those with more severe disabilities, observing how people spend their time, how they are supported, how staff interact with them is critical to getting a real sense of their lived experience (Mansell, 2011). Observation has not been a compulsory part of inspections although an observational tool for inspection has been available to inspectors for approximately 10 years. In addition, Beadle-Brown, Hutchinson & Mansell, (2008) and Netten *et al.*, (2010) showed that there was a lack of agreement between inspector's ratings of quality and more objective research measures of quality of life and quality of support, the closest links being with measures of process such as planning, assessment, staff training etc.

As already noted, research has generally found that active support is key to both achieving better outcomes for those receiving support and in making it easier to implement other elements of person-centred support such as effective communication, positive behaviour support and the provision of autism friendly environments (Stancliffe, Jones, Mansell & Lowe, 2008; Mansell & Beadle-Brown, 2012; Bradshaw *et al.*, 2013; Beadle-Brown et al., 2016; Bigby & Beadle-Brown, 2016).

Bigby & Beadle-Brown (2016) report that in terms of explaining why the quality of support is variable, the areas with the most evidence include a positive, person-centred staff culture and staff receiving practice leadership. In addition to having clear aims and values to guide the work of staff and shared vision that focuses on the quality of life of the people supported, those providing practice leadership need to have both a clear understanding of active support and other person-centred approaches and skills in working in this way in order to lead their team (Mansell & Beadle-Brown, 2012; Deveau & McGill, 2014; Beadle-

Brown, Mansell, Ashman, Ockenden, Iles & Whelton, 2014 and Beadle-Brown, Bigby and Bould, 2015). Most managers did not report a strong shared vision or aims for the service and whilst this should be led by senior management (Mansell & Beadle-Brown, 2012), mangers did not seem to relate what they were trying to achieve to the aims and values of the organisation. This may be for a number of reasons: lack of clarity of the mission statement of the organisation; lack of operationalisation of the aims and values into what frontline leaders and staff have to do day by day. Other elements of practice leadership such as modelling and observation featured in some managers' description of how staff were supported to become skilled in active support but mostly this was ad hoc and informal rather than systematic.

Whilst some managers felt that supporting people in this way was instinctive, that people just did it, echoing Bradshaw & Goldbart (2013), others felt that training was important. They particularly noted that classroom based training had a role to play but on its own was not enough to ensure the relevant skills were required. Again, this is consistent with previous research that indicated that classroom based training was not sufficient on its own (Bradshaw & Goldbart, 2013) and that hands-on training was required for implementation (Jones, Felce, Lowe and Bowley, 2001). Wider organisational support was rarely mentioned as facilitating the skills of staff.

The challenges experienced by managers in terms of providing skilled active support included the characteristics of particular individuals they support – such as the presence of behaviour they found challenging or supporting people as they aged. However, by far the biggest challenge mentioned by managers was funding and budget cuts. Assenova, Bailey & McCann (2015) highlighted the risk of spending cuts adversely effecting vulnerable groups

(such as people with intellectual disabilities). The managers highlighted the impact on training but also on the funding available for activities, transport and food. Managers reported that they felt any current funding was under threat and that, in some situations, they were managing through the introduction of volunteers. Another approach to dealing with austerity and avoiding cutting direct support was to share managers across services, meaning that they were less responsive, less likely to know what was happening in services, less able to provide practice leadership and having to pass on some management tasks to those staff who should have been in practice leadership roles, thus taking more time away from service users.

Adequacy of the data

Qualitative research can be appraised according to four principles (Spencer, Ritchie, Lewis &Dillon. 2003). Firstly, this research is contributory in that it increases our understanding of the views of managers around what skilled support is and around how this is implemented within services at a time of austerity. Secondly, it is defensible in design in that the research strategy enabled the researchers to gather views, with a flexible approach, using structure but enabling new topics to emerge. Thirdly, rigor has been addressed in collection, analysis and interpretation of the approach, the latter using Thematic Networks Analysis. Finally, in terms of credibility of claims, it is acknowledged throughout that there are possible differences in interpretation. Where other evidence exists, this has been discussed.

Why where there no differences between managers from good and less good services?

One possible explanation that requires some attention is the possibility that the definition of "good" support employs a threshold that may be too low. A score of 66.67% represents some good scores on items in the scale but does not equate to good on everything, or even

the majority of items. Although having a score in this range appears to differentiate in terms of better outcomes (XXXX, submitted) and is equated to better support in other areas, it may not allow adequate distinction between good and mixed active support in terms of possible underlying or predictive factors. However, if the bar is raised to a score over 80% (the mean active support score for those who made up the original good group was 83% with a range of 69-94), then only 19 people overall (8 with more severe disabilities), supported by 13 different services provided by 6 organisations, would be coded as receiving good active support. Interestingly, only 4 of these 19 people were living in individualised settings, three of whom were less severely disabled. Only two group settings provided good support for all of those they supported, one of these was providing for those who were all in the more able group and one for a mixed disability group.

However, the issue of the good cut off does not explain why so few services were providing good quality support that enabled and empowered people. Other factors were also identified. Managers typically did not share our understandings of skilled support, how to define, implement it, measure and sustain it. This may be for a number of reasons as identified by the qualitative analysis: managers appear to be spending little time in the services they manage and the time they do spend in the services does not typically include providing practice leadership, although a few managers did mention some elements of practice leadership such as modelling and mentoring but only in an informal capacity.

Factors raised related to austerity and cuts are likely to explain why managers are spending less time in the services they manage – multi-site working has become more common and is seen as a barrier to skilled support. These issues are discussed in more detail below.

Implications for research and practice

This research took place towards the start of the funding cuts in the UK and it is likely that the impact of these cuts is now even greater than it was then. Along with developments such as the introduction of the living wage, resources available for social care appear to be severely restricted. Impact on the capacity of managers as practice leaders may be particularly important for the quality of services. However, we also know (Beadle-Brown et al., (submitted) that the care packages of those receiving consistent active support are not significantly more expensive than the care packages of those receiving mixed or weak active support. Beadle-Brown et al., also found that staff were much more efficiently used in services where active support is already in place. This implies that in spite of overall lower financial resources there is room for greater efficiency in how services are commissioned and provided but with a greater focus on outcomes for those supported. Further research could usefully explore the impact of the cuts in different types of services (e.g. day services) and in services where staff are skilled versus not skilled. Increased use of volunteers and building natural supports in the community have been the focus of some organisations and gathering the strategies people have used to deal with the cuts would be a useful exercise with wider application for other countries were funding for social care is even less that in the UK.

The other issue highlighted by the findings here is that skilled active support requires staff to be trained in person-centred approaches but not just going away to classroom based training for a day but needing local, hands on and in situ training focused on the people they support. However, this is made hard for organisations especially in the context of reduced funding, as the compulsory training that organisations have to put staff through (Currently the Care Certificate) does not cover even the classroom based knowledge required for

active support. This has meant that organisations have to develop their own training or invest in external organisations coming in. Of course, training in itself is not enough – staff need motivation and ongoing support from senior managers and from their practice leader to work in this way. However, evidence that this was consistently happening in these organisations was scant. Perhaps this is not surprising given the fact that active support does not feature in any government policy or documentation, traditionally has not featured as part of inspection processes, does not feature in the qualifications staff are required to undertake and there is no training in practice leadership that is even recommended, never mind required, for those leading staff teams.

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Appendix 1: Manager's Interview Schedule: Interview Guide

Can you start by telling me the aims of this service? What is it here to do?

Where do the aims come from?

How do you know that this is what the service is supposed to do?

What are the challenges or disincentives to achieving these aims?

Do staff share your vision of these aims?

If not, what do they think the aims of the service are?

How do you turn these aims into reality?

Skilled Support

Given the needs of the people you support, what does the phrase "skilled support" mean to you?

What skills do your staff need to have to work here?

Do you see yourself as having those same skills?

If so, how did you become skilled?

Do your staff get acknowledged as being skilled, or allocated different tasks as a result? Can you give me some examples?

Do you think your staff's skills match the mission statement of the service?

Are there skills you'd like your staff to have?

How are individuals developed?

How do staff know that they are doing a good job?

What are the arrangements here for supervision, feedback or modelling?

Some of the skills and strategies we are looking at in detail are active support, intensive interaction, positive behaviour support and the SPELL framework.

Do you use any of those approaches with the individuals here?

If so, how are they used?

As a therapeutic intervention, normal ongoing practice, or in another way?

How are they monitored and recorded?

Quality of Life

This study is concerned with quality of life.

How do you measure that here?

How do you know if it is improving?

The future

What do you think are the challenges for the future?

Has the current economic climate affected these in any way?