Title

Occupational therapy empowering support workers to change how they support people with profound intellectual and multiple disabilities to engage in activity

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Keywords

Abstract

Background

People with profound intellectual and multiple disabilities may not always be well supported to engage meaningfully in activity at home, an injustice impacting on wellbeing and quality of life.

Specific aims

Research sought better understanding of how occupational therapists work to improve the quality of this support, in particular, how they encourage support workers and managers to adopt recommendations.

Method

A single, purposively-selected, case of supporting engagement in activity at home was investigated using a critical ethnographic case study methodology from an interpretivist and social constructionist stance. An occupational therapist worked with five people with severe and profound learning disabilities and their support workers over one year. Data were collected using ethnographic methods (participant observation, interviews and document analysis) and analysed using an emergent systematic strategy (formal coding and categorisation, alongside intuitive and affective analysis) and NVivo qualitative data analysis software.

Findings

The case's story (illustrated by an ethnographic vignette constructed from the data) highlights challenges encouraging others to follow recommendations as intended. It has two overarching themes: the impact of shifting support and leadership cultures; and characteristics of occupational therapy, seeking in particular to create and sustain cultural change by working with support workers in a collaborative and empowering way.

Discussion

To overcome the impacts of organisational culture on how support is given (thereby improving the quality of people with profound intellectual disabilities' lives) professionals need to collaborate with support workers. Occupational injustices they arguably may face, in particular risk of burnout where their roles are conflicting or ambiguous, may also need to be addressed. Implications are suggested for health and social care professionals working indirectly through support workers of people with profound intellectual disabilities (and others with high support needs) and for the education and training of these professionals.

Keywords

Occupational therapy, intellectual disabilities, activities of daily living, qualitative research, case study

Introduction

People with profound intellectual and multiple disabilities (henceforth "profound intellectual disabilities") are said to have a high level of cognitive impairment, though otherwise heterogeneous patterns of functioning (Nakken and Vlaskamp, 2007). They commonly have complex health needs, additional physical disabilities and communication abilities at an early developmental level (Zijlstra and Vlaskamp, 2005). To maintain good health and engage in activities, people need significant, skilled day-to-day support recognising individual abilities and developmental level of engagement likely to be possible (Vlaskamp and Nakken, 1999, Mansell et al., 2003). The home presents many opportunities for involvement in ordinary daily activities such as cooking, cleaning, gardening and own self-care (Mansell and Beadle-Brown, 2012). Engagement in such activities is suggested to underpin quality of life (Felce and Emerson, 2004) and the right support can facilitate partial, though meaningful, engagement (Mansell and Beadle-Brown, 2012).

People may not always engage meaningfully, however (Mansell, 2010). They may experience a 'hotel' model of care, where they are inactive whilst support workers cook and clean (Jones and Lowe, 2005). It is consistently suggested (for example Mencap, 2011, Mansell and Beadle-Brown, 2012) that many have extremely low levels of meaningful engagement, with activities often "lost in the whirl ... of physical and nursing care" (Vlaskamp and Nakken, 1999, p.108). Interactionist models such as the International Classification of Functioning, Disability and Health (World Health Organization, 2001) understand functioning and disability as dynamic interactions between individuals and their environment and successful engagement is dependent on available support directly facilitating this (Felce et al., 1999, Mansell et al., 2003). Injustice arguably occurs when the practices of individual workers (or the structures within which they work) result in people with profound intellectual disabilities not having engagement opportunities available to others (Townsend and Wilcock, 2004).

Occupational therapists in community intellectual disability teams often support engagement in self-care, domestic and leisure activities at home (Lillywhite and Haines, 2010). The literature (1991 to 2017) contains relatively few research sources regarding occupational therapy intervention supporting this kind of engagement. Over half of relevant research explores occupational therapists' own views about their practice, reflecting an emergent evidence base, exploring the nature of practice, rather than evaluating its effectiveness. Occupational therapists consistently refer to a key role of supporting meaningful engagement in activity (Tannous et al., 1999, Perez et al., 2012), a principle of practice in this field (College of Occupational Therapists, 2013). That document, however, largely draws on only one study (Lillywhite and Haines, 2010) and does not reflect evidence from outside the field, such as active support, a method of supporting people to engage in activity underpinned with significant research evidence and that occupational therapists themselves describe using (Lillywhite and Haines, 2010). Only a small proportion of occupational therapy evidence relates specifically to work with those with *profound* intellectual disabilities, with the latter study acknowledging, though providing limited insight into, this.

Tannous et al (1999) concluded that occupational therapy outcomes emerge from reciprocal relationships with people. A core principle is to work collaboratively, not only with people with intellectual disabilities themselves, but also with others (College of Occupational Therapists, 2013), including inter-professional colleagues, family members and (the focus of this article) those who are paid to support people on a daily basis (Lillywhite and Haines, 2010). Health and social care professionals have an important role in changing perceptions and improving care quality, particularly with a workforce that may not be well paid and trained and that may turnover rapidly (Bubb, 2014). Support workers' training needs are acknowledged in government policy (Department of Health, 2009) and occupational therapists describe delivering training regarding the value and importance of meaningful activity and support workers reacting positively to this (Lillywhite and Haines, 2010).

Health professionals, for example speech and language therapists (Chadwick et al., 2006), have highlighted challenges involved in this consultative role of encouraging support staff to improve their practice. Occupational therapists in Australia (Tannous et al., 1999) and the United Kingdom (Lillywhite and Haines, 2010) described interventions needing to be of sufficient length to enable rapport and relationship to develop and to change beliefs and attitudes of those providing support. To motivate support workers and managers, occupational therapists prefer to work alongside them, negotiating rather than dictating and remaining closely involved to facilitate implementation of realistic and achievable recommendations (Lillywhite and Haines, 2010).

There has been limited response to Mountain's call (1998) for further research into how occupational therapy can contribute to improving the quality of people with profound intellectual disabilities' support at home. The overall evidence base for the profession's role supporting engagement remains limited and more detailed understanding is needed, including research into how occupational therapists collaborate with teams to support adoption of new ways of working. A research study explored the ways an occupational therapist supported people with profound intellectual disabilities to engage in activity at home. One aim of this study, the focus of this article, was to understand better the consultancy aspects of this work with support workers and managers and how occupational therapists encourage their recommendations to be adopted.

Method

Methodology

Qualitative case study methodology was appropriate for the research question's exploratory purpose. Case studies classically establish "the how and why of a complex human situation" (Yin, 2009, p9), generating in-depth understanding from multiple perspectives (Simons, 2009). Thomas's conceptualisation (2011) supported construction of a case that in terms of subject is exemplary: a

good example of this kind of occupational therapy, an instrumental tool, illustrating and facilitating in depth understanding.

The approach taken was to bring the case to life, making it real for readers to make sense of themselves (Flyvbjerg, 2006). Interpretivism and social constructionism placed the first author centrally in the research, constructing findings jointly with participants as "*interpreter and gatherer of interpretations*" (Stake, 2008, p135). Subjective understanding was regarded as a strength, with reflexivity enabling recognition of the impact of knowledge, values and predispositions (Simons, 2009). A critical ethnographic case study resulted, with thick description and explanation of culture and structure (Finlay, 2006) and of arguable injustice within the setting (Madison, 2012).

In terms of process, it is a single case within which five people's occupational therapy is nested (Thomas, 2011). Trustworthiness was promoted by prolonged engagement; persistent observation of emerging issues; and opportunity to check raw data with sources (Simons, 2009).

Participants

All participants, places and organisations are referred to by pseudonym to preserve anonymity. A case of occupational therapy supporting a small number of people's engagement in activity at home gradually crystalised. Interest was sought from occupational therapists proficient in this work and Esther, an experienced occupational therapist from a community team for adults with intellectual disabilities volunteered. Criteria for a suitable case were agreed and it was mutually decided that her intended work at Cavendish House, in a suburban area of an English city, had potential to be relevant.

A series of carefully planned recruitment procedures ensured compliance with the Mental Capacity Act (GB Parliament, 2005) in recruiting Matt, Becky, Harold, Jane and Steve, five adults with profound or severe intellectual disabilities living at Cavendish House. Further participants were recruited purposively as Esther worked with them and they therefore became relevant to the case: an

occupational therapy assistant (Sarah); support workers (Jean, Olly, Doug, Tracy, Paula, Gemma, Julie, Robert, Dina and Ivan); a nurse (Adam) and house managers (Sue and Norma). They were first approached by Esther and then by the first author on showing initial interest. Data collection came to a natural end once Esther completed her work.

Ethics

Obtaining ethical approval was complex and is explored in more detail in Haines (2017): an evolving design made full explanation challenging and convincing benefit was needed to demonstrate proportionate risks. Esther and colleagues concluded that no adaptation to presentation of information could maximise Matt, Becky, Harold, Jane and Steve's capacity sufficiently for them to decide about participation themselves. The need for insight into the experiences of those lacking capacity to develop a research evidence base for how best to support them (Tuffrey-Wijne et al., 2008), justified best interests decisions about participation in accordance with Mental Capacity Act 2005, sections 30-33 (GB Parliament, 2005). Appropriate consultees agreed that the presence of a researcher would be unlikely to be experienced as unusual and that research methods were similar to and no riskier than routine support (Dalton and McVilly, 2004).

Data Collection

Data collection methods were characteristic of case study and ethnographic research. The first author spent time in the field with Esther, taking on the role of "observer as participant" in Gold's typology of participant observer roles (1958, p.217) and collecting data iteratively over one year. The data set contributing to the findings explored in this article consisted of jottings and field notes from his 17 observations of Esther's work with those in the house, along with transcripts of 25 formal interviews with her and with support workers and managers. These interviews were all transcribed in full. Using multiple data sources recognised the case's complexity, and contributed to identification of different converging and diverging realities, for example assisting interpretation of

observations through gaining interviewees' own perspectives. Some interviews were pre-arranged, others relatively quick and informal – more like opportunistic conversations, exploring an observed aspect of the case. Videoing was used in a reflective modality (Haw and Hadfield, 2011): playing some recorded aspects of Esther's practice back to her in interviews facilitated her reflection and allowed exploration of her tacit understandings and reasoning. In a similar way, reports, activity support guides and other artefacts created by her were also discussed and explored in the interviews.

Analysis

An emergent, though systematic, inductive thematic analysis (Bazeley, 2013, Braun and Clarke, 2013) of the data in field notes and interview transcripts allowed a conceptual, rather than purely descriptive, account of the case. Interpreting as much as analysing (Stake, 1995), findings were constructed jointly with participants (Thomas, 2011), notably Esther. Key to ensuring trustworthiness was reflexivity throughout, facilitating distinction between interpretations informed, rather than biased, by predispositions (Stake, 2008).

NVivo 10 software (QSR, 2013) supported a process of formal and more intuitive analysis, in particular repeated coding and categorising of the data (Saldaña, 2013) to organise and make sense of it. The first author openly coded data, initially '*in vivo*' (naming codes using participants' words), then in increasingly interpretive and conceptual ways. He coded values – the expressed, or implicit, world views of protagonists – and used versus coding where tension and divergence were visible. With the case seemingly often about actions, interactions and processes, he deliberately process coded observable and conceptual action. This process is described in more detail in his words in the appendix. Use of the NVivo software enhanced dependability of this analysis, not only by maintaining a record of all analytical decisions, but through using its coding, mapping and querying tools to explore the data thoroughly. Writing analytic memos supported refinement of ideas, whilst gradually shifting to a deeper, more conceptual analysis, paying more particular attention to broader patterns and eventually identifying themes.

Specific episodes, particularly where participants acted, reacted and interacted, could be seen as performance. Consciously considering dramaturgical aspects (including cast of characters, monologue, dialogue, soliloquy, and plot devices) (Saldaña 2011) was therefore insightful and some outcomes of this are visible in the vignette in Figure 2 below.

Findings

The context

Initial impressions of Cavendish House, recorded in a field note, are presented in Figure 1.

Insert Figure 1 about here

Matt, Harold, Steve, Jane and Becky were supported by a team of support workers, manager Sue and assistant manager Norma. They received additional health and social care input from the local community intellectual disabilities team, including community nursing and speech and language therapy alongside Esther's occupational therapy.

At 35, **Matt** was the youngest. Very sensitive to noise, he had diagnoses of agenesis of the corpus callosum, profound intellectual, motor and sensory disabilities, spastic tetraplegia and gastric oesophageal reflux. His often self-injurious behaviours seemed indicative of something, but were difficult to interpret. **Harold** was in his early sixties, described as having severe intellectual disabilities, though with considerably reduced abilities (and more complex health needs) following a cerebro-vascular accident a few years earlier. **Jane**, in her mid-seventies, had intellectual disabilities inconsistently described as either profound, or severe. Seemingly having some sense of her own personal causation, and with some ability to choose and communicate non-verbally, severe seemed more likely. **Steve,** in his early-fifties had profound intellectual disabilities and dysphagia. He was at risk of aspiration, very prone to chest infections and needed care to ensure tissue viability and prevent pressure sores. **Becky**, also in her early fifties, had severe-profound intellectual disabilities (secondary to meningitis), cerebral palsy, scoliosis and epilepsy.

By the beginning of the case, Esther had been an occupational therapist in the local community intellectual disability team for about 12 years, previously working with Matt (ten years before) and Harold (the previous year). The current referral arose out of concerns about the extent to which they engaged in activity and specific support had also been requested for Steve who was described by Norma (Assistant Manager) as particularly difficult for the team "to read".

Somewhat frustrated that previous work with Matt and Harold had not sustained increased levels of engagement (though nonetheless typically full of energy and enthusiasm) Esther saw this research as an opportunity for a more extensive occupational therapy project with all five residents and crucially also the whole staff team. She aimed for them to adopt a different way of working with more sustained outcomes by engaging the staff in a "project". She worked in Cavendish House from January to December 2013. The bounded system of the case can be described as: *"Occupational therapy supporting Matt, Steve, Becky, Jane, and Harold to engage in activity at home in Cavendish House."*

Overview of the story of the case

The findings are constructed as a story of the case with two overarching themes: the impact of shifting cultures on engagement in activity by those living in Cavendish House; and characteristics of an occupational therapy intervention promoting engagement. Following Simons' advice to "depict experience … with such veracity that others will have vicarious experience" (2009, p158), data are displayed in the form of quotations from participants and excerpts from field notes. The vignette in Figure 2 draws on Saldaña's suggestions (2011) regarding ethnodramatic play scripts as presentational methods for fieldwork. It illustrates aspects of the case discussed subsequently and is constructed in the form of a monologue using Esther's words as spoken in various interviews. Although re-ordered, these words are otherwise edited only sufficiently for her words to flow.

Insert Figure 2 about here

Recognising shifting and conflicting cultures

An important feature of the case and influence on the direction of occupational therapy was how varying and conflicting cultures influenced how people were supported to engage in activity. Initially built as a National Health Service inpatient unit where people with intellectual disabilities and complex health needs were cared for by intellectual disability nurses and nursing assistants, Cavendish House had transferred some 18 months earlier to not-for-profit organisation Futures. It now seemed situated somewhere between two different cultures or models of support, with team members identifying, to a greater or lesser extent, with one or other. Strong conflicts were thus apparent, with some embracing Futures' different ways of working and others struggling with or resistant to the shifting culture. The following three tensions illustrate ways in which cultural conflict contributed to low levels of engagement.

Futures and house manager Sue explicitly positioned their service as "social care" rather than "health", naming this "supported living". In reality, practice seemed to be influenced by both this and the previous nursing-led, health needs-focused model. There were differences of opinion surrounding the extent to which Matt, Harold, Becky, Steve and Jane's complex health needs should be the main focus of attention and Esther described a culture in the house which prioritised health needs over engagement. Assistant manager Norma identified how the transition was "*a big change, you have got to suddenly start seeing them as people, not patients and some people really found that difficult.*"

A second tension related to style of leadership and the relative merits of a directive style of management versus a leadership style encouraging autonomy and initiative. Participants described previous directive management by nurses telling support workers what to do: initiative was described (including by Adam, himself one of the nurses) as not encouraged or valued. Sue, on the other hand, now described a less hierarchical team, encouraging initiative and all staff to take on leadership roles, with any of five or six support workers on a particular shift acting as shift leader. Some

(support worker Olly, for example) experienced this increased autonomy as empowering. Others on the other hand, seemed to struggle with expectations of "*leading within a team of equals*" (Adam) and not all seemed to feel able to do this. Situated between these models, participants referred repeatedly to lack of leadership, which seemed to affect the planning of support for engagement in activity.

Passion, commitment and creativity were sometimes evident in the words and visible in the work of individual support workers, but this was not always so. A third tension thus related to what Adam, Esther, Sarah and Sue all referred to as "*lethargy*" in the team, in particular (though not exclusively) in some of the "*older*" staff members, pre-dating the transfer. They described creativity and initiative as having been stifled by years of following instruction and, in contrast saw more of it in 'fresher', newer members of staff. It seemed that many support workers did not feel valued in their roles with all long-standing team members referring to changes in working conditions such as pay reduction and removal of evening or weekend enhancements that were clearly sources of contention. A proportion of support workers not feeling valued seemed a partial explanation for lethargy and resistance to different ways of working.

These three cultural tensions, contributed to what Esther described as a general issue with levels of engagement in activity: "*whenever we turn up no one is really doing anything.*" She felt that it was also caused by limited understanding of *how* to support meaningful engagement, with efforts often tokenistic or superficial. Opportunities to promote more authentic engagement were missed, she felt, due to incomplete understanding of individuals' abilities, or "*cognitively or developmentally where they are functioning.*" There was an apparent lack of clarity about how Future's espoused goals of personalisation, independence and choice could be made relevant to Matt, Steve, Becky, Jane and Harold.

Characteristics of occupational therapy

Esther had a particular understanding in mind of how people such as Matt, Steve, Harold, Becky and Jane could be supported to engage in activity authentically. This article focuses on *how* she encouraged the staff team to adopt this way of working, but it is briefly summarised in Figure 3.

Insert Figure 3 about here

Esther had a characteristic way of working with the team. Recognising that her intensive project could nonetheless not be endless, she sought to create and sustain cultural change, working systemically with support workers and managers, as well as directly with those living in the house. She sought to change the team's outlook on the support they gave and to embed a different way of working into the organisational culture.

The project was both creative and designed to facilitate creativity, encouraging a "trial and error" approach allowing support workers to be experimental. Supporting increased awareness of subtle signs indicative of engagement facilitated this. This new and creative perspective from outside the team was particularly valued by some team members, such as support worker Jean. A persistent, problem-solving, flexible and above all optimistic approach mirrored the responsive way Esther wanted them to work with Matt, Steve, Jane, Harold and Becky. She created resources to support carrying out activity in recommended ways, ensuring these were of good quality and hoping they might be inspirational "*building blocks*" to be used and further developed:

- Detailed guidelines ("session plans") for specific activities and more succinct "prompt cards" on key rings.
- Recording sheets, allowing monitoring of how and how often plans were followed.
- A DVD illustrating filmed examples of supporting Matt, Steve, Harold, Becky and Jane's engagement in activity.

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Esther described working with support workers in a similar way to how she worked with people with intellectual disabilities themselves, highlighting apparent parallels between her work with those living and those working in the house. She built on existing relationships, avoiding being overly formal. In particular, she made efforts to be collaborative rather than directive, supporting them to feel that they 'owned' the intervention, rather than having it imposed upon them. This involved:

- A sufficiently ambitious project to create excitement, generate momentum and pull the team together behind agreed objectives.

- Avoiding being an outsider imposing recommendations by: making suggestions rather than telling what to do; checking agreement with conclusions; demonstrably making adjustments in response to feedback, or obstacles.

- Empathising with challenges faced by support workers, avoiding being overly critical, but nonetheless (gently, though assertively) challenging practice.

- Modelling how the team might support engagement.

- Feeding back regularly on progress from analysis of recording sheets, so the purpose of completing these was clear and the team's efforts appreciated: "*a way of saying to the staff 'I value what you do with these people'*" (Esther).

- Drawing on individual strengths and motivators: both Jean and Robert, seemed particularly to take to the recommended style of support and were key in passing it on, Jean very actively, but Robert less overtly, modelling to others merely by doing.

- Gradually stepping back and letting the team take more of a lead, building on her ideas.

Esther educated support workers and managers about reasons for supporting engagement in her suggested ways and the theory underpinning this. She made efforts to make this educative role informal, referring to it as "*educating gently*" and "*training with a small t*". Written recommendations were also explained verbally in detail, both to individuals and in informal

workshops with groups of support workers. Lack of regular team meetings within the house and only brief daily handover meeting between shifts meant that group discussions with support workers were difficult to organise, but their timing later than planned did at least mean that she could speak about Matt, Harold, Jane, Becky and Steve from a position of knowledge, having had time to complete thorough assessments and to get to know them well.

The collaboration notably also involved efforts to encourage manager Sue and assistant manager Norma to embrace recommendations so that they could "*lead from the top*" alongside the most motivated allies amongst the support workers. Esther took time on several occasions to explain the reports and recommendations for each individual in detail, including in a three-hour meeting with Sue. This proved to be a turning point at which Sue seemingly came to really understand what was proposed and to realise how this fitted with her own goals and those of Futures for those living at Cavendish House.

Discussion

Three aspects of these findings will now be discussed in relation to professionals' consultancy role with those who support people with profound intellectual disabilities: the impact of organisational culture on engagement; empowering support workers to sustain a different way of working; and how the case suggests implementation fidelity can be promoted.

Organisational culture impacting on engagement

The intervention recognised how organisational culture impacts on support for engagement. Four dimensions of culture seem particularly relevant to understanding low engagement levels. Three align with elements of Bigby et al.'s conceptualisation (2012) of culture within group homes with poorer engagement outcomes, whilst the fourth was recognised by Beadle-Brown et al. (2014):

- A powerful group of longer-standing members of staff with values not fully aligned to those of Futures (partially explained, see further below, by uncertainty about the relevance of such values to those supported).

- A tension about whether engagement in activity should be prioritised for people with complex health needs. Theoretical support for engagement, whilst stressing how health needs preclude it, is reminiscent of the "practice/ principle rhetorical device" discourse identified by Jingree and Finlay (2008, p.715). This perpetuates loss of activity in a focus on physical and health care (Vlaskamp and Nakken, 1999). Where complex health needs preclude opportunities to engage in activity, people are implicitly 'other' and 'too disabled' to be offered them, suggestive of the vicious circle of disempowerment in the 'hotel' model of care (Jones and Lowe, 2005) and, crucially, situating deprivation of opportunity firmly within individual pathologies. Esther's efforts to offer opportunities *despite* complex health needs, alternatively constructed people as capable (Jingree and Finlay 2008) and more 'like us' (Bigby et al., 2012).

- Embedding "sensory activity" into the team's work was sufficiently ambitious to require a "leap of faith" (Lewer and Harding, 2013, p.180) in completely supporting it. The willingness of some (Sue and Jean, for example) was important, but others were notably less supportive of innovation. A resistant orientation to new ideas and challenges to the status quo of practice from outsiders is a common cultural trait in homes under-performing at supporting engagement (Bigby et al., 2012). "Fragile" aspects of support likely to preclude delivery of good quality, person-centred care are more easily strengthened in staff teams demonstrating openness and adaptability (Killett et al., 2012, p.32).

- The shift from a very directive leadership culture to one that encouraged greater participation in decision-making by individual support workers now meant decisions about supporting engagement in activity were largely left to the initiative of those on shift, resulting in less

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advance support planning. Effective day-to-day practice leadership, allocating and

organising support in accordance with needs, has been found to be significantly positively-

related to the time people spend engaged in meaningful activity (Beadle-Brown et al., 2014).

Empowering support workers to sustain a different way of working

The case illustrates one of five recently-described (National LD Professional Senate, 2015) essential

roles of community intellectual disabilities teams: enabling others to provide effective person-

centred support. Increasingly consultative and indirect professional practice of this type has been

illustrated in speech and language therapy (Graves, 2007, Lewer and Harding, 2013, Goldbart et al.,

2014), physiotherapy (Carr et al., 1995, Stewart et al., 2009) and occupational therapy (Lillywhite

and Haines, 2010).

The apparent parallel between occupational therapy with those living and with those working in the

house was particularly reflected in awareness that outside input can be perceived as criticism or

interference (Potts et al., 1995) and in efforts to be collaborative (rather than directive). A respectful

relationship, with negotiated and jointly agreed goals (Lewer and Harding, 2013) and recognition of

individuals' different strengths are all emphasised in the literature and visible in the case. Frequent

presence provided opportunities for support, progress monitoring and feedback, all found elsewhere

to be important (Cocks and Boaden, 2011, Reynolds, 2013), including within active support (Mansell

and Beadle-Brown, 2012).

Those seeking to empower people with intellectual disabilities need first, it is suggested, to feel

empowered themselves (Zakrajsek et al., 2014). Whilst addressing paucity of opportunities for those

living in the house, Esther seemed also to recognise a link between the quality of working lives and

the quality of support that could be provided. Workplace stressors of role conflict and role

ambiguity are suggested to correlate with the emotional exhaustion and depersonalisation aspects of

burnout, a psychological response to chronic and uncontrollable stress (Maslach et al., 2001),

moderate levels of which have been found amongst those providing direct support to people with intellectual disabilities (Rose et al., 2011). Burnout can influence care quality (Innstrand et al. 2004) by reducing interactions and support (Rose et al., 1998) and increasing absenteeism and staff turnover (Jenkins et al., 1997, Mills and Rose, 2011, Kozak et al., 2013).

Role conflict may be experienced when workplace demands seem incompatible, or expectations unrealistic; and role ambiguity when an aspect of the support role lacks clarity, or where organisational values seem incongruent (Thompson and Rose, 2011). The clarity of an organisation's overall philosophy, direction and goals is closely linked to role conflict and ambiguity (Dyer and Quine, 1998) and three possible stressors were visible in Cavendish House:

- Conflicting attitudes towards leadership and the relative priority of meeting health and wider occupational needs of those living in the house;

- Incomplete understanding of how to support people with profound intellectual disabilities to engage in activity;

- A dominant discourse of empowerment, independence and choice that was nonetheless not well understood, in terms of how these goals might be realised for these particular people in this context. Policy (such as Department of Health, 2009) and mission statements of organisations like Futures make such goals appear superficially straightforward (Finlay et al., 2008), often with insufficient guidance. Support workers aiming to achieve "independence" in activities of daily living, who don't or can't see how this is achievable, may then reject this as irrelevant to those they support, or may feel that they are failing when not achieving it.

This resulted in an ambiguous and conflicted role, arguably risking support workers' wellbeing. Esther's extensive efforts to clarify how hers and Futures' goals might meaningfully be realised and to explain her reasoning can be seen as an attempt to reduce role conflict and ambiguity and promote role clarity. Investigating predictors of burnout, Vassos and Nankervis (2012) found that effective

feedback mechanisms were positively related to support workers' sense of personal accomplishment, suggesting that Esther was right to emphasise this. She could not influence employment conditions, but nonetheless some impact on the quality of support workers' daily lives was possible, alongside increasing engagement in activity by those living in the house.

Facilitating implementation fidelity

The idea of a lengthy "project" reflects the fact that embedding personalised support requires "considerable ongoing time and effort" (Cocks and Boaden, 2011, p.727). Support workers strongly prefer training by people with detailed knowledge of the individuals they support (Bradshaw and Goldbart, 2013), placing less value on more general training. Esther's extensive assessments, exploring each person's preferences and observing their support, meant that she could be said to have known them very well. Despite this, however, her credibility varied: Jean remarked on how well she knew each person, but more resistant Olly seemed less convinced that she had the required local knowledge for recommendations as an outsider to be valid.

"Implementation fidelity" – recommendations being followed as intended (Cross and West, 2011, p.19) – is promoted by seeking to change thinking as much as action, thus making practice more reflective (Koski et al., 2010, Bradshaw and Goldbart, 2013). In seeking to reduce role ambiguity and by introducing theory, Esther encouraged the team to think differently about those they were supporting and to be able to recognise when they had successfully supported authentic engagement. Training by example and modelling a desired approach, has been found more effective than theoretical training alone (Graves, 2007, van der Linde, 2014), potentially increasing both confidence (McDonnell et al., 2008) and knowledge (Chadwick and Jolliffe, 2009). Jones et al. (2001) emphasise working in context and in situ interactive training is central to active support (Totsika et al., 2008). Esther's video recording of examples of each person being supported to engage in the envisaged way is regarded as a good medium for promoting thinking changes (Dobson et al., 2002).

Maes et al.'s review (2007) concluded that issues maintaining and generalising newly-learnt practice often arise and examples include the fidelity of implementation of speech and language therapists' recommendations regarding food and drink modification, meal time positioning, pacing and prompting (Chadwick et al., 2006, Graves, 2007); and the implementation of behaviour support plans (Reynolds, 2013). Graves' findings (2007) led her to question whether the skills required to make collaborations succeed were sometimes under-estimated, with insufficient emphasis placed on how recommendations were to be implemented. Hornby and Atkins (2008) emphasised the complexities of the relationship between those making and implementing recommendations.

Despite efforts like those of Esther to be collaborative, power in such relationships is not equally shared, for there is a disparity of knowledge, expertise and perceived status (Graves, 2007). At the end of the day, Esther did have a particular way of working in mind and a tension can therefore be seen in the case and in the consultative role of professionals generally, between empowering a staff team, whilst at the same time seeking fidelity to a particular approach. Complex pragmatic reasoning is required to manage this tension between prescription and compromise. This draws on theory of situated cognition, emphasising the context in which reasoning occurs (Schell and Cervero, 1993), including organisational policies, support cultures, service history and support workers' knowledge, skills and attitudes. It was evident in Esther's realism and willingness to compromise, whilst throughout the case, nonetheless keeping her imagined ending of sensory activity embedded into daily practice in Cavendish House firmly in mind.

Cocks and Boaden (2011) reviewed literature on personalised support and concluded that someone needs to have a vision, to demonstrate ideas and lead the creation and embedding of new ways of working. This echoes Northouse's description (2013, p.185) of "transformational leadership" where a leader, perhaps with a charismatic, motivational personality, is an agent for change and inspires others to achieve higher standards by articulating a clear vision. Esther arguably took on this role

and leadership of this type may be an important way of both improving the quality of support provided and countering mistreatment and neglect within intellectual disability services.

Limitations

The findings are one particular interpretation (by a researcher who himself is an occupational therapist) of this single case and as such, they, cannot be generalised in a propositional way. Credibility may arguably have been enhanced by involvement of others in the analysis. The story of the case was shared with Esther and she agreed with what is, admittedly, a positive portrayal of her. Circumstances (in particular the departure of key respondents) only allowed partial gathering of others' perspectives on this story, unfortunate in view of the vision not necessarily being shared by everyone. Perhaps inevitably, with a research question about how an occupational therapist supports engagement and with that occupational therapist a gatekeeper for access to the setting, most observations at Cavendish House were with Esther present. It would have been interesting to have observed more of the staff team supporting engagement and on more occasions, at other times.

Furthermore, there is uncertainty about what happened afterwards, once Esther's work at Cavendish House had ceased: the extent to which a change of way of working was embedded and sustained in the long term. This uncertainty limits any conclusions that can be drawn regarding the effectiveness of these strategies, though this research did not set out to evaluate practice, but merely to explore it. The case does not necessarily represent typical occupational therapy practice and it could be argued that transferability of the findings is limited where insufficient funding in the current climate means that interventions of this type may not be possible. It could, however, represent *aspirational* practice, arguably of a type necessary if the complexities of achieving implementation fidelity are to be overcome.

These limitations do mean that the conclusions need to be read cautiously, which is why they have been expressed tentatively. The inclusion, however, of substantial detailed description and excerpts

from the data is intended to provide the reader with a sufficiently vicarious experience to provide an audit trail of how these tentative conclusions were reached, to allow judgment as to the plausibility of the case and to support transferability, in the form of naturalistic generalisation (Stake, 1995).

Conclusion

This research explored how an occupational therapist supported five people with profound intellectual disabilities to engage in activity at home, with a particular aim of understanding how she worked with support workers and managers to encourage her recommendations regarding supporting engagement in activity to be adopted. The findings suggest that aspects of the organisational culture where people with profound intellectual disabilities live may impact on how they are supported to engage in activity. Inevitably time-limited interventions seem therefore best focused on creating and sustaining cultural change amongst those providing support. Implementation fidelity may be promoted by empowering support workers, seeing them as "service users" like those with profound intellectual disabilities who are the ultimate beneficiaries of interventions. It seems more likely to emerge from collaborative and unthreatening relationships with support workers and managers and from flexible interventions that provide resources and ideas and encourage creativity. It may require recognition of challenges faced by support workers, including possible risk of burnout from role ambiguity where service goals of independence, choice and personalisation are not fully understood. In seeking to embed a different way of working, it may be helpful to adopt the role of a transformational leader.

A detailed interpretation of this case provides exemplary knowledge, useful for professional practice (Thomas, 2011). This tentative theory has implications for professionals seeking to embed changes into services for people with intellectual disabilities and also for others with high support needs. There may be a need to enhance curricula content on pre-registration health and social care professions courses regarding the skills of collaboration to embed sustained changes in support

practices. Further research is needed into this collaborative approach's potential to achieve

implementation fidelity.

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Tables and Figures

Figure 1: Field note – Cavendish House

"On approach it seems a large building. Glass fronted entrance, parking area outside. Button pressed on arrival, opaque glass sliding doors opened and we walked into a large, open, high-ceilinged, airy 'lobby' at (what turned out to be) the apex of the 'T' of the single-storey building. Wide corridors (not usual domestic scale) largely clear, with minimal furniture. Clean and very warm (Esther referred to the underfloor heating making your feet hot). Lino on floors, all walls in communal areas painted off white/ cream. High wooden window frames, light and airy." (Field note 11.12.12)

Figure 2: "A journey together" – Esther's monologue (from interviews with her)

I have come to this point where I am going "no, a project will be better", because it felt that I was dipping in and out with Harold and it wasn't enough to get people motivated and doing stuff.

What I want to do is to get it into the culture, I want to get everyone thinking about sensory activity, giving them ideas, giving them resources as a constant daily reminder that we are supposed to be doing that. I said that I would also do an activity file or a sensory ideas file. I am hoping that all these things are just going to get them excited.

And it feeling like it is a joint venture and not just "the OT coming in and telling us", but everybody is on board, everybody is thinking this is a good thing to do. You have got to get people on side, so they feel comfortable that I am going in and we work together on it and it doesn't feel threatening … a supportive process, so they feel like we are on a journey together to improve it.

If I am going to work with the staff team I am going to work alongside the staff team. So it is a way I guess of motivating them to take ownership for what's happening.

I'll tell you about the training I did last Monday, the workshop. You know I wasn't at all hopeful about it! Well it has been cancelled loads of times hasn't it? But it was brilliant, it was really, really brilliant. If I can win staff over and help them feel like they have got things to offer … and get them to sort of take some ownership by understanding where we are going with it and them telling me what they already know about the guys that live there.

Some of it is about me going back in there regularly, how are you doing, how are the sensory activities going? Not checking up, but just keeping it on people's agenda.

It does need to be led from the top and I feel so positive that I have won Sue over after that meeting, because I think unless she is on board we are not going to get everybody else on board are we? But people on the ground also need to feel like they own it. I think if you can get everyone signing up and everyone has heard it first-hand sometimes it is better than if you

ask a manager to introduce something and it takes a while to filter down and not everyone understands why they are doing it.

It is about finding allies isn't it? Once you've got one person on board and they are talking about it when you're not there, then it starts to spill over and other people start to hear it and it is not just coming from us.

I wonder whether this DVD might be my "parting shot". I am going to do a discharge pack with the DVD in it. One for each person, session plans, discharge summary, DVD Because I just feel that it has really captured well five people with PIMD with different needs and it kind of pulls out their different individual things, it looks at communication, it looks at activities. I think that is why it will be so useful as a training resource. People are more likely to engage with it than a written report.

Figure 3: Summary of "authentic engagement" approach

- An assumption that authentic or meaningful engagement is possible, but otherwise few assumptions about those supported.
- Openness to being surprised, with conclusions drawn always provisional and open to revision.
- Going beyond superficial or tokenistic engagement ("just jumping through hoops" as Esther put it, describing Steve's presence while his sheets were put in the washing machine, but no effort made beyond this to engage him in his laundry).
- Genuinely meaningful or authentic engagement implies engaging in non-typical ways (Esther's shorthand: "sensory activity", or "doing regular things in a very sensory way").
- Such engagement is observable, facilitated by close responsive relationships and skilled communication.

Appendix: Description by first author of the analysis process

Coding and categorising the data began soon after early observations and interviews, with analysis informing subsequent data collection. A large number of codes were needed to capture the complexity of the data. For each, I wrote a definition, as in the following example:

"Making it a project-y thing"

Working with the whole house and staff team rather than individual work. Investing time, working more intensively/ systematically.

The resultant 'code-book' of some 450 codes started as a simple, un-organised list until I began exploring and mapping possible relationships. Some codes seemed to be about issues or problems, some about culture(s) within the house and others about strategies evident in Esther's work. I

organised the codes into groups by categorising them (and continuously re-categorising them) within a framework of trees and branches. NVivo's ability to look at all text coded to a particular code facilitated comparison and contrasting of segments of text to establish similarity and difference. I noticed duplicates and codes containing multiple ideas and 'coded on' (Bazeley, 2013): lumping codes representing duplicate ideas together and splitting others into new codes, whilst continuously updating code-book descriptions. The many 'issues' and 'strategies' codes were sub-divided into separate 'trees' related to different types of issue, or strategy used, for example:

- *24 codes related to "ISSUES re activity levels and ways of supporting engagement", i.e. perceived problems with the way those living in Cavendish House were supported.*

- *44 codes under "STRATEGIES with staff team", relating to how Esther worked with the staff team and managers.*

Towards the end of data collection, I gradually moved into a second stage of deeper, more theoretical or conceptual analysis: 'second cycle coding' (Saldaña 2013, p.207), or 'focused coding' (Charmaz 2012, p.138). I made increasingly deliberate choices, for example to code specific aspects of the data, such as overt or implicit values, attitudes or beliefs of participants; or conflicts between participants. I began to realise that individual codes could also be seen as dimensions of wider categories and organising codes from different trees in the coding hierarchy together into such categories allowed me to reflect on meanings and relationships and to deepen my thinking. For each new category, I used concept mapping to model the data and emerging themes visually, drafting a memo about each and its possible meaning.

Paying more particular attention to broader patterns across the data in this way allowed me to move towards identifying themes. In doing this, I was not trying to explain or represent everything in the data, but selectively to tell a particular story about the case that answered my research question. These themes were identified through a continuing process of reflecting on and reviewing the codes

and the data coded to them. Through this I repeatedly reviewed and revised provisional themes to

determine how well they fitted with the data coded to them and my overall case and whether they told

me something meaningful about an aspect of the case in relation to my research question. I reflected

on whether further data collection, might be necessary to ensure sufficient meaningful data to

support themes and, using theoretical sampling, gathered some additional data (for example twice

seeking Esther's views on draft findings). I also reflected extensively, in discussion with the second

and third authors, on the analysis process and on the emerging themes as they evolved.

Conflict of Interest

No conflict of interest.

Ethics Statement

This research was approved by the University of Brighton Faculty of Health and Social Sciences Research Ethics and Governance Committee and the National Health Service National Research Ethics Service (NRES) (Ref: 12/LO/0319).