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Evaluating service users' experiences using Talking Mats™

Introduction

When considering quality of life (QoL) for people with intellectual and developmental disability (PWIDD), Schalock et al. (2002) conceptualised it across eight domains: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. They suggested that when measuring QoL, both objective (externally measureable, sometimes using valid and reliable tools) and subjective (that is the perceptions and satisfaction of the individual) measures be used. However, much of the research into QoL for PWIDD has focussed on objective or subjective, proxy rated measures of QoL, likely due to the complexity of formal measures of QoL (Perry and Felce, 2002). Where research has attempted to obtain the subjective views of service users themselves, this has tended to involve more able participants (e.g. Jones et al., 2001).

Mansell and Beadle-Brown (2012, p.39) state that 'lived experience is critical to quality of life' and QoL is influenced by individuals own views and values and experiences, (Schalock et al., 2002). It is important to consider service user experiences, and self-reports of QoL when considering the effectiveness of an intervention such as person-centred active support (PCAS) on an individual's or group's outcomes. It is likely research in this area has been hampered by methodologies which exclude all but the most verbally able. For example, 80% of people with severe intellectual disability are unlikely to develop effective speech (McLean et al., 1996) and would therefore be excluded from traditional, verbally-based interviews. The communication impairments prevalent in the population of PWIDD make it more difficult for them to voice their views and have their views heard (Murphy and Cameron, 2008).

Talking Mats (TM) provides a symbol-based, structured framework to supporting people's

communication (Murphy and Cameron, 2006) and has been shown to be effective in gaining the views of PWIDD whose understanding of verbal language is above a 2, information-carrying word level, (Murphy and Cameron, 2008). TM may also provide a more valid way of gaining the views of PWIDD by overcoming some of the issues of verbally-based interviews. It may shift the power balance (Bell and Cameron, 2008; Murphy and Cameron, 2008), and result in decreased acquiescence (Murphy, 2000). TM employs a relatively simple closed scale, but asks questions in an open manner that encourages elaboration (Stalker, 1998), either verbally or non-verbally. This may explain the findings of both increased quantity and quality of information reported in the research with PWIDD (Murphy and Cameron, 2008). As yet, the use of TM to evaluate PWIDD's subjective perceptions of QoL and quality of support (QoS) has not been widely reported.

The current study aimed to use TM to explore the experiences of individuals living in supported living services during the implementation of PCAS. PCAS focusses on four key principles to guide staff support: 'every moment has potential', 'little and often', 'graded assistance to ensure success' and 'maximising choice and control' (Mansell and Beadle-Brown, 2012, pp. 57-65). Good implementation of PCAS results in more skilled support for PWIDD (Mansell et al., 2002) and improvements in their QoL (Jones et al., 1999) across a variety of domains (Beadle-Brown, 2006) including engagement (Stancliffe et al., 2008) and relationships (Jones et al., 2001). It has generally been found most effective for those with higher support needs (Mansell and Beadle-Brown, 2012).

Methodology

Design

A mixed-methods pre/post study was undertaken. PCAS training was independently implemented by the local Positive Behavioural Support Team with all staff (n=23) working within the target service.

Participants and setting

The sample of PWIDD (n=27) was identified from one supported living provider. Of these, 15 did not meet remaining inclusion criteria e.g. did not have enough support hours, did not have a learning disability or autism. One participant was excluded on the basis that they did not have adequate comprehension to use TM, two declined to participate and the consultee of one other did not support their participation. Of the remaining eight participants, three participants were living with a partner, genders were equally represented, and ages ranged from 33-76 years, with an average age of 59 years. Participants had moderate to severe learning disability and two had an additional diagnosis of autism.

Measures

Quantitative measures

The Active Support Measure (ASM), (Mansell, Elliott, and Beadle-Brown, 2005) is an observational measure of quality of support with high levels of inter-rater reliability and internal consistency (Mansell, Ashman and Macdonald, 2003). It evaluates support across 15 dimensions related to providing good active support. Each dimension is scored against a 4 point scale, and an overall % score is calculated.

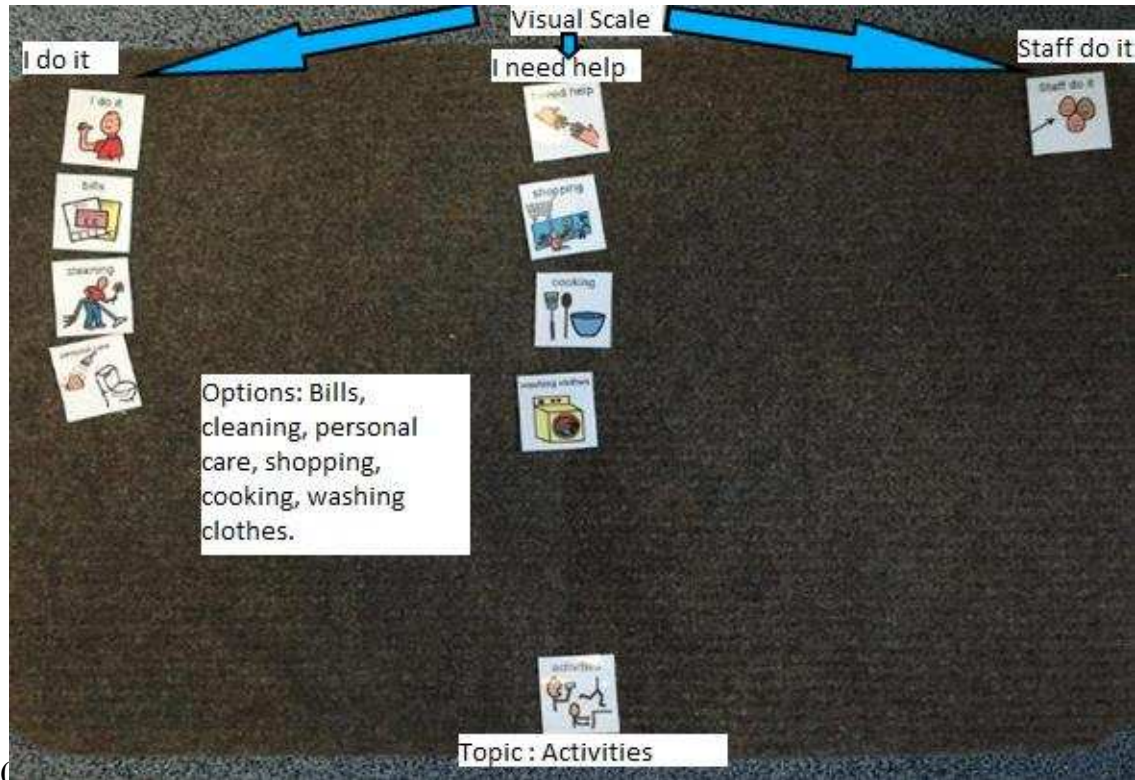
The Effectiveness Coding Framework (ECF) is an observational measure which scores an interaction across 7 dimensions and provides an overall score, categorizing communication as ineffective (total <21) or effective (total \geq 21) (Murphy and Cameron, 2008). While subjective, the ECF has strong face validity (Murphy et al., 2010). This measure was used to evaluate the effectiveness of the TMs.

Qualitative interviews

TM uses three sets of symbols, a topic, a number of options and a visual scale (see Figure 1). Once the scale has been explained, and the topic introduced, participants are handed a symbol and asked an open question e.g. 'what about cleaning?'

Figure 1

Topic: Activities



The TM topics and options were informed by published measures and standards (Cummins, 1997a; Schalock et al., 1993; Gitsham et al., 2002). Four topics were developed to measure perceptions of QoL and QoS: a main mat to explore overall satisfaction with QoL ('general satisfaction'), followed by three mats around sub-topics that might be impacted by the PCAS intervention: 'satisfaction with support', 'activities' and 'choice' (see Figure 1 for an example). The TMs were designed to be delivered in this order, with Choice presented last, as it contained the most abstract concepts. Symbol options were tested and piloted with service user representatives. All TM sessions were videod and TMs photographed for later analysis.

Procedure

Qualitative interviews and the ASM were carried out prior to PCAS training and, again, 6-12 months after

the completion of training, to allow new skills to be embedded in everyday practice. Inter-observer agreement for ASM observations was calculated by having a second independent observer during 20% of the observations and averaged 83% prior to the intervention (Kappa =.73) and 74% at follow-up (Kappa =.61) - an 'acceptable' level (Aspland and Gardeners, 2003). Observations were completed by a Speech and Language Therapy assistant, experienced and trained in PCAS with the second observer being the first author.

The ECF was used with all of the TM videos by the first author and an Occupational Therapist trained in using TM, and, following a consensus approach (Murphy et al., 2010), 100% agreement was achieved.

Ethical approval

Ethical approval was obtained through the University of Kent, and locally within the supported living organisation's own ethics committee. The research was carried out in Guernsey, where the Mental Capacity Act (2005) (MCA) does not apply. However, local policy required that MCA principles were applied. Accordingly, for participants were assessed to lack capacity to consent, the advice of consultees was sought and obtained.

Analysis

Interviewing participants who have limited verbal communication produces transcripts that are limited in content. Therefore, a theory-driven analysis (Braun and Clarke, 2006) which closely followed the questions and options presented to participants was used. Videos were reviewed for the process of producing a summary, verbal and non-verbal responses were collated, with the TM photograph, which, given the limited verbal data, provided a more meaningful context to consider responses than transcription alone.

Results

Quality of support

Percentage scores on the ASM can be categorised as good (67% or greater), mixed (between 33 and 67%) or weak (33% or less) (Mansell and Beadle-Brown, 2012, p. 68). Pre-intervention, the total average percentage score indicated 'good' PCAS was being implemented (ASM = 68.3%). At follow-up, the average percentage score had reduced to 60.96%, reflecting mixed implementation. However this masks wide variation in ASM scores (from 25% - 88.88% pre- and 16.67%- 91.67% post-intervention). Of the participants where pre and post data was available, ASM scores reduced for three individuals, increased for four individuals and remained the same for one individual.

Effectiveness of TM

Although one participant was not able to complete any mats effectively, other participants were able to give their views on at least some topics, using the TMs

One participant was able to effectively communicate on all mats post-intervention, following adaptations to the presentation of the TM (i.e. reducing the top scale to 2 points, and placing the items for the individual, at their direction, due to their physical disability). Although not yet directly evaluated in research, there is some suggestion from recent studies that there may be practice effects when using TM (Collard et al., under review). This may also have contributed to improved effectiveness post-intervention.

Interviews using TM

The results are reported under the main and sub-topic headings: general satisfaction, satisfaction with support, independence and choice. Within each of these topics, participants reported both positive and negative aspects pre- and post-intervention. The overall patterns of response prior to intervention will be outlined first with examples, and any differences after implementation of PCAS then described.

General satisfaction

Participants reported high levels of general satisfaction on the main TM with the majority of items placed positively. Participants elaborated on TM options occasionally with single words, or short phrases and non-verbally, through body language and facial expression, indicating that they were positive about aspects of their life like health:

‘health alright’ (P4).

And activities like writing:

‘writing’ (smiling) (P1).

After the intervention, one participant had moved house (support continued from the same team) and now placed their home option positively and expressed happiness non-verbally:

(placed positively, smiling and clapping) (P8).

After intervention, some participants also expressed satisfaction with aspects of their lives with which they had previously been dissatisfied but they were not able to elaborate further.

All but one participant expressed dissatisfaction with some aspect of their lives on the main TM. For example, some participants were unhappy with their activities at home such as watching television:

‘watch TV’, (stopped smiling, looked at TV, placed item on TM centrally, but slightly towards negative end) ‘not alright’ (moved item to negative end of the TM scale) (P1).

Participants were dissatisfied with personal relationships, expressing this both verbally and through placement of the symbol on the mat e.g. when talking about friendships:

[asked ‘have you got friends?’] ‘no’ (looked unhappy, placed symbol in negative column) (P3)

When discussing their families, participants placed TM items negatively and clarified with comments why they were dissatisfied e.g. because they had no family:

‘I ain’t got family’ (P6).

After intervention, participants expressed increased dissatisfaction across some topics e.g. feeling less safe in the community after a specific incident:

‘not happy, something happened’ (P7).

Satisfaction with support

The majority of participants placed the Staff option in the positive column on the main TM ‘General Satisfaction’. Participants made few comments but did specify for some options why they were placing them positively e.g. because the visual aids used by staff helped them know who would support them:

‘I’ve got my picture board every day, that makes my life happier’ (placed positively) (P7).

Although general satisfaction was relatively high on the main mat, some important patterns emerged from responses on the sub-mat ‘satisfaction with support’ which indicated dissatisfaction with the style some staff used to support people. In particular, there was a sense that some staff could be overly directive and/or intrusive in their style of support, and post intervention, participants experienced this as being treated badly. Participants indicated these issues were about specific staff, not the staff team as a whole e.g. by describing the problem and then qualifying it:

‘they’re too bossy, one or two people’ (P5).

Participants seemed more tentative and uncertain about reporting dissatisfaction:

[Spoke very quietly, barely audibly] ‘mean to me when talk to me’ [asked ‘did you say they were

mean?'] (nodded, looked towards door where staff voices could be heard, placed positively, looking at negative end of scale) 'I don't know' (P2).

Post intervention, all participants expressed satisfaction with the availability of staff and in general, expressed more positive views about the symbol '*How staff talk to you*'.

After intervention 'How staff treat you' was now rated more negatively, and this was supported by participants' comments e.g. describing feeling treated badly:

'treat me rubbish' (P4).

Activities

On the sub-TM Activities, participants both placed items and verbally presented themselves as capable e.g. independently doing activities of daily living like housework and clothes washing:

'me, I cleaning, I do it myself' (P3).

[laundry option] 'I do that myself' (P7).

Participants identified themselves both as getting and needing help. One participant described receiving help from staff with housework and giving staff help with the laundry:

[Cleaning option] 'I have a hand with that as well'.

'help them' (pointed to I need help part of scale.) (P7)

Half the participants reported at least one activity of daily living being done for them by a range of different people both paid and unpaid e.g. support staff doing their cooking for them:

‘cooking is staff’ (P4).

A pattern emerged for the three participants who completed the sub-TM Activities before and after the intervention, indicating they were receiving more help to do things with fewer activities being done completely for them by someone else.

Choice

There were very limited verbal responses within the Choice sub-TM to support placement of options on the mat. However, all of the participants reported ‘choosing staff’ was done for them e.g. by the staff themselves and that this was a part of their role:

‘it’s on the picture board, staff at {name of base} print that for me’; ‘they print the picture board to give to me, that’s their job’ (P7).

Participants represented themselves as having and making choices, which included larger life decisions, and using visual supports to do this e.g. using photos to help choose where they lived:

‘they build it before’ (placed under ‘I choose’) ‘picture’ [asked if they used pictures to choose] ‘photo book’ (P5).

Smaller day to day choices were also mentioned, e.g. choosing what activities to do at home:

‘I choose it’ (P1).

One participant also expressed a choice during the main TM on General satisfaction which indicated a sense that they saw themselves as having choices and being able to make plans, i.e. talking about pursuing educational activities:

‘perhaps me go back to night school’ (P7).

Post intervention responses were broadly similar. There was some indication that more choices were being made for participants, however they still reported being able to make bigger life decisions e.g. choosing to be living with their partner and smaller day to day life choices e.g. like what to wear:

‘I choose my clothes’ (P4).

Discussion

The literature suggests PWIDD find it difficult to criticise services (Merriam and Beail, 2009) and that TM can help people express dissatisfaction (Bell and Cameron, 2008). In this study, they were able to use TM to express dissatisfaction, supported with verbal responses. Participants’ responses were very similar to themes in other studies (Hoole and Morgan, 2011; McVilly, 1995) e.g. specific staff being ‘bossy’, not listening to participants, and not treating people well. These findings are important, given the value other people with disabilities have placed on staff attitudes and approaches when considering good social care (Gridley et al., 2014) and the emphasis in the literature on developing positive enabling relationships between staff and service users (Mansell and Beadle-Brown, 2012). The ASM results suggested that the quality of support provided was variable both before and after the intervention, with ‘poor’, ‘mixed’ and ‘good’ support being provided to individuals supported within the same service. Participants reported dissatisfaction with aspects of staff behavior related to interpersonal skills and it seems likely that staff who have poor rapport with PWIDD may find it difficult to implement other aspects of PCAS resulting in good QoS only being delivered to ‘some people, some of the time’ (Mansell et al., 2013).

Participants were able to express dissatisfaction with particular elements of their lives when asked. In this study there were high levels of general satisfaction with staff but some dissatisfaction with aspects of staff behaviour. This suggests the need to ask people about specific elements of their support, especially

when participants are less verbally able and less likely to elaborate spontaneously.

The patterns of responses that emerged are similar to those been found to be associated with reduced satisfaction in studies of other PWIDD e.g. around activities, money, difficulties with people they live with, problems when in the community, their environment and feeling safe (Maes, 2003; McVilly, 1995), problems in relationships and limited social networks (Forrester-Jones et al., 2006) that can lead to isolation and may be associated with dissatisfaction (Maes, 2003).

Participants reported their involvement in both day to day and larger life choices. PWIDD define self-determination partly by their ability to make choices and partly in terms of the presence of environmental characteristics that promote choice making (Shogren and Broussard, 2011). Some participants still experienced some choices being made entirely for them, suggesting staff may need to further develop their skills in supporting participants to make choices where they were unable to do this independently. A major threat to participants' ability to be self-determining could be the overly directive style of support from some staff.

Generalisability is limited in this study due to the small sample size, the older age of participants, and the restricted geographical and service model sampled. Interpretation was also made difficult by the inconsistent implementation of PCAS within the services. Overall, most people experienced mixed support prior to and following intervention.

Despite the methodology including more people with more significant communication difficulties than verbally based interviews used more commonly in qualitative research, one person was excluded due to their comprehension level, and one person was not able to use the TM effectively. This reflects issues highlighted in the literature around using augmentative communication for people with more severe disabilities (Harding, Lindsay, O'Brien, Dipper and Wright, 2010) particularly when some may not yet have reached a developmental level where they are using communication intentionally (McLean et al., 1996). Therefore the views in this study cannot be said to be representative of the whole population of PWIDD. When gaining the views of people with more severe communication problems greater

interpretation is necessary (Grove et al., 1999) and, while TM is considered to reduce some of these effects, response bias is common in PWIDD.

This study adds to that evidence base that suggests TM can be used effectively with PWIDD. It also suggests older PWIDD can benefit from the use of TM, an identified gap in the literature (Murphy and Cameron, 2008). It has extended the use of TM beyond its current use as a clinical service evaluation (Murphy and Cameron, 2008) to potentially evaluate QoS and QoL in research with participants with limited verbal skills.

These findings contrast with studies using other visual scales to evaluate services (McVilly, 1995) and measure subjective QoL (Cummins, 1997b) which found difficulties with less able participants. This suggests there may be unique features of TM that improve effectiveness of communication. Results for one participant support the premise that PWIDD on the threshold of using TM effectively may be helped to do so through adaptations (Murphy and Cameron, 2008).

Methodologies and communication tools which enable more PWIDD to have their views heard are of increasing importance in light of the ongoing movement towards participatory and emancipatory research (Walmsley, 2001), national and international standards which emphasize the involvement of PWIDD (Royal College of Speech and Language Therapists, 2013, United Nations, 2007) and legislation which makes reasonable adjustments and inclusive communication a government mandate (Equality Act, 2010; Mental Capacity Act, 2005).

Conclusion

This study indicates that the use of TM may extend the degree to which less verbally able PWIDD can participate in service evaluation and research. Using TM enabled most participants, with limited verbal skills, to feedback effectively both positive and negative experiences of QoS and subjective QoL.

Participants in this study highlighted issues in common with other studies of the views of PWIDD.

Participants' responses suggest that QoS would be improved by focussing on relationships and rapport,

and tailoring support to their needs, to maximise self-determination and independence.

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