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Title: Exploring the social care-related quality of life outcomes of adults with intellectual disabilities through the use of Talking Mats

Abstract:

Background: Views on social care related quality of life (SCRQoL) are typically gathered directly from individuals or from proxy informants. Easy-Read options are available, though such methods may not be accessible to those with greater communication challenges.

Methods: Fifteen people with intellectual disabilities were interviewed about their SCRQoL using Talking Mats® (TM). A descriptive approach was taken to exploring what people had to say.

Results: Participants reported high levels of satisfaction with living conditions and personal care routines. They were mostly satisfied with the level of choice and control they had and with their carers.

Conclusions: People with intellectual disabilities who have greater communication challenges can make meaningful contributions to the assessment of the care they receive. Talking Mats is one tool which can be used to support people with intellectual disabilities to give their views.

Introduction

Measures of Quality of Life (QoL) involve assessment of observed (objective) as well as subjective (personal) satisfaction with life conditions. ~~with the~~ The views of the individual ~~are of~~ should be of paramount importance (Schalock et al, 2002). There may be little relationship between observed QoLations and the degree of satisfaction perceived by the person themselves (Cummins, 1997) and this is the same for people with and without intellectual disabilities (Hensel et al, 2002).

Personal appraisal has become central to QoL assessment in the general population (Perry & Felce, 2003), however, the voices of people with intellectual disabilities are seldom heard (Beadle-Brown et al, 2012). Reports of the views and experiences elicited directly from those living in residential settings is sparse (Perry & Felce, 2003) and much of the QoL research in this population has focussed on observed life conditions (Perry & Felce, 2003). Objective data is often presented in the form of counts and frequencies applied comparatively with standards found in and imposed by the general population (Cummins, 1997).

When asked, people tend to report satisfaction with QoL (Perry & Felce, 2003). Subjective QoL is influenced by life experiences (Finlay & Lyons, 2001), the conditions under which people have become accustomed, the importance people place on aspects of their lives, their satisfaction with those aspects (Cummins, 1997) as well as achievement of personally meaningful outcomes and sense of well-being and happiness (Netten et al, 2010). Measuring subjective QoL **therefore** involves asking the person themselves about their life and is a question not easily answered by others (Cummins, 1997).

People with intellectual disabilities are in the best position to make critical and informative evaluation of services and the outcomes they wish to achieve (Cambridge & McCarthy, 2001; Kroese, Gillott & Atkinson, 1998). A range of research methodologies have been used to gather views **directly**, however personal and environmental factors place restrictions on **their people's** participation in research (Beadle-Brown et al, 2012).

Cognitive challenges may limit people's capacity to make informed decisions in relation to participation in research. Contact with this vulnerable population is justifiably guarded by ethical protocols and gatekeepers who can be barriers to access (Nind, 2008).

The cognitive demand and communication abilities required to interpret, and express personal perspectives is well documented in the literature (Bunning, 2011 cited in Bunning et al, 2017; Jones, Long & Finlay, 2006). The very nature of QoL assessment and qualitative research can be problematic for people with limited cognitive

and communication abilities (Beadle-Brown et al, 2012; Martella, Nelson, Morgan & Marchand-Martella, 2013; Sigelman, Budd, Spanhel & Schoenrock, 1981).

Difficulty in articulating personal perspectives goes beyond the consequences of limited communication skills. ~~It but~~ may also involves limited life experiences, anxiety and, low self-esteem (Booth & Booth, 1996; Swain, Heyman & Gilman, 1998). Interviewer-respondent misunderstanding and miscommunication, interpersonal power dynamics (Preston-Shoot, Temple & Wu, 1996; Swain et al, 1998) together with vulnerability to acquiescence, suggestibility and response bias all have ~~has~~ the potential to threaten the quality and validity of research (Baxter, 2005; Grove, Bunning, Porter & Olsson, 1999; Murphy, 1998; Perry & Felce, 2002; Sigelman et al 1981).

Where people with intellectual disabilities encounter problems with articulating their opinions, proxy informants; staff or family members, are often consulted (Beadle-Brown et al, 2012) and asked to respond on behalf of the person. Research findings are inconclusive as to whether proxies accurately represent the views of the person (Nota, Soresi & Perry, 2006). It is essential that alternative interview techniques are utilized to capture the views of this seldom-heard population (Beadle-Brown et al, 2012).

Eliciting the views of people with intellectual disabilities

Accessible, differentiated information and interview techniques are required if the subjective QoL of this population is to be captured (Netten et al, 2010). Developed by Murphy (1998), Talking Mats (TM) support neutral interviewing and open questioning and provide a framework on which to organise and reflect on views (Murphy & Cameron, 2008). Wherever possible, concrete rather than abstract information is given in small manageable chunks. Visual images are used to enhance comprehension, lessening reliance on spoken language (Bunning et al, 2017), easing pressure on processing and working memory and reducing distractibility (Cameron & Murphy, 2002; Murphy & Cameron, 2008). TM empower the person to articulate their views independently, lowering the risk of

suggestibility and shifting the balance of power towards the person being interviewed (Murphy & Cameron, 2008).

Social Care Related Quality of Life (SCRQoL)

The QoL construct has been applied in the evaluation and development of services for people with intellectual disabilities (Netten et al, 2010). Paid care and support i.e. that which is not provided by family or unpaid carers, is referred to as 'social care services and intervention' (Personal Social Services Research Unit (PSSRU), 2018). It can be reasonably be assumed that social care services and intervention will affect a persons' QoL and this is described as SCRQoL (PSSRU, 2018).

SCRQoL is conceptualised within the Adult Social Care Outcomes Toolkit (ASCOT) which explores satisfaction within eight domains; control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort, and dignity (Netten et al, 2010, 2012).

With SCRQoL at the heart of social services intervention it is crucial to elicit peoples' a person's personal satisfaction with the care and support they receive (Rand & Malley, 2017). Towers et al (2016) and Rand and Malley (2017) demonstrated how the ASCOT can be used at a personal level to improve outcomes as well as to shape organisational, local and national policy.

Using the ASCOT as a foundation this study used TMs to interview people with intellectual disabilities in receipt of social care services and intervention. Exploratory in nature, it aimed to give a voice to people with intellectual disabilities, describe what people had to say about their SCRQoL, consider this within the context of wider research and explore the potential implications.

Methods

Ethics

The study received favourable opinion from the Social Care Research Ethics Committee and Local Authority Research Governance approval. Where possible, supported by easy-read information, informed consent was sought directly from participants. Where this was not ~~possible personal~~ consultees were ~~consulted~~used. For all participants, assent was gained directly prior to and monitored throughout the interview process. Participants were free to withdraw from the study at any point.

Discussion of QoL can bring up sensitive issues. An accessible distress protocol was used to signpost people to appropriate services and described actions the person could take to help them make changes to their lives. Safeguarding protocols were in place to address and raise any issues disclosed by participants with appropriate authorities.

Participants

A purposive sample of 21 adults meeting inclusion criteria was recruited through local authority, private and third sector providers of day care services. Participants were aged 18 or over, described as having learning disabilities and communication difficulties, resided (full time) within community residential or supported living settings, able to take part in face-to-face interviews, and had the visual and physical ability to access a TM framework. Participants from all ethnic and socio-economic groups were considered for inclusion as well as those with additional conditions. Participant characteristics are summarized in Table 1 and included people with a wide range of cognitive and communicative abilities

Participants typically responded using single words, short phrases or non-verbally. Some, with greater communicative abilities, were able to elaborate on their views using sentences and for one this involved writing key words on paper.

Talking Mats

Abstract concepts relating to SCRQoL require complex mental manipulation. Adaptations were required to maximise the potential for people with limited cognitive and communication abilities to express their views effectively using a TM framework.

Table 2 shows the composition of each of the mats; the SCRQoL domains they explored and the items related to each of these domains. The mats were designed to be delivered in order, with more concrete concepts presented in earlier mats. To avoid potential misunderstanding and confusion the top scale; going well, unsure, not going well, and open questionprobe; “how do you feel about?” remained the same for all mats.

Procedure

The study was conducted in two stages with interviews conducted by the first author. Stage One determined whether the participants had the cognitive, visual and physical ability to use TMs. The Stirling Understanding Screening Tool (SUST) (Murphy & Cameron, 2008) was administered to establish functional comprehension. The starter TM determined accessibility of the TM framework to the individual, and developed rapport. It provided the opportunity for the interviewer to assess participant comprehension and familiarize themselves with communication style.

Participants who continued to meet inclusion criteria progressed to Stage Two and the three TMs. Each mat was introduced, with the purpose, the topic and top scale explained. Participants were then presented with a series of cards in turn, each depicting an aspect of SCRQoL. As the card was handed over the participant was asked the open question “how do you feel about ...?”. The participant then rated their satisfaction by placing the item card along the three-point top scale to indicate whether they felt things were; going well, not sure or not going well. Participants were given the opportunity to expand on their views and questions such as “tell me more about” “what could be better with” “what is not going so well with?” explored responses in more depth.

Interviews were recorded using video and photos and later transcribed. The first author reflected on understanding and communication using the Effectiveness Framework of Functional Communication (Murphy et al, 2010) to evaluate whether participants had communicated effectively.

After interviews had been transcribed each participant was sent a photo of the completed mat and a transcript of the interview.

Analysis

~~Ratings of satisfaction were summarised, with information from transcripts used to illustrate these ratings.~~ Participants' communication and understanding was assessed using the SUST (Cameron & Murphy, 2008) and the TM EFFC (Murphy et al, 2010).

All forms of communication were considered through the transcription process i.e.; both verbal and non-verbal responses. Ratings of satisfaction were summarised, with information from transcripts ~~have been~~ used to illustrate ratings and the points made by participants.

Reliability

A random sample of interviews i.e. one TM for each participant, amounting to 27% of all data, was independently reviewed by the second author and rated using the EFFC. Kappa values as well as percentage agreement was calculated to investigate inter-rater reliability.

RESULTS

Sample

Over the course of the study six of the twenty-one participants had either insufficient comprehension (P18-21) or were unable to use the mats to communicate effectively (P16-17). Only the data of those reaching threshold for functional communication is reported.

Reported QoL

Participants responded positively to an average of 85.6% of items ranging from 75.3-93.4% across domains (Table 3) which indicated a high level of general satisfaction with SCRQoL. Responses in relation to the three mats central to the ASCOT-TM together with some of the key issues participants' experienced in understanding the concepts under discussion are described below.

Mat 1: Work and Social Life

Mat 1 explored the domains of Occupation as well as Social Participation and Involvement. Up to ten items investigated satisfaction with time spent participating in activities that the person enjoyed as well as with social networks and relationships with others (Table 2).

Where participants were able to grasp the concept being investigated and were able to elaborate on their responses, some suggested they wanted to try activities;

“well, I would like to have a go at doing it” (laundry/unsure) (P10)

Respondents were especially enthusiastic about opportunities for meaningful daytime occupation and opportunities for employment but highlighted barriers to employment.

“not allowed to work, pity.... I used to work... I'd like to work.... but there's nowhere they'd put me” (unsure) (P12)

Participants responded positively to 84.4% of items exploring social participation. They expressed satisfaction with interpersonal relationships, frequently seeing the people they lived with and staff as their friends. Occasionally participants cited problems with the behaviour of other residents, but this did not influence satisfaction with social engagement.

People described the value attached to friendships at day services and clubs and how these relationships extended into the wider community;

“Games here ... play a lot, friends to play with” (P1)

“Oh, I love it, Gateway club ... absolute massive evening People from the Gateway club I see coming past the window, giving me a wave, asking how you getting on?” (P2)

Some participants found understanding around ‘doing an activity as much as you would like to’ difficult. For example, one participant initially placed activities that they were not doing but would like to do positively. Reflective questioning sometimes aided participants understanding;

Question; “so if you would like to work but you haven’t got a job, where would you put it on the mat?”

The participant responded by altering placement from ‘going well’ to ‘not going well’ (P4)

Mat 2: Your Life

Thirteen items explored participant satisfaction with accommodation and personal cleanliness and comfort as well as having enough food and drink (Table 2).

In comparison to other domains, accommodation was where participants expressed greatest satisfaction, placing 93.4% of items positively (Table 3). Where people were unsure or expressed ~~dissatisfaction~~dissatisfaction, this revolved around the environment not meeting their needs;

“can’t get in the bath.... they have to give me a shower” (P11)

Personal Cleanliness and Comfort related to feeling clean, presentable and comfortable in clothing. Most responded positively with just a couple highlighting issues with physical ability to complete personal care routines or dissatisfaction with choice of preferred clothing.

“Hmm, might need a bit of help with that” (dressing) (P10)

“Shaking head and gesturing no” (preferred clothing) (P6)

The cognitive demand of understanding abstract concepts such as ‘amounts’ was difficult for many people. Although 82% of items relating to having enough food were placed positively participants comments were limited, a few were unsure of their feelings and none placed items negatively [\(Table 3\)](#).

Mat 3: Your Care

Mat 3 asked participants to reflect on their opportunities and experiences for Control Over Daily Life, access to and choice of Food and Drink, Safety and Dignity [\(Table 2\)](#).

Participants suggested that they were able to choose and participate in activities they wanted to do and that their routines were respected;

“all six tenants go to bed when they want” (P1)

Physical limitations ~~that~~ [sometimes](#) impacted satisfaction with choice of activities;

“not very well.... can’t move properly.... small letters, can’t read them hardly”

(choosing activities/negative) (P11)

Most people expressed satisfaction with choice of and access to food, drinks and snacks. Some, all living in residential placements, talked about environmental restrictions that limited independent access to snacks ~~although~~ [however](#) this did not necessarily result in negative placement;

“ask the staff people, because (name) eats it” (access to snacks placed positively) (P5)

Participants were asked about feelings of safety in the environments they might find themselves in e.g. at home, in the community, at work. Ninety percent of items were placed positively ([Table 35](#)), and all participants felt safe at home and work. Four were unsure of

their safety; in the community (2) or when with carers (1), one was dissatisfied their safety at college.

Two aspects to dignity were explored; satisfaction with paid support and feelings around needing to ask for help. Verbal responses around asking for help were limited and comprehension difficult to ascertain. Participants indicated things were 'going well' with many aspects of their care.,- ~~describing~~They described -positive experiences in relation to the attitude and approach of staff. Sometimes people found asking for help difficult.

“It is difficult, but I do try and ask for it” (P9)

Occasionally participants recounted negative experiences;

“Sometimes they're alright ... sometimes they can be a bit not alright” (P12)

“It depends, some of the support workers, key workers, can be a bit grotty about it”
(P12)

Reliability

Participants reaching the threshold for effective communication decreased over the four mats (Table 4). No participants whose communication dropped below criteria for effective communication on earlier mats were assessed as having effective communication on the mats that followed.

The EFFC was completed by the first author. Inter-rater agreement calculated on the 5-point scale of the EFFC yielded a percentage agreement of 56% with a Kappa value of 0.2. Reducing the scale to 3 points yielded percentage agreement of 82% with a Kappa value of 0.5. There was 100% agreement as to whether the overall threshold (>75% of the measure) for effective communication had been reached.

Responding

Patterned responding and acquiescence was noted particularly where participants placed all items positively, no participants placed all items solely within other levels. One participant appeared to place items positively when they did not attach any great importance to the item. Sometimes consistent positive placement corresponded with comments but there were occasions where participants were unable to elaborate. One was found to have a 'set phrase' used in response to reflective questioning. Others were concerned that they give the 'right' response or when unsure of where to place items were found to look towards carers (if present) or to the listener for affirmation. It was noted that for one participant reflective questioning would prompt alteration of placement.

Participants expressed that they had enjoyed completing the mats and found the TM framework a useful thinking tool;

Signing "thumbs up" (P15)

"Innit good ... it's good for deaf people innit" (P5)

"I think it's great, I think it's good, it certainly helps with things, the way they are ... you know you can lay stuff out and move it around" (P9)

DISCUSSION

Most participants (88%) were able to comment reliably on at least some of the topics explored. What they had to say, implications and limitations are explored below.

General Satisfaction

Satisfaction with QoL usually falls within 70-80% of the scale measure (Cummins, 1997) but this ~~study was~~ exceeded ~~this~~ in all but one domain; occupation. Level of general satisfaction was high, congruent with those reported by Stewart et al. (2018) but outstripping those reported within 2018-19 Adult Social Care

Survey (ACSC) (NHS digital, 2019) in which just over 64% of respondents reported being extremely satisfied with the care and support they received.

The ASCS gathers the views of all those in receipt of social care interventions and is not confined solely to those with intellectual disabilities. The high levels of satisfaction expressed within this study may ~~be a reflection of~~reflect a combination of difficulties that people with intellectual disabilities may have in self-reporting QoL and satisfaction with the services they receive. Dissatisfaction with services can be problematic for people with intellectual disabilities to report (Merriman & Beail, 2009). Even people with a good ~~grasp of~~vocabulary can have difficulty drawing their thoughts together and expressing their views effectively (Bell & Cameron, 2008). The visual and structured framework and neutral questioning approach used within TMs can support people to express dissatisfaction (Bell & Cameron, 2008) however, this may not have been the case for all participants in relation to all the concepts under discussion.

Choice and Control

The ASCS 2018-2019 found positive correlations between choice and control and SCRQoL (NHS Digital, 2019). In this study, although the majority expressed satisfaction, some environmental restrictions were apparent in relation to free access to food and drinks. Congruent with Turnpenny et al. (2018) participants living in residential settings had less freedom of access than those in supported living, however, this did not always result in dissatisfaction. It is conceivable, that people may have become accustomed to restrictions. 'Normalisation' to living conditions is known to influence subjective assessment of QoL (Cummins, 1997).

People with intellectual disabilities are vulnerable to restrictive practice and limitations on freedoms. While personal views are paramount it is important to consider the views of this population through the lens of generally accepted standards held by the wider population and those enshrined in legal and human rights frameworks.

Occupation

~~Article 26 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2007) enshrines the rights of people with disabilities to “full inclusion and participation in all aspects of life”.~~

The flexibility of thought required to reflect on the value of activities and then indicate satisfaction with time spent participating in these was too great for many. Participants found it particularly difficult to report -satisfaction with time spent in domestic and leisure activities, impacting the reliability of responses within this domain.

Where people could express their thoughts, they suggested opportunities were limited and expressed a wish to take more of an active role in daily life.

Article 26 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2007) enshrines the rights of people with disabilities to “full inclusion and participation in all aspects of life”. However, ~~T~~his cohort are often dependent on their support networks to offer opportunities and provide assistance that enables participation in every-day activities (Mansell & Beadle-Brown, 2012). Frequently more mundane tasks are completed by staff (Beadle-Brown et al, 2016). While research suggests that approaches such as Person-centred Active Support are particularly successful in supporting the participation of those with complex needs (Mansell & Beadle-Brown, 2012), implementation in community services is not the norm (Netten et al, 2010).

If people with intellectual disabilities are to be enabled to live active and fulfilled lives the participation of service users in everyday meaningful activities needs to be given greater emphasis within service models and person-centred planning.

Work and Social Participation

All ~~the~~ participants attended day services and expressed how much they valued the opportunities they had for meaningful daytime occupation and social opportunities. People

stressed the importance of friendships formed within these segregated environments and described how these extended into the wider community. They saw members of staff and the people they lived with as friends. Few were employed and ~~they~~ highlighted problems with finding and securing a job.

Small, dense social networks can limit the personal aspirations of people with intellectual disabilities. People are at risk of experiencing a lack of privacy and of more powerful members of the network influencing them (Forrester-Jones, 2006). Attendance at day centres as well as supported employment programmes is known to widen the social networks of people with intellectual disabilities and enhance QoL (Beyer et al, 2010; Forrester-Jones et al, 2004). More opportunities for supported employment and inclusion within everyday communities should be a priority. This may enable people with disabilities to experience a wider range of relationships besides those paid to provide support. A balance needs to be struck between opportunities in the wider community and the continued provision of daytime occupation and social opportunities within segregated settings which people value and in which they have established relationships.

Accommodation

Participants found it easy to ~~relate~~ understand the concrete nature of items presented ~~in~~ relation to satisfaction with their homes with respect to their homes. It is conceivable that people found these items easy to relate to everyday life experiences.

People said they felt safe within their homes. Reflecting the findings of Rand & Malley, (2017), where dissatisfaction existed, this was in relation to home design not meeting needs rather than cleanliness/comfort. Conflict with co-residents was reported but this did not necessarily result in dissatisfaction

Local authorities are required to develop a range of housing solutions which meets the needs of their local population (DoH, 2001). The reality is that people with learning disabilities

have little choice over ~~with~~ whom they share their home even when this results in conflict and restrictions on personal liberties.

Housing quality and its suitability to meeting individual need is an important factor in QoL and strongly associated with health and psychological wellbeing (Rand and Malley, 2017). Housing associations and commissioners need to work together to provide housing that not only meets assessed need but also takes into consideration people's aspirations and preferences.

Personal Care

People reported that personal routines were respected and were mostly able to dress as they wished. They were predominantly satisfied with the care they received although some struggled to ask for help when needed. Reflective of wider research (e.g. Hoole & Morgan, 2011; Stewart et al, 2018), people who expressed dissatisfaction, and were able to elaborate on their views, spoke of concerns in relation to the attitude of some but not all staff. This suggests that thought is needed in relation to how those with more limited communication abilities are supported to make complaints and, in the absence of advocates, have choice and autonomy over the care and support they receive.

Limitations

Generalizability is limited. No formal assessment was conducted in relation to cognitive or communicative ability. All participants were recruited from one geographical area. Just three participants were from ~~racially minoritised groups-ethnic minorities~~ and are ~~therefore~~ are under-represented. The older age range (average 46 years) may mean that younger adults are also under-represented.

~~No formal assessment was conducted in relation to cognitive or communicative ability.~~ Assessing communication is subjective in nature (Murphy & Cameron, 2008) and no prior accord was reached between raters in relation to scoring the EFFC which is reflected in poor inter-rater reliability. It is important to stress that raters were 100% in agreement as to whether participants' communication had been effective and only the data of those reaching threshold for effective communication was included in analysis.

The complex nature of measuring the abstract and multi-dimensional concepts of QoL and applying to people with learning disabilities is well documented in the literature (e.g. Cummins, 1997, Schalock et al, 2002).

Drawing comparisons across contexts and the ability to think introspectively to reflect and express personal opinions are skills that people with limited cognitive and communication difficulties may find challenging (Cummins, 1997, Hartley & MacClean, 2006) but are inherent in assessment of SCRQoL. The design of the TM aimed to circumnavigate or reduce these difficulties.

Breaking down abstract concepts into concrete items that people could relate to enhanced comprehension and where possible negated the need for participants to make judgements across contexts. Responding in relation to satisfaction with individual elements participants were able to respond reliably within some of the mats.

As literature suggests (e.g. Finlay & Lyons, 2001) respondents struggled with making judgements in relation to frequencies and amounts and then apply this to satisfaction. This particularly influenced reliability when reporting satisfaction with time spent in activities that people valued and enjoyed.

Breaking 'occupation' into specific items, resulted in participants being required to express satisfaction with activities that they may or may not place value on. Discretionary questioning could have assisted people to rule out irrelevant items. However, this may not

have enhanced comprehension, would have interrupted the flow of the mat and, in the Starter Mat, potentially hindered the acquisition of skills needed to use talking mats successfully.

Problems with application of the top scale further compounded problems with relevant responding. There was a poor relation between respondents' interpretation of 'going well' and 'satisfaction with time spent'.

These factors impacted the reliability of responses in this domain for all but a minority. Future development needs to consider how best to present items in a way that enhances comprehension and enables participants to express satisfaction in relation to time spent doing the things they value and enjoy

There was a risk of patterned responding, occasionally participants responded solely within one response level. Where this was apparent, and not justified by participant comments or demeanour, the listener explored understanding through reflective questioning.

Reflective questions were a useful tool to support participants to elaborate on their responses. However, for one participant this risked introducing bias in the form of suggestibility. Others were at risk of responding in socially desirable ways and seen to 'want to get it right' or seek affirmation. Where bias was noted this was ~~later~~ accounted for in scoring decisions made in relation to functional communication.

Functional communication was assessed for each participant on each of the mats delivered. However, where multiple domains are contained within one mat, scoring is not reflective of whether communication was effective in relation to the specific item or concept under discussion. This is a limitation within this study and future research should focus on reliability of individual responses and participants understanding of specific concepts.

Social Validity

High levels of engagement were noted throughout the mats demonstrating that respondents enjoyed the process of completing the mats. Participants' comments suggested that they

found the TM a supportive and socially valid mechanism through which to express and reflect on their views.

Conclusion

The voices of people with learning disabilities often go unheard and there is a pressing need to find alternative methods that support the participation and engagement of this cohort (Beadle-Brown et al, 2012). As would be expected, more abstract concepts remain challenging to those with complex communication challenges. Introspective reflection, drawing across contexts together with judgements relating to frequency and amounts were problematic for some. The support provided by the TM framework may have enabled people to maximise their communication skills, though comparisons of responses with and without TM were not made.

While recognising that personal views should be at the centre of assessment of QoL it is essential that these are balanced with objective evaluation and considered within a human rights framework. TM have the potential to provide an additional means by which people with intellectual disabilities can contribute meaningfully to holistic assessment of their SCRQoL.

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Table 1 Participant Characteristics

Participant	Gender	Age	Ethnicity	Service Type	Co-occurring conditions	Comprehension (No words)
Completed Talking Mats						
1	F	32	White British	Residential	Autism	3
2	M	46	White British	Residential	Autism	3+
3	M	43	White British	Residential	Hearing loss, Dementia	2
4	F	53	White British	Residential	None	3+
5	F	72	White British	Residential	Hearing Loss	3+
6	M	39	White European	Residential	None	2
7	F	34	White British	Residential	None	2

8	M	22	White British	Residential	Autism, ADHD	3
9	M	53	White British	Supported Living	Hearing loss, Visual loss, Epilepsy	3+
10	M	50	White British	Residential	Physical disability	3
11	F	65	White British	Residential	Hearing loss	3
12	M	58	White British	Supported Living	None	3+
13	F	40	White British	Residential	None	2
14	M	46	White British	Residential	Autism	2
15	M	24	Indian Asian	Residential	Down's Syndrome, Visual loss	3
Unable to complete Talking Mats						
16	F	66	White British	Residential	Epilepsy, autism	3
17	M	30	White British	Residential	Physical disability	3
18	M	27	White British	Residential	Autism	1
19	M	55	White British	Residential	Autism	1
20	M	72	Black British	Supported Living	Visual loss	1
21	F	43	Indian Asian	Residential	Epilepsy	1

Table 2 Composition of Talking Mats

Mat	Domain	Item
Starter Mat: Activities	Occupation	Holidays Swimming Eating out Bowling Cinema/theatre Gardening Clubbing Clubs Listening to music TV Ipad/Computer Knitting/sewing Reading Games/puzzles Arts and crafts
Mat 1: Work and Social Life	Occupation	Your day service Work College Cooking Shopping Laundry Cleaning
	Social Participation and Involvement	Seeing family Seeing friends The people where you live

Mat 2: Your Life	Accommodation Cleanliness and Comfort	Where you live Your bedroom Your living room Your dining room Your kitchen Your bathroom Your garden
	Personal Cleanliness and Comfort	Washing Brushing your teeth Brushing/combing your hair The clothes you wear
	Food and Drink	Amount of: Food at mealtimes Snacks and drinks
Mat 3: Your Care	Control over Daily Life	Being able to choose activities Having the food and drinks you like Being able to snack when you want Being able to choose when you do things
	Dignity	The way carers support you The way carers talk to you The way carers listen to you Asking for help
	Safety	Being safe at home Being safe with carers Being safe at your day service Being safe at college/work (if relevant) Being safe when out and about

Table 3 Domain Ratings

Domain	Positive (going well)	Neutral (unsure)	Negative (not going well)	No. of possible responses
Control over Daily Life	85.4%	10.4%	4.1%	48
Personal Cleanliness and Comfort	86.5%	9.6%	1.9%	52
Food and Drink	82%	14%	4%	50
Personal Safety	90.5%	7.5%	1.8%	53
Social Participation and Involvement	84.4%	11.1%	2.2%	45
Occupation	75.3%	13%	11.5%	207
* Leisure	70.6%	15.5%	13.9%	122
* Domestic	83.3%	10%	6.6%	60
* Day service Education Employment	80%	8%	12%	25
Accommodation Cleanliness and Comfort	93.4%	2.1%	4.3%	91
Dignity	87.7%	10.2%	12.2%	49
* Support	81%	5.4%	13.5%	37
* Asking for help	66.6%	25%	8.3%	12
Average across domains	85.6%	9.7%	5.25%	595

Table 4 Effectiveness Framework of Functional Communication Scores

Participant	Starter Mat	Mat 1	Mat 2	Mat 3
1	93% (26)	93% (26)	89% (25)	82% (23)
2	85% (24)	78% (22)	75% (21)	75% (21)
3	100% (28)	85% (24)	75% (21)	85% (24)
4	92% (26)	92% (26)		
5	100% (28)	78% (22)	92% (26)	85% (24)
6	100% (28)	85% (24)	92% (26)	75% (21)
7	78% (22)	82% (23)	78% (22)	64% (18)*
8	78% (22)	85% (24)	100% (28)	96% (27)
9	82% (23)	82% (23)	92% (26)	92% (26)
10	89% (25)	92% (26)	100% (28)	96% (27)
11	82% (23)	89% (25)	100% (28)	96% (27)
12	96% (27)	89% (25)	85% (24)	92% (26)
13	78% (22)	75% (21)	96% (27)	85% (24)
14	92% (26)	78% (22)	42% (12)*	46% (13)*
15	92% (26)	92% (26)	100% (28)	92% (26)
Average	89%	85%	90%	87%

*not effective