

'Everyone thought I was a very very bad person... no one want to know you like the nurses and doctors': Using focus groups to elicit the views of adults with learning disability who use challenging behaviour services.

Accessible Summary

We wanted to find out what adults with learning disabilities who receive challenging behaviour services thought about challenging behaviour and the services they receive.

We met with people in small groups and talked with them about challenging behaviour.

There were barriers to attending the groups like services not having enough staff or transport.

People in the groups told us what they thought of words like challenging behaviour, what they understood about challenging behaviour services and what it was like meeting with them.

Abstract

Following scandals such as Winterbourne View, Transforming Care (2012) seeks changes in challenging behavior services. A key part of this change is ensuring people with learning disabilities who use challenging behavior services have more personalised support and their voices heard. This paper describes a study that used focus groups to explore challenging behaviour and challenging behaviour services with people with learning disabilities who used community based challenging behaviour services. We analysed the focus groups using thematic analysis and found 3 main themes: Engaging with service terminology; The language of Challenging Behaviour; Locating and Framing behaviour; Engaging with Professionals. This study has led to a larger funded study currently in process.

Introduction

Inclusion has long been a stated goal of services for people with learning disabilities (e.g. Department of Health (2001). More recently following Winterbourne view and other scandals, Transforming Care (2012) seeks changes to challenging behaviour services provided by health and social care. A key part of this program is ensuring people with learning disabilities and their families have more personalised support provided by multi-disciplinary teams. This requires a commitment to the inclusion agenda, to creativity in our work and to engaging with those using services, including those for challenging behaviour. A widely recognised definition of challenging behavior is as follows:

“Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.”

(Emerson, 2001)

Research into the experiences of people with learning disabilities who use challenging behaviour services is sparse. Where it does exist the results can reveal the experiences of people are rarely acknowledged. Jones & Kroese (2007) interviewed services users for their views on being physically restrained. Participants reported on the potential for restraint by staff leading to abuse and the need to attempt alternatives first.

This study used Focus Groups as our data collection method. Focus groups can be a method of achieving ‘thick’ or ‘rich’ descriptions (Geertz, 1993) of the experiences of participants. They also offer participants an active role in the research. Additionally Focus Groups allow *‘the researcher to capture responses of the group to the expressed opinions, beliefs, feelings and experiences of other group members. Other data collection strategies simply... cannot capture such things’* (Howitt, 2010: 107). This inclusive process may provide, as Howitt (2010) describes, an empowering experience as participants become part of the decision making process in the research making this a popular data collection method in feminist research. There is a growing literature on Focus Groups with people learning disabilities (e.g. Bollard 2003; Fraser & Fraser 2001; Martin et al. 1997; Barr et al. 2003; Cambridge & McCarthy 2001; Abbott & McConkey 2006; Gibbs, Brown, & Muir 2008; Kaehne & O’Connell 2010; Mactavish, Mahon & Lutfiyya, 2000; Northway et al 2013.) Gates & Waight (2007) highlighted the practical and methodological difficulties with the use of focus groups with people with learning disability but noted that these can be overcome and provide the possibility for accessing stories and experiences about the lives of people and the support they might require.

The aims of the study are as follows.

1. To elicit the views of people with learning disabilities who use community based challenging behaviour services about challenging behaviour and challenging behaviour services.
2. To employ knowledge gained from the study to influence local service delivery.

Method

Focus Groups

We took our ideas about using focus groups to Powerful Trainers, a local group of trainers who have learning disabilities. Powerful Trainers told us about the importance of engagement and shared their ideas with us. We decided to use background music, especially at the start of sessions and at breaks, to support a welcoming atmosphere, about the potential usefulness of carefully sharing our personal experience, of being clear about what is expected of participants, the importance of taking plenty of time to engage with participants. We also decided to use images to support communication in the groups. The images portrayed emotions, personal care, daily living activities, transport, relationships, food and drink, and health. We brought with us blank A1 paper, coloured pens and printed images so participants could write, draw, or dictate to facilitators. The focus group followed the format of introductions, a warm-up or getting to know each other exercise, a discussion about the term 'challenging behaviour', making posters and talking about what makes a 'good and bad day', what helps on a good or bad day and what services they have received and how they had been experienced. The warm-up exercises involved a facilitator or participant saying out loud a category, for example 'Eastenders'/'Marmite'/'Romantic Films' and everyone would walk to either the 'like' or 'dislike' end of a continuum line drawn on a large piece of paper on the floor to indicate if they liked or disliked the category. This set the scene for participants having different opinions, for welcoming disagreement and debate, and for 'not liking things' as being a valued part of the talk, as well as the focus group being a place where people could have fun. At the conclusion of the session we thanked people for their participation and discussed their experience of the meeting. If they wished to talk to us about anything that happened in the group they could contact us after and contact details were given.

Participants

The selection of participants was based on the following criteria:

1. Participants were required to have used or currently be using Learning Disability Services
2. Participants were referred to a local community learning disability team for issues related to managing behaviour and were or had been placed on the Challenging Behaviour pathway.
3. Participants would be able to be supported in the group setting.

Participants were recruited by contacting practitioners in local learning disability teams. They were asked to recommend clients who may be willing to take part in focus groups and who fitted the eligibility criteria. We contacted clients and their carers to discuss what participation would involve. If clients wanted to participate then a consent form and information letter was sent. Clients also read and signed an easy-read consent form. The study received ethical permission to proceed from both NHS and Social Care departments. Recordings of the focus groups were stored in line with Trust policy.

Three groups were carried out in three areas of the South of England. In total, five participants with learning disabilities took part; two participants in focus group one (with one carer), one participant and their carer in the second meeting and two participants and one carer in focus group three. In the second meeting three individuals did not attend the focus group. The remaining participant and his support worker joined with the three facilitators in the warm up games and discussions. Our decision to include this as a focus group is due to the similarity of conversations and ideas generated in this meeting. In all there were three men and two women participants' with an age range of 21 to 56. Difficulties were encountered with recruitment as previous authors have noted (Lennox, Taylor, Rey-Conde, Bain, Purdie & Boyle (2005); Gates & Waight (2007)). Additionally, five participants invited did not attend the focus groups; reasons for this were transport problems and staffing difficulties in the residential services in which they lived. These were likely exacerbated by the rural nature of some of the locations across which the groups occurred.

Data analysis

A voice and video recorder was used to collect the data from the focus groups. Thematic analysis was chosen as the analytic method for this study. Thematic analysis (Braun & Clarke, 2006) is a useful method of qualitative analysis when what is most important is what the participants are saying (content) – rather than how they are saying it (process). Thematic analysis is not driven by a particular theoretical orientation although it may be allied to an orientation if this is necessary. This study's focus on finding out about the views and experiences of the participants suggested thematic analysis as a useful method for coding and organising the data. Data analysis proceeded through six steps. Data familiarisation, initial coding, searching for themes based on initial codes, reviewing the themes, defining and labelling the themes and writing the report. In practice these steps are both interconnected and also iterative – i.e. it is a back and forth process. This process is important for rigour and in honouring the participants who gave of their time to engage in the study.

Three main themes were located in the data.

Findings

Engaging with service terminology: The language of Challenging Behaviour.

Challenging behaviour is a part of the lexicon of services. Engaging with services entails engaging with service terminology. Where do participants encounter the language of challenging behaviour? Participants had heard of the term but were mostly unsure where, although one participant in focus group 3 told us about hearing it on the services answerphone:

Participant 1: *Yeah when they call it you...This is the Challenging Behaviour Community Team and we will call you back as soon as possible.*

This was the first time the participant recalled hearing this language. Participant 2 in Focus Group 3 when informed about the teams name (a name that includes the words 'Challenging Behaviour') said:

Participant 2: *'Oh wow, do you like being called that?'*

Encountered through contact with services, participants had a negative perception of 'challenging behaviour' and of those who carried the label as illustrated in focus group 1:

Participant 2: *'Is that when people are hyperactive and they can get quite violent?'*

When asked about challenging behaviour participants 2 and 3 in focus group 3 characterised it using language more usually associated with describing the behaviour of children ('play up'), difficulties with coping, and problems with anger:

Facilitator 1: *What does that mean to you?*

Participant 2: *I'm not too sure.*

Participant 1: *It means that you play up sometimes and you are out of control it.*

Participant 2: *It's like anger problems isn't it?*

Facilitator 2: *Anger problems?*

Participant 1: *I have problems like behaving...coping'.*

When participants spoke of their own behaviour they used terms such as 'emotions', 'annoyed', 'angry', 'sad', 'upset' and action focused expressions such as 'hit staff', 'take it out on staff', 'running off', 'rude', 'smash things'.

In focus group 3 we received a clear answer to our question about the language of challenging behaviour:

Facilitator 1: *Do you think they are good words, do you like them?*

Participant 2: *No!*

In focus group 1 the following exchange took place:

Facilitator 2: *Do you think challenging behaviour is a good way of talking about those problems or do you think we should use different words?*

Participant 1: *Like help us to be good or help us to change our behaviour.*

Participant 2: *I don't know really, I don't know whether it is a good thing or not.*

Participant 1: *I think it's a bit rude.*

The use of 'good' or 'bad' by participants highlighted participant's views of challenging behaviour as a moral evaluative term. In the excerpt below we see participants from Focus group 1 declining to use the term challenging behaviour and suggesting alternative terms:

Participant 2: *I would say I'm (name) and I have got a learning disability*

Participant 1: *Hi and I'm (name) and am behaving good or I am behaving bad*

When we asked what might be a better word for Challenging Behaviour focus participant 1 in group 2 provided us with:

Participant 1: Emotions.

Participants who were familiar with the term 'challenging behaviour' had encountered it when engaging with services. Participants found challenging behaviour an undesirable term. Person-centred language was preferable to participants, in particular using the persons name, that they have a learning disability, particular difficulties and experiences or emotions as well as whether they were behaving well ('good or bad'). One participant suggested a term that indicates that the service purpose is to help those referred.

Locating and Framing behaviour

To what extent and how did participants identify with challenging behaviour?

Challenging behaviours were most often located within the self. They were characteristics belonging to a person that could be activated when external pressure outstripped the resources of the participant. In Focus Group 1 participant 1 said: *I have problems like behaving...coping.*

Holding onto these emotions is hard and sometimes they cannot be contained: Participant 1 again: *Some things slip out when I get angry, hard to stop everything, angry, hitting.*

When pressure outweighs resources participant's emotions (frustration, anger and sadness) overwhelm them and they describe behaving in ways that get described as challenging. In Focus Group 3 we see a participant negotiating and identifying with challenging behaviour and we hear more about pressure.

Participant 1: Sorry to interfere... may I ask you what is that cos I have got a funny feeling I am one of them.

Facilitator 2: Ok

Participant 1: ...got challenging behaviour'

Facilitator 1: You tell me about that. Why do you think you might be one of those?

Participant 1: Um when everything gets on top of me I freak out...I just explode and then go upset don't I'

This participant went on to say that engaging in hitting and shouting released frustration however this was not to say that they wished to continue with these behaviours:

Facilitator 1 And one of the things is that you want to stop hitting?

Participant 1: Yeah but its very difficult

A recurring pressure was the experience of not feeling listened. When feelings were not perceived as being heard and understood this led to frustration and then behaviours followed in these accounts. Participant 1 in focus group 3 describes this as follows:

Participant 1: 'When people don't understand. When people don't understand you yeah... how you feel.'

Participant 1 goes on to describe an episode with a health professional whom she felt did not understand the pressure the clinical interview was placing upon her.

Participant 1: 'I went ballistic with her once... She had a piece of paper and she said 'you do this and you do that'... 'and you do that' and do you know what made me freak out I went the paper went with her I went like this (mimes pushing the papers off the desk) whack it went flying and I said the 'no I am not doing that'.

Though identifying as being a person who has 'got' challenging behaviour this person subsequently made sense of her behaviour and responses to it in the context of an impairment label, namely Autism.

Participant 1: Autism, Autism right. Everyone thought I was a very very bad person... everybody thought I was so bad person no one want to know you like the nurses and doctors.

This changed when her diagnosis was understood by local services:

That's what I found out I have got autism and I got naughty but I am not really naughty its just my.... Make me... I had to have security guards – come on in them with me come on in there with me (into local health centres) ask my mother that its true and I am not like that I am a softy... But I am not violent. I would do anything for anyone.

For this person challenging behaviour represented unwanted behaviour, and the kind of behaviour that led others to construct negative attributions ('naughty', 'violent'). In this instance Autism provided a diagnostic frame or story that helped her and those around her to make sense of the behaviours in new less judgmental terms. Participant 1 shares an alternative identity story in the focus group.

Engaging with professionals.

Participants across groups spoke of being unsure of the kinds of professionals that might make up a learning disability team. When discussing these issues there was also uncertainty concerning the differences between professions.

Participant 2 (FG3): *I have seen a psychiatrist... is that the same thing? (as a psychologist) That's the same thing isn't it?*

Participants described individual practitioners they had met and with whom they had formed useful working relationships.

Participant 1: Umm well, I did, umm well, ages ago I did see a speech and language therapist at my house that was 6 months ago, like once a week, yes

Facilitator 1: Do you know what helped you? Did it help you?

Participant 1: It helped me to talk properly

Facilitator 1: It helped you to talk properly?

Participant 1: Yes

Facilitator 1: Was that a good thing?

Participant 1: good thing...She helped me with my mood... I think

Facilitator 1: You think

Participant 1: that's what she was there for- in't that right? I don't know

Support worker with Participant 1: Well, how do you think she helped you?

Participant 1: With me mood and keep my nice and relaxed

Facilitator 1: Ahh, do you think that was good? Good. What things did she teach you?

Participant 1: to go in my sensory corner for about 15 minutes and read to me story but haven't been doing that for ages, I've been lazy!

Participant 2 in FG1 also describes an intervention that helped:

Participant 2: *talked about my anger problems*

Facilitator 1: *and what did they do that helped?*

Participant 2: *showed me some things about how to calm down a bit*

The following interchange shows Participant 1 in group 1 addressing a clinician she had previously worked with and we see the potential complexities and unintended outcomes of the relationships between the helper and helped, both with the clinician in the focus group and the understanding the participant has of what it means to 'have a carer'.

Participant 1: *Ohh I'm talking about you now (The clinician was helping with the setting up of the day was invited into the room by Participant 1)*

Clinician: *Shall I go and wait outside?*

Participant 1: *no, no, this is okay, umm (clinician) little good but umm she's a bit bossy sometimes.*

We are curious about Participant 1's experience of 'bossy' and after several minutes the conversation returns to this theme:

Participant 1: *I'm only joking she's not bossy*

Facilitator 1: *But do you think she was helpful?*

Participant 1: *Yeah- sorry about that! I like to joke around*

Facilitator 2: *You can say whatever you want- its fine*

Participant 1: *Are you sure?*

Facilitator 2: *Yeah Definitely*

Facilitator 3: *Yes*

Participant 1: *I was a bit jealous because I want a baby for my own (The clinician was pregnant when working with this person)*

Facilitator 3: *Ahh*

Participant 1: *Unfortunately I can't have a baby because I've got a carer*

Engaging with learning disability teams could entail encounters with medication. There was ambivalence about medication. Participant 2 describes his experience as follows:

Participant P2: Medication, I have medication but is that a good thing, I don't know?

Facilitator 3: Is it a good thing I don't know? What do you think?

Participant P2: I don't like taking them but I have to don't I...they help with the anger doesn't it?

Facilitator 1: Do you like taking it?

Participant 2: No

Facilitator 1: Has anyone ever asked you if you like taking it?

Participant 2: No I just have to

Facilitator 1: Why don't you like taking it?

Participant 2: I don't know I just don't like doing it. It makes me sleepy I don't like that

Facilitator 1: Has anyone ever given you the choice to stop?

Participant 2: No I don't think they have, no what do you reckon, it's a hard one isn't it.

Discussion

In this paper we found that, for participants, engaging with services may mean engaging with service terminology. Challenging Behaviour was a term disliked. Preferred was Person-centered language, the person's name, that they have a learning disability, particular difficulties and emotions. One person spoke of the usefulness of a diagnostic frame for making sense of her behaviour and for protecting her reputation and identity. This suggests service terminology may influence the identity of those served. Participants negotiated the meanings of and identification with Challenging behaviours. Challenging behaviours were framed most often as characteristics belonging to a person that could be activated when overwhelmed by external pressure. As with previous research (Hoole & Morgan, 2011) we found experiences of exclusion and not being listened to. Containing emotions can be difficult and at times they cannot be. At this point participants behave in ways that may get described as challenging. Participants had a number of ideas about how to create positive experiences. With regard to professional support participants were unsure of the kinds of and differences between professionals in the community learning disability teams. When discussing the name of the service one participant

suggested a services name should indicate that the services purpose is to help those referred. There was ambivalence and a lack of comprehension about medication, its purpose and issues of consent. Professionals were useful to participants though they may bring pressure with them for example during assessment and differences in status between the professional and the person may also be noticed and difficult to manage.

Implications and Future Research

The findings suggest further consideration of the understanding about and impact of service terminology on those served, their identity and reputation. Informed engagement with services was also highlighted in this study and as described by Sheehan, Hassiotis, Walters, Osborn, Strydom & Horsfall, (2015) those who use our services must be supported to understand, question and if they wish refuse medications prescribed. The study also supported previous work (Gates & Waight, 2007) that people with a label of learning disability (and this case also receiving challenging behaviour service) are able to participate in focus groups. Engaging people with significant emotional and behavioural needs required careful planning and detailed thought concerning environment and accessible communication. Funding has been secured to develop this work further, to continue to give people with a learning disability a voice in their care. Our experiences to date suggest that this needs to be a dedicated and funded resource; otherwise the time demands on clinical services will mean that endeavours continue to be patchy and tokenistic. We want to be open to changing our referral processes and how we provide information to the people using our services and their carers. We want people to be involved in all decisions made about them. We also wanted to further involve people who would need more support to have a voice in service evaluation.

Limitations

This project is very small scale and the focus group methodology, though it may create a space for rich conversations between participants (in way that interviews do not), it does not allow for detailed collation and analysis of individual stories. Additionally the study did not follow participants journey of engagement with services, which may have provided important information about their experiences. Finally, the design of this study was such that those persons who were deemed to be unable to engage in group discussion were not represented.

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