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Abstract

Background

Client-centred models of care emphasise the importance of collaborative working between staff and clients with intellectual disabilities. How people with ID perceive the nature of their engagement with staff is relatively unknown. This study investigated the perceptions of staff and people with ID about the goals for their meetings and what aspects of the meetings they viewed as important.

Method

Interviews were carried out with nine client-staff dyads. Prior to their meeting, both staff and clients were asked about their expectations. Afterwards, both parties were asked about what they believed happened during the interaction. The participants' answers were subjected to a thematic analysis.

Results

People with ID appreciated the opportunity to tell their story and valued reliable practical support and advice. A trusting relationship was important to both clients and staff. Only staff viewed promoting clients' autonomy as important.

Conclusion

Staff and people with ID appear to differ in their expectations and perceptions regarding regular support meetings.

Key words: Staff- client interactions, collaborative relationship, intellectual disabilities, interactional patterns, social interactions, staff and clients perspectives

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) promotes the rights of clients with an intellectual disability to be part of decision-making processes about their own lives. The UN declaration is consistent with current client centred philosophies of care. For example, staff members are encouraged to actively seek the opinions of clients with an ID and negotiate the support they need. In order to reach common ground, staff and clients require a degree of mutual understanding and shared goals (Clark & Brennan, 1991; Steenbeek & Van Geert, 2007).

The general assumption that support meetings between staff and people with an ID have a major influence on the quality of life of people with an intellectual disability is widely acknowledged (Embregts, 2011; Schalock, 2004). Still, there seems to be a paucity of research investigating the views of people with an ID about the quality of their meetings. However, in a recent study conducted by Roeleveld and her colleagues (2011), people with mild intellectual disabilities were interviewed about their relationship with staff. During these interviews, clients indicated that they valued interactions that are characterized by honesty, trust, caring, and a feeling of being both emotionally and physically protected (Roeleveld et al., 2011). Similar views have been expressed by clients when asked for their views about good quality of care, stating that support staff should be respectful and accepting, and have caring and nurturing attitudes (Clarkson, Murphy, Coldwell, & Dawson, 2009).

The body of literature investigating interactions between staff and people with an intellectual disability includes observational work about the quality of everyday interactions between people with intellectual disabilities and care staff (Embregts, 2000a, 2000b; Finlay, Antaki, Walton, & Stribling, 2008; Finlay, Walton, & Antaki, 2008). Other studies have focused on the effects of client characteristics such as cognitive skills, psychological problems and psychiatric illness on social interactions (Bromley & Emerson, 1995; Dekker & Koot, 2003; Emerson, 2003; van Nieuwenhuijzen et al., 2006; Wallander, Dekker, & Koot, 2003). These studies have tended to emphasise the abilities of the people with an ID or on the competences of staff (Dagnan, Chadwick, & Proudlove, 2000).

Few studies have investigated the pattern of interaction between staff and people with intellectual disabilities during routine meetings (McConkey, Morris, & Purcell (1999). By routine meetings we mean regular meetings in which staff support the people with an ID with a broad range of daily living tasks, such as helping with household jobs, planning social and

vocational activities, arranging appointments, healthcare, and managing relationship difficulties. Several studies have investigated the quality of the interactional patterns between staff and people with profound or severe intellectual disabilities and/or communication problems (Bradshaw, 2001; Edge, 2001; Purcell, Morris, & McConkey, 1999). Yet, few studies of this kind have been undertaken with young adults with mild to borderline intellectual disabilities, who have the communicative ability to be more equal partners when interacting with staff.

Recent studies by Reuzel et al. (2012, 2013, 2014) investigated interactional patterns between staff and people with mild to borderline intellectual disabilities during routine meetings. Reuzel and her colleagues investigated the attunement of staff and people with an ID both on a content and on a process level. Attunement refers to the reciprocity of staff and clients' verbal and non-verbal behavior during their routine meetings. To achieve a shared dialogue at the content level, staff and people with an ID must reach a mutual understanding and common ground about what is said (Linell et al, 1988). Reuzel et al. (2012) used the Initiative-Response Analysis of Linell et al. (1988) to determine the level of dominance of staff and clients during their regular meetings and the different turn types they used. This type of analysis determines whether interactions are balanced in terms of power distribution and the strategies people use to influence the interaction. At the process level, staff and people with an ID should be able to accurately predict the beginnings and endings of each others' communicative turns. Accurately predicting the ending of the other speaker's turn, allows the individual to gauge the correct time to begin his or her turn, allowing the conversational partners to achieve synchrony (Delaherche et al., 2012). Attunement of turn-taking patterns was measured using Cross Recurrence Quantification Analysis. Reuzel and her colleagues found that staff and clients seemed to be sensitive to different aspects of their interaction together. In general, staff seemed to be sensitive to dominance and balance in their interactions with clients, both in terms of verbal and non-verbal behavior. Dominance in this context is the level of influence a person has on the course of the interaction, for example, by taking the initiative. Whereas, Reuzel et al. (2013, 2014) found that the clients with an ID appeared to be more sensitive to attunement, namely, synchronization of non-verbal behavior.

One explanation for the finding that staff appeared to be sensitive to dominance and balance during their regular meetings with clients is that staff placed a strong emphasis on empowering people with an ID, which is consistent with the value placed on client-centred approaches. People with an ID, on the other hand, were sensitive to synchrony. Since

synchrony is assumed to be related to rapport, people with an ID may therefore have been more concerned with building good relationships with staff. In order to gain a better insight into the quantitative analyses of the interactions reported by Reuzel et al (2012, 2013, 2014), the current study aimed at exploring what both staff and people with an ID said about these kind of regular meetings.

There has been important work using conversational analysis to examine interactions between staff and people with learning disabilities (Antaki, Young & Finlay, 2002; Antaki et al. 2006, 2008; Antaki, Finlay & Walton, 2007; Finlay, Walton & Antaki. 2008). However, there has been little research where people with ID and staff members are simply asked about how they think about the conversations they have during their regular meetings, including what they want to achieve and what they think is important. Knowing how staff and clients perceive their regular meetings could help staff to be more aware of their own viewpoint and sensitive to clients' needs and wishes during their meetings. As the aim of this research was to shed more light on the experience and opinions of support staff and people with an ID, without making prior assumptions, qualitative interviews were used. The interviews were then thematically analysed using a general inductive approach (Thomas, 2006).

The following questions were addressed:

- What were staff and people with an ID's expectations and goals for their regular support meetings?
- What did staff and people with an ID consider to be the most important aspects of their support meetings?

Method

Framework and Recruitment of Participants

Individuals with mild to borderline intellectual disabilities receiving services from the JP van den Bent foundation in the Netherlands and staff working within this foundation were recruited to participate in the study. The JP van den Bent foundation provides services to people with an intellectual disability. The role of staff is to support people with an ID with a broad range of daily living tasks, such as helping with household jobs, planning social and vocational activities, arranging appointments, healthcare, and managing relationship difficulties. Staff members discuss their input with people with an ID and agree on a support action plan, which sets out the nature of support to be given and how it will be provided. Ethical approval was obtained from the board of the JP van den Bent foundation.

Managers and psychologists were provided with information about the purpose of the study. They selected staff working with people who have mild to borderline intellectual disabilities. Nine staff members stated that they were interested in taking part in the study. Each of these staff members was asked to select a client who they worked with on a regular basis or who they met at least once a week. Staff were asked to gauge the clients' interest in participating in this study without putting any pressure on them to do so. We asked staff to invite clients, as we believed that the clients would feel less inclined to refuse a researcher's request to participate in the research.

After the clients agreed to participate in the research, the researcher contacted each staff member and the individual with an ID they supported, in order to explain the main goals of the study. Each dyad was sent a letter explaining the purpose of the research. The researcher explained that participation in this study was voluntary and that staff and people with an ID could withdraw from the study at any time. Written consent was sought from all participants.

Nine staff members (2 men and 7 women), working at the JP van den Bent foundation, participated in this study. The staff members who took part in the study worked in different regions and settings. Most staff members ($n = 5$) worked in community-based residential houses. One staff member worked in an outreach service for people living in their own homes, and three worked in crisis care, which offers support to people who require urgent help for a number of reasons, such as unstable home situations. Their mean experience of working in services for people with an ID was 9.2 years ($Range = 6 - 13$ years).

The mean age of the participants with an ID was 30.1 ($SD = 7.3$) and ranged from 23 to 42 years. Five of the people with an ID were men and four were women. They all lived in community care settings and received support from services. One person lived by himself in an apartment with outreach care and four lived alone with 24-hour support available. Another person lived in a staffed house for training purposes and three were staying in staffed houses on a temporary basis due to crisis situations. The Wechsler Adult Intelligence Scale (WAIS-3) was used to assess their level of cognitive functioning. Their scores ranged from 61 to 77 ($M = 71.6$; $SD = 5.9$). All people with an ID had sufficient verbal ability to express their thoughts and feelings.

The regular support meetings between staff and the individuals they supported were required to meet the following criteria: 1) the topic concerned an aspect of the person's support needs, and 2) it was the type of conversation that occurred on a regular basis, at least

once a week. No instructions were given to staff or those with an ID, other than to carry on as normal. All meetings were video recorded. The camera was placed unobtrusively in a corner of the room. Different types of topics were discussed including: planning or evaluating people's goals, planning activities or making a weekly schedule, administrative tasks, dealing with finances, discussing problems at work, talking about possibilities for future housing, dealing with problems related to drug addiction, coping with interpersonal conflicts and finding solutions to various problems the person was dealing with.

Interviews

Interviews were carried out with nine people with an ID and staff, before and after they had their regular support meeting. The average length of the interviews was 14 minutes (ranging between 10 to 25 minutes). The individuals with an ID and their staff members were interviewed separately by the researcher, both before and immediately after their regular meeting. Participants with an ID were interviewed at home and staff members were interviewed at the office where they were based. The interviews were carried out on the same day the meetings took place, as soon as possible after the meetings. The interviews were video recorded and transcribed verbatim.

The participants' responses to the questions concerning a) their expectations and goals for their regular meetings, and b) what they considered to be the most important aspects of their meeting, were extracted from the transcripts and subject to thematic analysis, using a general inductive approach. To obtain this information, the type of questions asked were: "Why are you having this meeting? What do you want to discuss? What is the purpose of this meeting? What do you hope to achieve or what do you hope this meeting will bring you?" After the meeting the participants were asked about the nature of the meeting and how the meeting went. The type of questions were: "How was the meeting? What did you discuss? What went well, what did not? Did you manage to discuss the items you wanted to? What did you find important while you were having this meeting? Were you satisfied with the meeting? What did you think of the way in which the items were discussed?"

Analysis

We used a general inductive approach to identify the themes that were evident in the data. A primary objective of our research was to identify the expectations of staff and people with an ID about their regular meetings and what they viewed as important aspects of the meetings they held.

The following procedures were used for the thematic analysis (Thomas, 2006):

- i) *Close reading of the text.* The transcripts were read in detail until the researcher was familiar with the content.
- ii) Identifying themes: The first transcript was read by the first author again and emergent themes noted and put in a table.
- iii) Continuing revision and refinement of themes: The original table of themes formed the basis of the analysis of subsequent transcripts, with a new table being produced for each transcript. Where additional themes emerged within subsequent transcripts, earlier transcripts were re-examined for data that might also reflect the new theme. The resulting tables were compiled and compared to produce a master-table of clustered themes and corresponding sub-themes. These themes represented not only the commonalities between transcripts, but also all variations between them.
- iv) Identifying major themes: Where possible, specific themes were grouped into broader categories to reflect perceived relationships between them. The labels used for these themes represented a higher level of abstraction and interpretation (Joffe & Yardley, 2004). For example the themes ‘listening sincerely to clients’, ‘taking an interest in clients’ and ‘thinking along with clients’ were clustered under the higher order theme, namely the ‘relationship between staff and clients’. All emergent themes were recorded in a table.

The primary analysis was completed by the first author, who also completed all the research interviews. To ensure that the analysis was carried out with rigor, the decision making about the extraction of themes was recorded as the process of analysis was carried out. Secondly, the analyses were discussed with other members of the research team, one of whom examined a number of transcripts independently of the first author. Finally, the extracted themes were linked back to verbatim quotes to ensure that the themes were firmly grounded within the data.

Results

What are staff and people with an ID’s expectations and goals of their regular support meetings?

General well-being

A majority of the participants said their meetings were about the general wellbeing of the client (for staff $n = 6$, for people with an ID $n = 7$). As one participant with an ID stated: “She asked me how my week was” or “there is always something we can talk about. Usually staff asked me how I’ve been”. Participants with an ID also expressed the view that being able to talk about their concerns helped them to remain calm. Comments made by staff were similar: “we just make conversation: what happened, what went well?” or “when I come to his house, I usually sit down and see what’s going on”.

Practical support

The second most important goal of their regular meetings for both staff and people with an ID was offering or receiving practical support. Staff ($n = 4$) and people with an ID ($n = 4$) talked about receiving support with administrative tasks, arranging transport and making appointments with authorities.

Teaching skills and evaluating interventions

Other goals mentioned by both staff and people with an ID included teaching new skills (for staff $n = 2$, for people with an ID $n = 2$) and evaluating an intervention (staff: $n = 3$, participants with an ID: $n = 2$). Staff also referred to practical skills that people with an ID wanted to learn, like managing their finances. A few staff members mentioned that they hoped that people with an ID would gain some insight into their behaviour, such as dealing with their emotions. One person with an ID talked about things she wanted to learn about raising her sons: “like when to discipline, how often do I have to discipline the little one and how often the oldest?” Another person with an ID said that she wanted to be more assertive: “That is what I should learn, when I don’t like something, I have to say it to that person or to staff”.

Obtaining advice

Three participants with an ID said they hoped to get some advice from staff on how to handle specific issues. One person with an ID had fallen out with her sister and she wanted to know from staff how she could start a conversation with her sister. Another participant with an ID wanted advice on how to deal with a colleague, who was always complaining about him.

Support action plan

Two staff members wanted to use their meeting to work on their clients' support plan. None of the people with an ID mentioned this.

Other

One person with an ID had no idea why he was meeting with his staff member and had no goals or expectations for the meeting. The staff member said that she wanted to know what the client with an ID thought about his support.

What do people with an ID consider important aspects of their support meeting?

The result of the meeting

After their meeting with staff, people with an ID were asked about what they thought was important about their meeting. Table 1 shows that seven people with an ID felt they received helpful advice from staff. Being able to tell their story and get practical support were also important for people with an ID. Most participants said they appreciated the advice from staff. "I like it when they give advice about how to solve this problem". People with an ID also valued the practical support from staff: "I want things to be done for me, when they are too difficult for me. I just have to mention something and staff make sure it gets done. Like I wanted to go to the gym and he arranged that immediately." The outcomes that the people with an ID talked about were consistent with the goals and expectations they outlined before their meetings.

Insert Table 1 around here

Communication

People with an ID thought that the way staff members' communicated was also important. They highlighted three aspects of staff communication as being of particular importance, namely clarity, use of language, and communication style.

Clarity: People with an ID placed importance on receiving clear information from staff. For example, when arranging appointments they found it helpful to know what would happen, when it would happen, where, with whom and how. Negotiating these arrangements meant people with an ID knew what they had to do. For example, a few people with an ID mentioned they had made clear plans about what they should do when they became upset.

Use of language: Two individuals with an ID talked about how staff adjusted the language they used. For example, one person said they were able to understand staff perfectly, because staff talked slowly and handled issues one at a time. Another person with an ID said: “She told things in my own words and that is what I like”.

Communication style: people with an ID felt that the way staff talked was important. For example, they appreciated staff talking calmly, giving compliments, speaking in a straight forward manner and letting them finish speaking. Several people with an ID said that they thought that they could judge whether staff were being genuine or not.

Relationship

Finally, participants with an ID talked about their relationships with staff. Seven people with an ID mentioned that staff took them seriously and felt that staff listened to them carefully. Five people with an ID mentioned that staff took a genuine interest in them and that there was mutual understanding. For example, people with an ID mentioned that they felt a ‘connection’ with staff. One person with an ID said: “I do trust her. I discuss different things with her, personal stuff.” One person with an ID said it was important that staff kept their promises about what they said they would do. People with an ID wanted staff to be reliable, like being on time, and being honest.

What do staff consider important aspects of their support meeting?

The results of the interaction

Staff thought it was important for people with an ID to be able to tell their story and to talk about the concerns they had (Table 1). Staff also thought that providing advice and practical support was vital. Three staff members hoped people with an ID would gain coping skills, such as learning how to deal with their emotions and developing parenting skills.

Communication

Staff also thought communication was important and referred to clarity, use of language and communication style. However, there were subtle differences between the views expressed by staff and people with an ID.

Clarity: Staff thought it was important to make very clear arrangements, such as appointments where both staff and clients know what to do, when, with whom, where and how. They also thought it was worthwhile keeping notes about the conversation, in order to be able to give feedback about what had been agreed. Two staff members made an agenda in advance of the

meeting, so that they knew what they would be talking about. As one staff member said: “I like things to be structured, that is why I write down what I want to discuss”.

Use of language: The majority of staff tried to ensure there was mutual understanding about what had been said. As one staff member commented: “I noticed I had to ask questions carefully in order to get concrete answers.” Another staff member stated: “I tried to verify what I heard, so I checked with him if my interpretation was right.” It was regarded as essential to communicate clearly and follow the pace of the person with an ID in order to establish a meaningful dialogue. “I used to run ahead and the xxx (the person with an ID) followed. I had all kind of ideas, but before people with an ID could process the information... I had to learn to follow their pace.”

Communication Style: Using humour was thought to be important by staff, as well as keeping their own emotions under control. One staff member thought it was good to give compliments. Two staff members mentioned that it was essential to stay focused, and to be careful to avoid drifting away in their own thoughts. Three staff members said that they focused on their clients’ nonverbal communication, trying to gauge their feelings.

Relationship

Relationships with their clients were also seen as important by staff. Most staff thought their clients felt at ease, because they were open and talked easily. Three staff members said that they listened carefully to clients, and tried to ensure that they felt heard. One staff member thought it was vital to be accessible: “I told her that she can give me a call. That is possible, because we are there 24 hours a day. That is why you can always come to us for help”.

Autonomy

One issue that was only mentioned by staff was a wish to promote their clients’ autonomy. Most staff members stated that they wanted their clients to do things themselves, whenever they were able to. As one staff member said: “She has a meeting with her consultant at work and she wants me to be there. She finds it stressful. But if she can manage to do this on her own we say: Can you go yourself? And then she says: I think so. Well, then we are going to try that and if it does not work out, we will talk about it later.” All staff emphasised the importance of communicating in a manner that helped to promote their clients’ agency. As one staff member said: “ I asked questions, so she could make a considered choice”, “ I had to let her think for herself more.” In contrast, one staff member

said he had to restrict his client's autonomy by setting boundaries, and making it clear what was acceptable and not.

Plan based working

Only one staff member referred to the need to plan for their regular meetings. She said that since they had started planning their regular meetings together, her client had felt more involved.

Discussion

This study investigated the experiences and opinions of individuals with an intellectual disability and support staff in relation to their routine meetings. The results suggested that all participants were primarily concerned with the general wellbeing of the person with an ID. The purpose of the meetings was not usually set in advance, and topics that emerged on the day were discussed. The type of unstructured support examined in this study, where people with an ID are able to express their thoughts and feelings, seemed to help foster good relationships between staff and clients. Indeed, the participants with an ID frequently stressed the importance of being listened to properly. This finding is consistent with other studies where clients placed emphasis on their relationship with staff (Clarkson et al. 2009; Kilbane & Jahoda, 2011; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Roeleveld, et al., 2011). Clients appreciated staff characteristics like being caring and understanding, qualities that might be associated with a supportive friend (McVilly et al., 2006).

Although the meetings in this study may have been experienced as warm and supportive by clients, it is not known whether these interactions helped to empower them or promote their self-efficacy. This is despite the fact that empowering people with an ID was one of the aims that staff talked about. In contrast, it was noticeable that relatively few people with an ID made comments about self-efficacy. This may be due, in part, to the nature of the questions that the participants with an ID were asked, which referred specifically to what happened at their last meeting rather than general themes that were important to them. If participants with an ID had been asked directly about what was important in their lives, they may have mentioned their autonomy. Whereas, staff references to the self-efficacy of their clients with an ID may have reflected their beliefs about their role as staff more generally, rather than what actually happened during the meetings.

There are other possible explanations as to why staff referred to self-efficacy more often than people with an ID. Several researchers have suggested that individuals with intellectual disabilities are likely to remain more dependent on external support rather than their own resources, even when this is unnecessary (Langdon & Talbot 2006; Wehmeyer & Palmer 1997; Zigler & Balla, 1972). It may be argued that the ad-hoc nature of the support reinforced dependency, because there was no regular monitoring or evaluation of how these meetings contributed to people with an ID's longer term needs or goals. Nevertheless, people with an ID clearly stated that they wanted to receive advice and practical support from staff to deal with difficulties they encountered. Therefore, our findings point to a potential tension between policies and practices for support staff. On the one hand they are encouraged to enhance people with an ID's self-determination and independence, and on the other hand, people with intellectual disabilities express a clear need for ongoing support and help (Donner, Mutter, & Scior, 2010).

Whether or not the meetings helped to foster the people with an ID's wider sense of self-efficacy in their lives, staff did appear to be aware of how to adjust their communication to enhance their attunement with clients who have an ID. For example, staff talked about using language that people with an ID could comprehend, carefully pacing the conversation and checking to ensure there was mutual understanding about what had been said. These findings were in line with the results of a recent study by Reuzel et al. (2014). They found the support staff they studied made efforts to synchronize their interactions with people with an ID. The ability of staff to synchronize with people with an ID, not only helped to build rapport but was also closely linked with greater cooperation between the communicative partners (Delaherche et al., 2012). These findings suggests that staff may have the skills to help empower people with an ID as partners in an interaction. This skill could be used to positive effect if, for instance, people with an ID wished to obtain advice or practical support as experts on their own lives.

There may be value in carrying out a larger scale study of this nature, in order to ascertain whether views and experiences articulated in the present study reflect those expressed by staff and people with an ID in different contexts. The study had a number of limitations. Firstly, researchers carrying out qualitative research may hold views that can impact on the research process, including the nature of the data collected and its interpretation. However, within the present study, attempts were made to acknowledge and explore the researchers assumptions, by making explicit the decision making process when

carrying out the analyses and by means of external supervision and an independent audit of the themes. Secondly, the fact that the participants were interviewed before their meeting might have influenced their subsequent interaction. Moreover, the meetings were video recorded and this could have made the staff and clients with an intellectual disability feel self-conscious resulting in the rather short communicative turns that were observed.

In conclusion, staff and people with an ID largely in agreement about important aspects of their support meetings, but there were also subtle differences in the views expressed by staff and people with an ID. Both staff and people with an ID emphasised the need to work at maintaining their relationships. Staff were aware that being reliable, taking people with an ID seriously and listening to them carefully were necessary for a successful dialogue. However, there is a possibility that staff concerns with empowerment may not always be in keeping with people with an ID's wishes and expectations. Past findings have shown that people with intellectual disabilities' voices are not always properly heard in interactions with support staff (Antaki, et al., 2002; Antaki et al., 2006; Antaki et al., 2008, Bradshaw, 2001). It would be paradoxical if an attempt to foster agency resulted in people's own wishes and needs being overlooked. This is an area that requires further investigation.

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